THE PRESIDENTIAL COMMISSION on the HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC

HEARING ON South Florida

November 12, 1988

August 24, 1988

TO OUR READERS:

The Presidential Commission on the HIV Epidemic held over 45 days of hearings and site visits in preparation for our final report to the President submitted on June 27, 1988. On behalf of the Commission, we hope you will find the contents of this document as helpful in your endeavors as we found it valuable in ours. We wish to thank the hundreds of witnesses and special friends of the Commission who helped us successfully complete these hearings. Many people generously devoted their volunteer time in these efforts, particularly in setting up our site visits, and we want to fully acknowledge their work.

The staff of the Presidential Commission worked around the clock, seven days a week to prepare and coordinate the hearings and finally to edit the transcripts, all the while keeping up with our demanding schedule as well as their other work. In that regard, for the South Florida Public Meeting, we would like to acknowledge the special work of Peggy Dufour, Victoria Thornton and Frank Hagan in putting together the hearing, and Reginald Andrews in editing the transcript so it is readable.

For the really devoted reader, further background information on these hearings is available in the Commission files, as well as the briefing books given to all Commissioners before each hearing. These can be obtained from the National Archives and Records Administration, Washington, D.C. 20408.

One last note--We were only able to print these hearings due to the gracious and tremendous courtesies extended by Secretary Bowen's Executive Office, especially Dolores Klopfer and her staff, Reginald Andrews, Sandra Eubanks and Phyllis Noble.

Sincerely,

Polly L. Gault
Executive Director

Gloria B. Smith
Administrative Officer

PRESIDENTIAL COMMISSION ON THE

HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC

COMMISSIONERS

ADMIRAL JAMES D. WATKINS, CHAIRMAN
UNITED STATES NAVY (RETIRED)

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CORY SerVAAS, M.D.

WILLIAM WALSH, M.D.

PRESIDENTIAL COMMISSION ON THE HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC

The Hearing was held at the
University of Miami/
Jackson Memorial Medical Center
Mailman Center for Child Development Building
1601 Northwest 12th Avenue
8th Floor Auditorium
Miami, Florida

Thursday,
November 12, 1987

COMMISSION MEMBERS PRESENT:

ADMIRAL JAMES D. WATKINS
CHAIRMAN

COLLEEN CONWAY-WELCH, Ph.D.

JOHN J. CREEDON

THERESA L. CRENSHAW, M.D.

KRISTINE GEBBIE

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FRANK LILLY, Ph.D.

BENY J. PRIMM

PENNY PULLEN

CORY SERVAAS, M.D.

COMMISSION MEMBERS NOT ATTENDING:

CARDINAL JOHN O'CONNOR

RICHARD M. DEVOS

WILLIAM B. WALSER

POLLY L. GAULT
Executive Director

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I-N-D-E-X

I-N-D-E-X (continued)

I-N-D-E-X (Continued)

P R O C E E D I N G S

(8:30 a.m.)

OPEN MEETING

MS. GAULT: Mr. Chairman, I am the designated federal official, and I officially open this meeting today.

CHAIRMAN WATKINS: I would like to welcome our members today, the presenters, and observers to this meeting of the President's Commission on the HIV epidemic. I would particularly like to mention to those present today our two new members, Ms. Kristine Gebbie, Health Administrator for the State of Oregon, and Dr. Beny J. Primm, Anesthesiologist, President of the Urban Research Institute, focusing on some of the complex urban inner-city problems regarding the disadvantaged. Dr. Primm is also President and Executive Director of the Addiction Research and Treatment Corporation, which has a staff of about 300, treating some 1,700 patients with a history of drug abuse. These two additional members have joined us in Florida for their first time to serve with the Commission, and we are very honored and pleased to have them; they particularly add strength to our group.

Some of the Commissioners will be arriving in a few minutes, and some a little later in the morning. Unfortunately, we were unable to work out the schedule for Cardinal O'Connor, Mr. DeVos, and Dr. Walsh; they are on other duties. Dr. Walsh, in particular, is the Chairman of our working group on international health and he is in Geneva working for the Commission in that regard. For the past two days, several Commissioners have been in Florida visiting a number of AIDS related health care and human service providers.

We've been briefed extensively by local, county, and state officials regarding the extent of the epidemic, and the health and human services facilities available to meet the challenges currently faced in Florida. We've been greatly impressed by what we've seen in the past two days, and have developed a number of questions to be asked during our next set of Commission hearings with federal and state officials in Washington.

Today's hearing will offer presentations representing a broad range of viewpoints from researchers, public health officials, treatment providers, heavily impacted populations, people with AIDS, attorneys, ethicists, law enforcement officials, and insurers. All of our witnesses will give the Commission an overview of the HIV epidemic as it impacts local communities and the State of Florida. This wide range of viewpoints will assist us as we narrow our focus to highest priorities areas of concern in the days ahead.

The Commissioners are currently reviewing a tentative agenda for hearings on specific issues of importance, such as patient care, incidence and prevalence of treatment, prevention, and IV drug abuse. All of these issues will be integral components of our final report. Today's hearing will outline issues as they affect the local community, bringing perspective to the Commission's future areas of inquiry.

I know all of those who work on AIDS related issues are dedicating vast quantities of time and energy to this labor. For that reason, I am particularly grateful for the willingness of our presenters today and our hosts over the last two days for giving of their precious time to share their knowledge with the Commission.

I want to remind witnesses that we have many people to hear from today, and that each witness will be allotted five minutes for his or her statement. This must be strictly enforced to give all those scheduled today an opportunity to speak. Of course, all of the witnesses' longer and more detailed statement will be accepted for the record and factored into our future thinking. Again, while we know how much work each of you have put into your statement today, we really need to stay within this five-minute rule.

I'd also like to announce that the Commission's next hearing will be November 24th in Washington, D.C. to review findings of a number of biomedical studies which have recently been published on the HIV Epidemic. At that time, we will also discuss the interim report due to the President on the 7th of December.

I would now like to recognize any of the other Commission members for any opening statements that they may have and may like to make this morning, and then we'll proceed on with the hearing from our other presenters.

Are there any statements from the Commission members that they would like to make this morning?

(No response.)

CHAIRMAN WATKINS: Very well. Let's proceed then with the agenda.

MS. GAULT: Dr. Fogel?

CHAIRMAN WATKINS: Dr. Fogel is being replaced this morning by Dr. Gerald Kaiser, Deputy Dean, Clinical Affairs. Dr. Fogel has been bogged down in the fifteen inches of snow in Washington, I understand.

WELCOME TO UNIVERSITY OF MIAMI/JACKSON MEMORIAL MEDICAL CENTER

DR. KAISER: Chairman Watkins, members of the Commission, ladies and gentlemen:

It is indeed my pleasure to welcome you here to our medical center which is comprised of, as you know, the University of Miami School of Medicine, Jackson Memorial Hospital, which is governed by the Public Health Press and the Miami Veterans Administration Hospital. Dr. Fogel had hoped to welcome you personally, but as you heard, the unexpected and rather large snow storm that hit the Capitol yesterday kept him there, and I am here in his stead.

All of us in this room are aware of the enormous impact that AIDS has had upon medical centers, and particularly upon ours in that it has impacted on our educational programs, our research programs, and particularly on our clinical programs. We are pleased that you have chosen this sight to have your hearing today. We are happy to host this event, and we are sure that during the rest of the day you will hear and learn information which we hope will be of great benefit to you as you prepare your report for the recommendations that will be coming forth later this year. Thank-you for coming, and if there's anything we can do to help, please don't hesitate to ask.

CHAIRMAN WATKINS: Thank-you very much, Dr. Kaiser. We want to thank you and the University of Miami/Jackson Memorial Medical Center for allowing us to use this lovely room this morning for our hearing; thank-you. Next on the agenda, Mr. John Witte, overview of AIDS in Florida.

OVERVIEW OF AIDS IN FLORIDA JOHN WITTE, M.D., M.P.H., ASSISTANT STATE HEALTH OFFICER, STATE OF FLORIDA

DR. WITTE: Mr. Chairman, members of the Commission, I'm pleased to welcome you to Florida. As I'm sure you've learned over the last two days, we have been devastated by the AIDS epidemic here, and we feel gratified that you have come to Florida to hear and to see for yourselves, and we hope that what you do observe and what you do hear over this period of time will help all of us in combating the epidemic of AIDS. Florida has

consistently ranked third in the nation in the cumulative number of AIDS, going back to the time that we first started collecting the data in 1981. We have consistently had about 7 percent of the national total. We have just crossed the 3,000 number in the count of AIDS, and over half of those individuals are dead. Our Department of Health and Rehabilitative Services has maintained good surveillance of the epidemic in Florida.

Current projections made by our office show that the cumulative case count in Florida continues to double every twelve to fifteen months, so that early in 1988, we anticipate 4,000 cumulative cases; 8,000 by 1989; and 16,000 by 1990; and by 1991, 32,000 cumulative cases of the disease in Florida, which approximates the current national total. These grim projections, as you know, cannot be averted. Persons diagnosed with AIDS, as you well know, represent only a fraction of the problems associated with the epidemic. The Centers for Disease Control in Atlanta estimates that there are from 2 to 10 persons who suffer from the lesser illness, AIDS Related Complex, for every diagnosed case. Doing the multiplications, that means as many as 29,000 persons in Florida currently have AIDS Related Complex or ARC.

In addition, CDC also estimates that an even larger number of persons are infected with the virus. They estimate that 50 human infections occur for every reported case of full-blown AIDS. For Florida, that number would be 145,000 individuals currently infected in the state. Seventy-five (75) percent of the cases in Florida have been reported from four counties; you have been to three of them, Dade, Broward, Palm Beach. The fourth is Monroe, which is just south of here, in Key West. Nevertheless, 47 of our 67 counties, which is 70 percent, have had at least one case of AIDS, and it's gradually spreading throughout the state.

As with all other sexually transmissible diseases, the occurrence is widespread because of the population mobility and specific personal behaviors. National data show that the AIDS epidemic has disproportionately affected minorities, with 25 percent of the cases reported nationally Black, and 14 percent Hispanic. Those proportions are even higher in Florida. Thirty-eight (38) percent of our cases are Black, 12 percent Hispanic. Florida also differs in other significant parameters from the national averages. Only 4 percent of the national cases have been reported to be heterosexually spread. Here, 15 percent of the reported cases are heterosexually spread. Ten (10) percent of Florida's cases are from individuals who have immigrated here from high-risk countries, such as Haiti, where heterosexual

transmission of the virus is thought to play a major role in the spread of the disease.

Other numbers are also grim. Florida has reported the third greatest number of cases of AIDS among children. Like other states, 83 percent of the children in Florida infected with AIDS were born to mothers who were infected with HIV at the time of their birth. In coping with the epidemic, at the present time we have four million dollars in federal funds, and we can break down for you, if you would like, how those monies are currently allocated.

Our state legislature in this fiscal year has appropriated twelve-and-a-half million dollars in state general revenue dollars, and again we can provide breakdowns for you as to how those monies are being spent. In the interest of time, I will not go into that.

In summary, AIDS cases in Florida have been reported from a broad cross-section of the population. Homosexual and bisexual males, intravenous drug users, heterosexuals, and children of many race and ethnic groups are casualties of the epidemic here. We welcome you here; we look forward to your assistance, to your support, and to your leadership on how to most effectively cope with this most devastating problem.

CHAIRMAN WATKINS: Thank-you, Dr. Witte. Commission members, if you'd like to make any questions at this time. Mr. Creedon?

MR. CREEDON: Dr. Witte, in your statement you indicate that 15 percent of the reported cases in Florida are heterosexual, whereas the national average is 4 percent. One of the things that obviously concerns the Commission, as well as our society, is the extent to which the virus will spread in the heterosexual community. I wonder if you have any opinion as to why it's 15 percent in Florida as compared with 4 percent nationwide.

DR. WITTE: I think there probably are a variety of reasons for that. As I mentioned, one of them is that we have a large Haitian population here in South Florida. A lot of the spread among these folks is heterosexually.

MR. CREEDON: Do you know why?

DR. WITTE: For whatever reason, it spread heterosexually in Haiti and in Central Africa. These people

apparently are sexually very active with a lot of partners. I'm not sure I've satisfactorily answered your question.

MR. CREEDON: Thank-you.

CHAIRMAN WATKINS: Any other questions? Ms. Pullen?

MS. PULLEN: I would like you to detail how the funds are spent briefly, please.

DR. WITTE: Certainly. We have four million dollars in project grant funds from the Centers for Disease Control, and that's for the current fiscal year which will terminate, as far as these grants are concerned, in the spring of 1988. We have $388,000.00 for surveillance. We have three-and-a-half million dollars for prevention activities, which include health education, promotion, counselling, and testing. We have a special project in Belle Glade, which I think you became acquainted with the other day, in which CDC is supporting to the tune of $61,500.00.

We're doing a special study of HIV infection in children that we are receiving $115,000.00 from the Centers for Disease Control to support. The state general revenue dollars are broken as follows: Six-and-a-half million dollars come to Dade County, which is Miami, for patient care network activities; 1.7 million dollars are going to patient care network activities in other high prevalence counties; 1.2 million dollars are being expended in the area of health education and awareness; $450,000.00 is being spent in what we call laboratory enhancement, and that is research laboratories at three of the universities to work more effectively with the HIV virus; $800,000.00 evaluation component, and I think you'll hear more about that from Ms. Quick later this morning, and $300,000.00 for AZT funding. I have copies of both budgets, and I'll leave them with the Chairman for those of you who are interested.

CHAIRMAN WATKINS: Dr. Primm?

DR. PRIMM: How much money, sir, is spent in Belle Glade itself?

DR. WITTE: The special study in Belle Glade is $61,500.00.

DR. PRIMM: That seems a paltry sum compared to the problem that they have there.

DR. WITTE: Well, we feel that all the dollars we have in all categories, from patient care to education, to risk reduction, to counselling and testing are not adequate to meet our current needs, and Belle Glade is certainly an example of that, sir, I agree.

CHAIRMAN WATKINS: Dr. Witte, what should they be, in your opinion? I recognize there are all kinds of budget constraints that the state's going to have to face. On the other hand, it seems as though in our visit to Belle Glade, that they had great enthusiasm and great spirit for what they were doing, and their requests seemed modest to us. For example, they're unable to get the right skills in the medical professional available to them. People apparently don't want to serve in that area. Aren't there alternatives that can be provided to them to give them a hand? They have a very simple request for transportation. It seemed to us to be very reasonable; a couple of vans. It didn't seem as though it was an overwhelming task to focus some resources in one of the most unique areas in the country to us. It seemed as though they had a good set of plans, they knew what they were doing, they were highly motivated to get on with the project, and they were pleading for very simple things.

DR. WITTE: You're absolutely right, and we're going to be going to our Legislature when they meet after the first of the year, and requesting supplemental funds to do just those kinds of things. We agree a hundred percent.

CHAIRMAN WATKINS: Any other questions? Yes, Dr. Lee?

DR. LEE: What's the status of the waiver on the ACLF facilities?

DR. WITTE: Florida, unfortunately, in Adult Congregate Living Facilities (ACLF), had a regulation that prohibited people from residing there that have an infectious disease. It was clear then that individuals infected with HIV virus could not be residing in an ACLF, which would be an appropriate place for them. We have gone through the bureaucratic channels to attempt to change this. It's processing, and I'm confident that's it's going to change, hopefully within the next couple of weeks, so that we will have a waiver, and that we will be able to do this. It involves not only ACLF's, but nursing homes, and we recognize the need to be able to provide appropriate facilities for folks.

CHAIRMAN WATKINS: Ms. Gebbie?

MS. GEBBIE: When you say a waiver, will that be a universal waiver for all persons with HIV infection, or will it be a system for individual waiver, home by home, person by person?

DR. WITTE: No, it will be a rule to enable us to have individuals with infectious diseases in nursing homes and in ACLF's.

MS. GEBBIE: Thank-you.

CHAIRMAN WATKINS: Any other questions?

(No response.)

CHAIRMAN WATKINS: Thank-you very much, Dr. Witte.

DR. WITTE: Thank-you.

MS. GAULT: The next witness will be Linda Quick, Executive Director, Health Council of South Florida.

PLANNING FOR MULTIPLE IMPACTS OF AIDS LINDA QUICK, EXECUTIVE DIRECTOR, HEALTH COUNCIL OF SOUTH FLORIDA

MS. QUICK: Good morning Mr. Chairman, members of the Commission, friends and colleagues in dealing with AIDS epidemic. I don't normally like to read a presentation, but I'm going to do that today because I want to make sure I stay within your time limit. The Health Council of South Florida is a voluntary, not-for-profit corporation serving Dade and Monroe Counties. The Council's purpose is to provide effective health planning for the area, and to promote the development of health services, manpower, and facilities which meet identified health needs in a cost-effective manner. For those of you from elsewhere in the country, perhaps the term Health Systems Agency would give you an idea of what we were and are.

Our agency has provided this kind of leadership in South Florida since 1968. In October of 1985, the Health Council began a massive and concentrated effort to assist Florida in their efforts to address the impact of AIDS. Initially, the Health Council Board of Directors authorized the establishment of an Ad Hoc Committee to develop a plan. The committee, with 35 members, was an effort to assure representation and participation from affected parties, political and social leadership, and those segments of the health care community already actively involved in South Florida AIDS efforts.

Nearly 50 people were put on the interested party list, receiving notices of meetings, and offered an opportunity to participate. The first three meetings were spent on orientation, education and issue clarification.

The plan chapters and content areas were selected. The Ad Hoc Committee members and interested parties were asked to serve on four work groups identified earlier by the full Ad Hoc Committee, and representing chapters in the plan: public education and information; care and treatment; legal and ethical dilemmas; research and prevention. Discussions were lively and emotions often high, as the struggle for priorities, direction, and exactness of expression took place at work group meetings. Surely, completing and preparing the written plan for full Committee and ultimate Health Council adoption belies the effort and emotional energy committed to the planning process itself. The planning process and the plan, which we've enclosed for you, that resulted in April of 1986, was not complete, and I might add it probably still isn't. AIDS is a dynamic disease and does not lend itself easily to absolutes. Even as the over 150 people engaged in the plan development process were asked questions, studied the issued and available data, new reports were being published, new treatments being pursued, and unfortunately, new cases were being diagnosed.

In the year-and-a-half that followed, many positive things have also happened, and the Health Council of South Florida is proud to say that we've been a part and participant in these plan implementation processes as well. Most importantly, and in a large part as a result of congressional action, the care and treatment network and the portion of the plan that it identified has been implemented.

In Dade County, this effort is characterized by the South Florida AIDS Network, a federation of service providers centered and administrated here at the University Of Miami Medical School/Jackson Memorial Hospital, with participation from the Visiting Nurses Association, Hospice, Health Crisis Network, Dade County Human Resources Health Center, which is our county run nursing home, the Florida Department of Health and Rehabilitative Services, and an ever-widening circle of care givers for persons with AIDS, persons with AIDS related conditions, and those already having tested positive for the HIV antibodies. This Network operates with a complex combination of federal, state, and private money that you'll hear about later.

Similar, but smaller treatment networks have also begun in Broward and Monroe Counties, as well as in West Palm Beach, and I know you visited two of those areas yesterday. The goal, of course, is to link all of southeast Florida with a sophisticated and accessible care and treatment system that is in a position to provide humane and appropriate services, regardless of the stage of infection or the ability to pay. Initially missing, but services for which new funds and programs are being developed, are residential facilities for adults and children, specialized care of addicts, both IV and other drugs, with AIDS, programs addressing the interface of mental health and AIDS care, and efforts to reach minority group members at risk for AIDS, a large proportion, I might add, of our own population. As part of this implementation process, the South Florida AIDS Advisory Committee was formed and funded in part by the Robert Wood Johnson Foundation and HRSA of the U.S. Government.

The Committee was organized by the Health Council as a standing committee to effectively mobilize and coordinate the whole community to address and resolve the non-treatment issues surrounding AIDS, as well as to provide advice and coordinated assistance to Dade, Broward, and Monroe Counties' care and treatment networks. There are currently 32 members on the Committee from the tri-county area that has a population of approximately three million; the membership is attached for your perusal. As part of the advisory function, the Committee is very active and has itself developed several goals: Certainly to continue the dialogue is first; To undertake additional plans and projects; To encourage and nurture plan related implementation; To fulfill a leadership role in the continuing effort toward community-wide approach; To serve as a community-wide advisory board to the Trust and its foundation funds; To provide requested advice and information; And last but not least, to seek and expand financial resources related to this problem.

To this end, as planning is an ongoing process, the Committee will continue to update, as well as add, additional chapters to the current plan within the next couple of years. This past month, a policy statement on HIV testing was adopted and presented to the Florida legislature for its deliberations; that also is attached for you. One member of the Committee, Citicorp Savings of Florida, has even begun what we hope will be a common practice among private industry, by funding a generous $10,000.00 donation to Health Crisis Network. With the $100,000.00 that Dr. Witte mentioned from the Florida Legislature, the Advisory Committee has just begun conducting an objective data collection and analysis effort to help the state

evaluate its expenditure of resources, particularly those earmarked for Southeast Florida. The Committee is also talking about the best way to include Palm Beach County within the development of an even broader regional plan for South Florida. Part of this effort has taken place through an informal Consortium of AIDS Related Education Services, and you'll hear more about them later today, and its effort to implement the public information and education chapter of the plan.

In the past nine months, the Statewide Health Council, a consortium of Florida's eleven local health councils, like ours, has published two extensive policy reports addressing public schools, AIDS and insurance, and related discrimination issues. Dr. Terrence Collins, Chairman of that work group is on your agenda for later today.

Finally, I want to add that the opportunity to address distinguished members of the President's Commission would be wasted if we did not point out the Health Council of South Florida's concern about state and federal legislation. This year's policy statement of the Advisory Committee is attached to your packets. As you listen to my friends and colleagues today, you will come to understand that South Florida is, thanks to a sound plan, prepared and progressing, if not perfect. We are united, if not unified, in our efforts to support research, disseminate accurate and honest information, and assure humane treatment in the work place and in the health care system. But as I told Senator Chiles and his committee last August, and I want to reiterate that to you today, that since AIDS kills and people are dying, the country is frightened.

We must not let our fear be of other people. We must concentrate the country's anger on the virus, not its carriers. We must understand that this public health dilemma is a public policy dilemma as well. And you, our President's own specially selected leaders, must lead. Florida's own leadership, as you'll hear today, will walk with you and work with you, but the nation needs real leadership. No group I've addressed in the past two years on this issue has a clearer opportunity or obligation to provide it. Thank-you very much.

CHAIRMAN WATKINS: Thank-you very much, Ms. Quick. Let me start off with a couple of questions here, and then I'll ask the other Commissioners. What is being done within your network system in the educational process to address the attitudinal issue within communities? For example, we all know how these infectious diseases impact on society, and the response of society is generally hostile at the outset. There are times

when very simple things, such as intermediate care facilities, Hospices, and so forth, are not well received at all in communities, perhaps affecting real estate values in their minds, or whatever the perceptions are. We sense some of that as we move around. What are you doing, either at your level, or at the state level, to address that as part of the educational process, to focus on it specifically, where you find these kinds of obstacles to progress?

MS. QUICK: Well, unfortunately, I want to mention that those issues are not just true related to AIDS. Zoning questions have been a big problem in this community for years; whether you're talking about group homes for the retarded, community mental health facilities, even services and programs for the elderly have been universally rejected in some parts of the community. I think that there are a couple of things that can be done. Clearly, as you point out, education is more than cognitive information. It is some kind of a change in attitude.

I think that one of the things that we've attempted to do at the Advisory Committee level is make sure that the people who are normally leaders in those endeavors, Legislators, Commissioners, City Council members, are participants in the process, so that as they change their attitudes they can lead the way. Things like corporate donations, the American Red Cross activities, and others, I view a lot of it to be, you know, as a citizen, if I say, "He's done that, Citicorp has done that, so maybe it's okay for me to do that; Red Cross has done that, so maybe it's all right for me to do that; the Legislature has taken their position; maybe there is in fact something to it."

Clearly, for example, in the school system, you'll hear from our school system that they're a particularly enlightened group of people on our school board, and they've made sure that children have access to the classroom, as well as teachers not losing their jobs, but it is not easy. The cognitive information is only a piece of it. I frankly think that some of the mixed messages that the public has received, even from the highest levels of government, further exacerbate our local efforts to deal with it, but I share your concern. We go and talk, and every time somebody wants the Charlie Project for a dependent youth to move into a neighborhood sponsored by the Menninger Foundation and the Junior League -- you couldn't get two more respectable organizations -- and everybody says, "Not in my neighborhood." I'm concerned, as you are, that they've not been accepted. I think there are two aspects of education. Certainly that what's provided by the media will help.

Some of the situational kinds of programs showing people that have AIDS in close contact with other people, for example, I think will help. It is an attitudinal thing; it's not a cognitive thing. I hope church leaders can help in that, and we have them as well. Clergy are involved in our committees and task forces. If they say, from the pulpit, as they have, "This is a disease; this is a virus; this is not a curse; and we have a right and a responsibility to care for people humanely," I'm a little bit more confident that as people like that address that issue that way, that others will follow, but I share your frustration.

CHAIRMAN WATKINS: Isn't one way to impact on that particularly to take a hard look at the degree to which AIDS in the workplace is accepted and, hopefully openly accepted when it may be suppressed within the various businesses and industries in the local area? I know we're inundated in the office in Washington with rather impressive documents on AIDS in the workplace; how large organizations, businesses are handling this. An entire business council meeting at Homestead, some of the top CEO's of the nation spent the entire day on AIDS in the workplace and how it would affect them, their liabilities, their insurance, and so forth, to awaken them to this particular issue. I'm just wondering the degree to which that has been done here. It doesn't sound to us, as we sampled the water going around, that there was that kind of business involvement in the networking system. In many networks around the country you have some of the most prominent business leaders personally involved in that networking because of the bridge that's necessary between the workplace and other elements of the entire equation that surrounds the AIDS epidemic.

MS. QUICK: I really couldn't speak for Palm Beach and Broward County, but the Health Coalition, which is our business and industry coalition, which I might add that our Health Planning Council put together some years ago, initially concerned about health care cost containment, has done some educational things with their membership, and they represent the 20, 25 major employers in South Florida. John Sforza is on your program later today, and I would encourage you to ask him similar questions, if he doesn't respond in his presentation to your satisfaction. I think that they have tried. Again, I think there are two issues: One is the cost to the employer, and their obvious concern with respect to insurance issues and days of work lost and opportunity costs. The other is the fact that the realistic nature of the transmission of the disease, that it's unlikely to get it from a fellow worker, whether you're

sitting across an assembly line or across an office, and making sure that they understand that there's no threat to their other employees by having people that are HIV positive or even moderately ill in the workplace. I think that those are two issues.

We've got representatives of that kind of business community participating in our planning processes, both for this and everything else we do, but I would tell you that it's slow because again it's a leadership issue. You have to have the CEO say, "It's okay for me to have my personal secretary have AIDS," before the guy down in the factory is willing to have the guy across the assembly line from him also have AIDS.

CHAIRMAN WATKINS: Do other members have questions? Dr. Primm?

DR. PRIMM: Ms. Quick, I just wonder what particular efforts have you made to target those groups who seem to be in greater numbers represented among those persons diagnosed to have AIDS, like Blacks and Hispanics, and of course, Caribbean Blacks?

MS. QUICK: Again, the Health Council, and I think it's part -- you'll notice today, I think, that part of being in Miami is that you're very aware, and I'm a born and raised Miamian, that this is a multi-ethnic community. Everything that we've done, every committee we've ever had, mental health, AIDS, long-term care, we always make sure that we involve both the leadership and grass roots people, all segments of the community. The minority health symposium that was held last month had a whole track on AIDS in minorities. Dr. Beam, Reverend Beam, whom I'm sure most of you have heard of, was one of the major presenters at that. We've gotten involved with the Urban League efforts, the Metro Miami Action Plan efforts. Some of our minority based community health centers and community mental health centers are competing for conference of Mayor's money and state education money to better target and reach out to both with educational efforts, as well as care and treatment efforts in minority populations with whom they work every day.

The biggest problem, frankly, with the minority issue, that I would bring to your attention and ask you to pursue as you go along, has specifically been with the Haitian community, for whom their own leadership has had very mixed emotions about acceptance of the high rate of the cases within their population. It's a real Catch-22, if you think about being already a minority group member, speaking Creole, not Spanish, in a bilingual community, being here for economic rather than political reasons,

having difficulty with education and jobs, and then someone says to them that you would like them to also put an "A" on their forehead and say, "We have a disproportionate share of AIDS." That's been a problem for their own leadership, but I think that you'll find this as you talk to people, that they're coming to recognize that the recognition of that problem also means resources, and they're prepared to make that tradeoff now, even more than they were when we started our planning process two years ago. Clearly, we cannot do everything. I want you to understand that when the Health Council sat down to write this plan we had no earmarked resources for planning, and to date we still have no earmarked resources for planning. The South Florida AIDS Advisory Committee is funded through a combined purse of foundation projects to total $23,000.00 this year. That was for all the materials, mailings, meetings, for a 37-member committee. We do what we can. We've been fortunate that we have a really good relationship with our media, and I think that they've helped us, especially the media in the Black community and in the Hispanic community.

CHAIRMAN WATKINS: Thank-you very much, Ms. Quick. We're going to have to move along to our next witness. Thank-you very much.

MS. QUICK: Thank-you so much.

MS. GAULT: Dr. Joyner Sims, State AIDS Program Administrator.

CARE & TREATMENT CONCERNS JOYNER SIMS, Ph.D., STATE AIDS PROGRAM ADMINISTRATOR

DR. SIMS: Mr. Chairman, I want to talk just briefly about patient care networks in Florida. My task will be made especially easy because of the previous presentation. Our premier patient care network in Florida of course is here in Dade County. It's functioning very, very smoothly for reasons that I'm sure are already obvious to the Commission from your visit yesterday at Jackson Memorial, and from the comments that Linda Quick made. Our patient care networks have just I think one objective in mind: that's to provide a continuum of quality care for persons with AIDS and persons with ARC at a minimum cost. That's certainly taking place in Dade County where the network is fully established and functioning so very, very smoothly.

Our state role in this effort has been relatively easy. That role has been to channel some six-and-a-half million dollars of state general revenue monies to Dade County. The community

effort here has made that process so easy; the planning work that Linda Quick spoke of, the incredible spirit of cooperation that exists in this network in Dade County. So let me go on and talk about networks briefly outside of Dade County. We do look at the work occurring here as a model for other counties in Florida, as the epidemic spreads north. We frequently say, in talking about AIDS, that Florida is filling up like a glass of water, from the bottom up. Forty (40) percent of the cases in Florida are in Dade County. Dr. Witte gave you other data. Forty-seven (47) counties in Florida have reported one or more cases. There's no indication that any county will be spared in the next few years. So with that knowledge, the state legislature has provided general revenue funds, not only for Dade County, six-and-a-half million dollars, but for 11 other counties outside of Dade. That sum is a million seven hundred thousand dollars this year. We have made that distribution, and networks are beginning. They're in various stages of development. For example, Broward County has reported 18 percent of the cases of AIDS in Florida, and their network is well underway.

If we had an opportunity yesterday in such a busy schedule, you would have seen the Northwest Clinic in Broward County. Basically, what other counties are doing initially with state general revenue dollars, these are last paid provider dollars; they're behind insurance, private pay, Medicaid. They round out the system, and basically what we're doing, particularly in counties outside of Dade, is to use those dollars to provide services that simply are not available elsewhere by other health care providers. In Broward County we have the personal example of that. Broward County has established a patient care clinic with a very popular dental clinic. Dental services are very scarce for people with this infection, people with ARC and people with AIDS. Likewise, in Palm Beach County, where you visited on Tuesday, patient care dollars have been used to round out that state general revenue patient care dollars; have been used to round out that network process to provide services that otherwise are not being provided. Palm Beach County is in the process now of planning for a dental clinic and providing services that otherwise would not be provided.

Let me tell you that of the 11 counties outside of Dade, and Dade County, taking those 12 counties into account, we either have established or have assisted in establishing through state funds, networks in counties where more than 90 percent of all the cases of AIDS have been reported in Florida, and we feel real good about that. We have a long way to go in terms of bringing other counties up to the level of patient care services

that exist here in Dade, but we have a great model to learn from in Dade, to share with other counties as the epidemic spreads north. I would close with that, and let you ask questions.

CHAIRMAN WATKINS: Questions from the members?

(No response.)

CHAIRMAN WATKINS: One of the questions I'd like to ask is what is the overall Health Department budget, and what percentage of that is in the AIDS program at this time in the state?

DR. SIMS: I will have to share that with you later. Had I anticipated your question, I would have brought that with me. State Health Office is a part of this big Department of Health and Rehabilitative Services. I can tell you that State Health Office and Health Departments in 67 counties have a budget that's well over a hundred million dollars a year, and I can give you that exact figure later. And of that amount, you heard Dr. Witte say that monies dedicated to AIDS exceed 12 million dollars now. That may seem proportionately relatively small, but let me tell you that the first state general revenue appropriations for AIDS was the 1985/'86 state fiscal year. A year-and-a-half ago it was like a half million dollars. Last year, '86/'87, it was seven-and-a-half million dollars. This year, it's approaching thirteen million dollars. We've seen an incredible response of the state legislature in just the last three sessions, and we are certain that that response will continue.

CHAIRMAN WATKINS: One of the things that you saw, and I think you were with us at the time, Dr. Sims, as we toured around, was an expression of some concern that the growth rate in the epidemic was not being matched in a way to close on the target. There's a saying in the Navy that when you want to hit a target, if you shoot your Salvo short, you've got to shoot the next ones long in order to hit the target, and the question is are you closing on the problem in terms of the budgetary addressal of the issue.

We heard of waiting lists for people getting into interim care facilities, and the kinds of things that you need, inadequate resources to provide minority representation on the crisis network hereduing the last two days. There's just many things, and then next year there will be, perhaps, continuing delays and that sort of thing. Are you closing on it from a budgetary standpoint from your point of view?

DR. SIMS: I can say without hesitation that we've made incredible progress in the last three years. There's still that gap, and we feel confident that year by year we're going to close that even further. I would just say what you already know about Florida, all of you, that it's a big state; that there are literally hundreds of people every day moving in; that there are all kinds of demands placed on our Legislature. I think you know that in recent months much discussion about our prison system and early release of prisoners for lack of housing, and the list of concerns that our state leaders have to address are long and expensive, but looking at that bigger picture, and looking at the funds directed towards the AIDS effort in Florida in recent years, we feel very good, and we feel the response has been very fair. We have no criticism at all.

CHAIRMAN WATKINS: Thank-you, Dr. Sims.

MS. GAULT: The next witness is Dr. Fournier.

CARE & TREATMENT CONCERNS ARTHUR FOURNIER, M.D., AHEC PROGRAM DIRECTOR, UNIVERSITY OF MIAMI

DR. FOURNIER: Good morning. I'm Dr. Arthur Fournier; I'm an Associate Professor in the Department of Medicine. I've had a nine-year experience in teaching primary care education to medical students, interns, and residents, and I've also had an eight-year experience in treating patients with HIV infection. What I'd like to do this morning is share with you some of my perspectives with regard to the impact that AIDS has had on medical education, and the health care delivery system, and point out some ways that I think you might be able to help. It's my opinion that a generation of physicians were trained and matured in an atmosphere of complacency. Beginning with the discovery of penicillin and spurred by the development of antituberculous medicines and various vaccines, we operated under the assumption that the major infectious diseases could either be cured or eliminated through vaccination programs.

Although we all hope that a cure or a vaccine for HIV infection is just around the corner, the epidemic has shocked us back to the historical mainstream. The physician can diagnose, he can counsel, he can comfort patients and their families, but seldom can we cure. The AIDS epidemic has challenged the profession to deal with some previously tolerated inadequacies in our education and delivery systems in the following areas: 1. Continuing medical education concerning burgeoning knowledge and

new technologies. 2. The mal-distribution of physicians, both with regard to geography and specialty choice. 3. Medical ethics. 4. Medical economics.

Since the epidemic first surfaced in 1979, we have witnessed the delineation of clinical syndromes associated with immunodeficiency. We have worked through the basic immunology. We have conceptualized risk behavior. We have identified the virus. We've developed screening tests and partially effective treatments. The currently existent systems for continuing education of practicing physicians, the usual being hourly didactic sessions at monthly staff meetings, or tax-deductible courses in desirable tourist locations, are inadequate distribution vehicles to deal with this information explosion.

Recently developed programs at HRSA and the National Institute of Mental Health to involve academic medicine and the continuing education of community health providers should be encouraged and expanded. It's my belief that there are several reasons why primary care physicians should be encouraged to be the principal longitudinal providers of care to HIV infected individuals. 1. Patients with AIDS represent a minority of those exposed to HIV infection. Those in need of screening and counselling are usually asymptomatic and should be dealt with in an ambulatory setting. 2. If the epidemic meets current projections, the resources of tertiary centers will soon be overwhelmed. 3. The epidemic is spreading from its point of entry Eppi (phonetic) centers into every region of the country. Tertiary referrals resources may not be available to all infected or at risk patients. A related phenomenon is the phenomenon of going home to die. Although many patients are diagnosed and counted for statistical purposes in the major cities where the epidemic has first manifested itself, when resources are exhausted, they frequently return to their families in every corner of the nation. 4. Tertiary care is by nature discontinuous, costly, and frequently more impersonal than that provided by primary care physicians. 5. Modern primary care physicians receive special training and interviewing techniques, such as how to take a sexual history, interpretation of screening tests, and counselling. These skills are especially germane for the care of HIV infected patients. 6. The full-blown illness is multi-system and patient management frequently requires a broad base of general knowledge that transcends some specialty concerns.

Therefore, an optimum health care system for dealing with the AIDS epidemic should foster already existent programs, which are designed to redress the mal-distribution of physicians

in terms of both specialty choice and geographic location, and encourage primary care trainees to become knowledgeable about AIDS related matters. The relative absence of well trained primary care physicians, knowledgeable about AIDS, willing to serve in our inner-cities, and care for people exhibiting risk behavior is the most glaring deficiency of our current system. Federal programs such as training grants and general internal medicine, pediatrics, and family medicine, the Area Health Education Center Program, the National Health Service Corps, and federal funding for community health centers are all designed to address the mal-distribution problem and should be given full support of the President and the Congress. These programs, in turn, should be encouraged to develop the training of primary care physicians in AIDS related matters. A related issue is the impact of AIDS on career choices.

Having to deal with AIDS patients is already seen as a negative factor for choosing training in internal medicine and its procedure oriented specialties, such as gastroneurology and pulmonary medicine, and in surgery, particularly in training programs located in cities with large numbers of AIDS patients.Only a combination of accurate information concerning the relative risks of infection, effective risk reduction policies concerning exposure to blood and body fluids, and an appeal to the professional responsibilities of our trainees towards our patients, can reverse this alarming trend. The epidemic has also brought into focus the need for ethical training among physicians. Physicians are only human. We are not immune to the irrational fear of contagion or prejudice against patients who have practiced high risk behavior. A consensus among the profession on generally recognized ethical principles concerning such issues as confidentiality, refusal to treat, intensive treatment of terminal illness, and equal access to care need to be addressed and disseminated publicly. I've been told my time is up, so I'll stop at this point.

CHAIRMAN WATKINS: We really hate to cut you off, Dr. Fournier, because what you're telling us is very useful to us, and I hope we will have your statement here for review by the Commissioners because I think we may want to follow up with you. This will be a major focus of this Commission's effort, and I think you've given us some very sensible comments this morning and insights on one of the key obstacles to progress, as we view it also. I want to thank you for that, and we'll have to move on to the next witness.

MS. GAULT: Dr. Paula Sparti.

CARE & TREATMENT CONCERNS PAULA SPARTI, M.D., MIAMI, COMMUNITY PHYSICIAN

MS. SPARTI: Over the past two years, I've had the privilege of working with a great number of persons with AIDS and ARC. These individuals have displayed incredible courage, and in a very significant way have affected my life. I agreed to come here today and share some of my thoughts and feelings about the AIDS crisis because many of these special people are no longer with us, and I feel an obligation to speak for them. I don't wish to discuss the statistics concerning the epidemic, yet I hope you're aware of the magnitude of the problem. Unchecked, this epidemic will stress and rupture every leaky seam in our society.

We can take this opportunity to correct some of the inculturated injustices or continue to ignore them. The following are areas of particular concern to my patients and myself: The first is upcoming legislation related to mandatory testing in various settings. The word mandatory is frightening because it implies abandoning the principles of informed consent and the protection of individual rights. It is, however, becoming more obvious that this sort of legislation may very well come to pass. I ask that you strongly recommend that such testing and reporting not be done prior to confidentiality and anti-discrimination laws being on the books and enforceable.

I further encourage a recommendation that state legislators confer with state medical association AIDS task force groups in order to evaluate whether their intended outcome of a bill is likely to be achieved. There's a strong desire on the part of many well intentioned people to do something, yet frequently their recommendations are based on fear and inadequate knowledge. This has a great potential to divert energy and money from areas of desperate need. Education, access to health care, terminal care facilities, and research must be our priorities. I encourage you to meet with the people who work in these areas every day to begin to delineate the problems and potential solutions. Individuals, because of denial, are continuing to expose themselves to this horrible disease. We need to intensify our efforts to break through this defense, and help those individuals not already infected to remain disease free. This is not an easy task, and requires a concerted effort on the part of educational and psychological experts. Continued failure to give this crisis the attention it requires is nothing short of criminal. The Helms Amendment is further sad evidence that people are not willing to put their personal prejudices aside in order to save lives and our society.

The Surgeon General of the United States has had the courage to support all measures necessary to end this epidemic, including situationally specific safer sex education, clean needles for IV drug users that continue to use, and abortion counselling for HIV positive women. He's come to these conclusions despite his conservative personal views, and I commend him on his objectivity.

The area of access to medical care for persons suffering from this disease is of great concern to me. I see people every day who find themselves faced with a terminal illness and no access to health care because they're uninsured, and the public health care system is overwhelmed and can't accommodate them. The only humane thing to do in this situation is to decrease the waiting time to receive Medicare benefits to no more than six months for those individuals who paid into the system, but will not live long enough to realize their benefits. You may ask, "Why are AIDS patients any different than other people with a terminal illness?" In some ways they're not. My hope is that we can use this nightmare as a catalyst to right some of the wrongs that exist in our society; one of those being that access to health care is based on one's ability to purchase it as though it were an expendable commodity. Laws and regulations regarding the exclusion of persons with infectious diseases from terminal care facilities must be changed to accommodate the large number of people that won't have the benefit of dying at home with loved ones in attendance. We can't continue to allow people to die alone without any supportive care. Last but not least, we need to look at the barriers to rapid yet academically sound research of all promising substances, not just substances of particular interest to notable researchers or those with substantial corporate backing. We also need to make possible the acquisition of any substance that is of potential benefit to persons that are unlikely to live long enough to await the outcome of ongoing research. You would want nothing less for your loved ones.I hope that the recommendations you arrive at are not based on fear and prejudice, but arise instead out of a dedicated effort to understand the problems ahead and formulate solutions based on knowledge and love.

(Applause.)

CHAIRMAN WATKINS: Thank-you, Dr. Sparti. We have time for a question from Commission members.

(No response.)

CHAIRMAN WATKINS: One issue raised in the last few days was that many doctors, particularly specialists, resist placement of AIDS patients in hospices or home health care situations.It was even suggested in one of our visits that their consulting fees are a motivating factor. I wonder what your observations are as to whether the doctors in this case are part of the problem.

DR. SPARTI: In placing people in home care?

CHAIRMAN WATKINS: Yes, that specialists resist that placement for some reason.

DR. SPARTI: If someone becomes a part of a hospice program, and is admitted to an in-patient hospice program, you have the option of taking care of the person yourself or assigning the care to a hospice physician, and you can be paid, so I don't understand that comment. In terms of home care, I don't know if you're talking about like South Florida AIDS Network. That's a problem because the patient has to be a patient of a Jackson physician. I recently came upon a case where I was called by the lover of a person with AIDS who was terminally ill and needed some basic kinds of things. He wanted him to have a feeding tube so that he could give him his medicines. Even though he was imminently dying, his lover was not ready to let go yet. He also needed to have an air flow mattress so that he could try to deal with his decubitus ulcers that had come up. I wasn't able to get him into Jackson; I wasn't able to contact the physician who he had an appointment with six weeks in the future to see. I admitted him to South Miami Hospital, and because of that his home care benefits through South Florida AIDS Network stopped, because I'm not a provider in that system. That's a problem, but --

CHAIRMAN WATKINS: What is the solution to that? Is that a local regulation? Is that something the state has to get into?

DR. SPARTI: That's probably a rule on the part of South Florida AIDS Network that clearly needs to be changed because there's a real access problem to Jackson Memorial Hospital. I literally do see patients every single day that are brought in, carried in by their family members or by their lover, and they are terminally ill, imminently terminally ill, and they've been either turned away by the triage nurse, or seen a house staff member who decided for whatever reason this is not an appropriate admission. It sounds like people are making decisions about scarce resources and access to scarce resources,

not at the administrative level, but like house staff members and triage nurses.

CHAIRMAN WATKINS: Are you a member of the Network?

DR. SPARTI: No, I'm not.

CHAIRMAN WATKINS: Have you made recommendations to the Network along these lines?

DR. SPARTI: I've spoken with people in the Network, yes, specifically about this case, but as things come up, yes.

CHAIRMAN WATKINS: Thank-you very much.

MR. CREEDON: Doctor, is this a problem of there not being enough hospital beds here? What is it; I don't understand. Are there not enough hospital beds in the area to accommodate somebody who comes in and looks like they're terminally ill?

DR. SPARTI: If they don't have money, sure. It's a matter of money.

MR. CREEDON: It's not a question of the adequacy of the number of hospitals, it's a question of them not having money?

DR. SPARTI: There are hospitals in our community, many, that are running occupancies of 50 percent, and would do anything to have people in their beds. Jackson Memorial Hospital is a 1,250 bed hospital and is full. I've had patients in the Emergency Room for two and three days with pneumocystis carinii pneumonia and being given medications that need to be monitored in little holes in the Emergency Room.

MR. CREEDON: But if those people were taken to a different hospital, would they be accepted there?

DR. SPARTI: No, not in this county.

MR. CREEDON: Because of financing. In other words, they have no money.

DR. SPARTI: Right. In other counties where they don't have a Jackson Memorial Hospital, the responsibility on the part of each and every hospital of taking care of some indigent patients is there.Here, all the hospitals in the community feel

that Jackson's supposed to take care of indigent care. If the person arrives at South Miami Hospital, Doctors Hospital, Larkin Hospital, any other hospital in this community, and is not going to die while being transferred to Jackson, they won't be accepted.

MR. CREEDON: What about Medicaid? Medicaid doesn't cover in these other hospitals?

DR. SPARTI: There are hospitals that accept Medicaid, including South Miami Hospital. I've tried admitting Medicaid patients to South Miami Hospital. The difficulty is even if I'm willing to accept 10 percent of what my charges are -- that's about what I receive from Medicaid in-hospital care -- my consultants won't, not on a repeated basis. I can say, "Look, I've given you lots of business; you have to do this," and try, but they're already a small group of consultants that are willing to see my patients.

MR. CREEDON: But a big part of the problem then is that the Medicaid allowances are not adequate?

DR. SPARTI: It's very, very inadequate in the state. I know that it's supposed to be going up this October past. I don't know what it went up to, but I'll be interested to find out.

MR. CREEDON: Thank-you.

CHAIRMAN WATKINS: Yes, Ms. Gebbie.

MS. GEBBIE: Just to ask an additional question about this access to specialists. You've already said one of the problems with referrals to specialists is simply the fee structure for those on Medicaid, but the other issue that we've heard about is that many specialists who are not as immersed in the care of AIDS patients as some primary care physicians are still caught up in fear and some lack of information about the epidemic and therefore refuse to accept patients, perhaps without articulating that. Is that your experience? Are there surgeons or specialists who simply stay away from AIDS patients?

DR. SPARTI: Yes, and with articulating that. I mean, I've had specialists say to me, "These people should be warehoused; they're going to be a terrible drain on the financial resources of this country. "Yes, physicians are not without their prejudices also. I mean, those kinds of prejudice plus personal concerns. Surgeons that I speak with every day at

the hospital, in the lunchroom or the conference room, are panicked because as they hear about, you know, even if it's four in a thousand needle sticks, you can't help but do surgery and stick yourself, it happens, or repairing an episiotomy for the obstetricians, it happens, so there is some exposure, possibility.

CHAIRMAN WATKINS: Thank-you very much, Dr. Sparti. We'd like to talk to you longer but we must move on to the next witness.

MS. GAULT: Dr. Seckinger.

CARE & TREATMENT CONCERNS DANIEL SECKINGER, M.D., CHAIRMAN, FLORIDA MEDICAL ASSOCIATION TASK FORCE ON AIDS

DR. SECKINGER: Thank-you very much. Members of the Commission, I'd like to welcome you here on behalf of the 16,000 members of the Florida Medical Association, and to take a minute or so to acquaint you with our activities in the AIDS arena. I think you now have before you a formal review of our activities. I'd just like to take one minute to give you what I think is probably the most functional and successful model for a statewide organization that I have seen to date, having participated with American Medical Association and development of its policy documents as well.

Last year when we decided to be the private sector organization that would try to collate all of these activities, we at that time had existing committees in the areas of substance abuse, corrections, public health, and education. Now it's a very fortuitous fact that all of these areas have a significant AIDS component. I asked the chairman of those ongoing standing committees to participate as the matrix, and we requested that physicians in the areas of infectious diseases, family medicine, pathology, oncology, and hematology enter as well into this discussion. Very early on it became aware to us that the medical community was not an island unto itself. We therefore have enlisted the support and active participation by the Florida Dental Association, the Florida Osteopathic Association, Florida Nurses Association, Florida Practitioners in Infection Control, and the Florida Hospital Association. A number of our members have faculty appointments at the University of Florida, University of Miami, and the University of South Florida. We feel now that we have an effective matrix which transcends this spectrum from care at the interface with the patient into the research area and to a number of policy decisions that we're looking at.

I would like to, in the limited time, depart from my published remarks to emphasize what I feel is something fundamental and something that has not previously been adequately ventilated as far as this issue, and that is the matter of education. It seems to me that so much emphasis, particularly on your visit here to South Florida, and from what I've seen nationally, so much emphasis is on programmatic development. This is important, but I don't think we're going to see the events, the tragic events that took place in Arcadia cured, or alleviated, or corrected by programmatic development, whether it's in South Florida, Florida, or in other high prevalence areas. What we must have is a comprehensive broad based educational program that bring into play the lay community, the professional community, and paraprofessionals. Three months ago, I commissioned an editorial sub-committee to look into this. We are now well on the way of developing an AIDS manual for the 16,000 physicians in Florida. The Florida Medical Association has contributed $25,000.00. Dr. Praitha, a health officer, and I'd like to acknowledge the support from HRS which has been marvelous, they have committed to publishing this, but we're still about $100,000.00 short. I really feel that one of the major areas that we have to look at, and here again there is a short-term aspect which I've already touched on, but I think as you get a little bit downstream we're seeing such things, particularly within isolated areas of the dental community and medical community, of access to care. There is an apparent negative physician bias, and other professionals as well, who through lack of education and understanding, perhaps, do not want to care for these patients. We've also heard that nurse recruitment downstream may be negatively affected if we can't do something to understand the hospital environment and to see that adequate safety is available. We know, for instance, that perhaps eighteen billion dollars will be necessary in 1991 for the care of AIDS patients. Nobody has said to date how we intend to fund this. I've heard that we may topple the private insurance industry if this is superimposed on an already stressed area. We know that the public sector at this time is not prepared to handle this. The public must be educated if we are to deal effectively to create the forum in which we can ventilate and make decisions in this regard. Our committee is a standing resource, a reservoir of expertise. I serve as a consultant to the Department of Education. Others are associated with HRS. We have functioned with corrections, and as you know, there are any number of problems. We're trying to interplace the national policies, for instance, as enunciated by the Surgeon General, into the State of Florida, and it requires a great deal of time and consideration.

This major area, not that we aren't interested in programmatic support, and in seeing that all individuals receive the care, but we know we're dealing with a finite matter of funding, and I truthfully would like to make a point that we must educate those throughout the country, and particularly in lower prevalence areas where misunderstanding seems to be more apparent. Thank-you.

CHAIRMAN WATKINS: Thank-you very much, doctor. We're going to have to move along to our next witness.

MS. GAULT: Tom Arnold. I believe that Mr. Arnold's plane has not gotten in yet, so we'll have to get back to him. Hugh Westbrook.

CARE & TREATMENT CONCERNS REVEREND HUGH WESTBROOK, PRESIDENT, CHIEF EXECUTIVE, HOSPICE CARE, INC.

REVEREND WESTBROOK: Mr. Chairman, members of the Commission, I'm Reverend Hugh Westbrook, President of Hospice Care, Incorporated. We operate comprehensive in-patient and home care hospices here in Miami, as well as in Dallas, Fort Lauderdale, Florida, Fort Worth, and Chicago. We provide case management and direct palliative care services to more terminally ill people than any other hospice or hospice-type organization in the United States.

We regularly care for persons with AIDS in all of our hospices, and have done so since 1984. Mr. Chairman, while all Americans look to you and this Commission to do everything possible to develop public policy leading to the cure of AIDS, I'm here today and Hospice is here today, because absent that earnestly sought for cure, 100 percent of persons with AIDS are terminally ill. One hundred (100) percent are likely to die. A IDS is a terminal illness, and as someone involved in the care of the terminally ill for more than a decade, I believe that one of the reasons that we as a nation seem to be at a loss in responding to the AIDS patient and misunderstanding the AIDS patient, and perhaps even fearing the AIDS patient, is not just because we have perception that that patient may come from a segment of society that we don't like, but that also that is a dying person. In this country and in our culture we're not that well equipped to deal with terminally ill people. We simply don't know how to respond no matter what the disease, no matter what the diagnosis. Few of us want to confront the notion of dying in ourselves or in our patients. Like Woody Allen said, "I'm not afraid of death. I just don't want to personally be

there when it happens." Hospice isn't afraid of being there when it happens, of the death or of the dying.

It is what we do; to comprehensively manage and deliver all of the services in-patient and out-patient, home care at home, that relate to the management of the person's terminal illness, physically by directing, employing, and providing the care of physicians, nurses, therapists, aides, homemakers, specially trained, specially supervised, and specially committed to the dying patient. The philosophy, organization, delivery mechanism, and reimbursement mechanism which governs and defines the service of a hospice is diagnosis-specific case management. All we do is care for terminally ill persons and their families. We provide all the care related to their terminal diagnosis. We at once are the case managers and the care providers. The reason Congress pays separately for Hospice Care is because we are also cost accountable. For a set, pre-determined, all inclusive price, hospices provide all inclusive services. Because we are the case managers, and the care providers, and because we are cost accountable, every time a terminally ill person chooses Hospice as a comprehensive alternative to the traditional system of health care, the public or the private payer of that health care saves money. It seemed to us a natural part of our mission that when AIDS patients were first diagnosed in this country, some of them Haitian refugees here in Miami, that we should care for them.

AIDS patients are dying people. Hospice is the expert in caring for dying people, and in managing all of the resources compassionately and cost effectively, so we thought caring for AIDS patients was our job, and we're trying to do that job. In San Francisco, here in Miami, and hopefully in Chicago, and elsewhere in the nation, hospices have played pivotal roles in not only caring for persons with AIDS, but in organizing community networks of care. I believe that Hospice is, however, underutilized in the care of AIDS patients, as it is uniquely prepared and able to care for those patients. Both the cost and the comprehensiveness of AIDS care are tied directly to how the care is managed and by whom. You heard Dr. Sparti speak of a patient who fell through the cracks of the system; that could not get and access the services necessary to meet the needs of that patient. I think that that's an outcome of some of the approaches that we are struggling to develop that are not quite working up to speed in care of the AIDS patients. In general, it seems that there are three ways to manage AIDS care and AIDS costs. First, unmanaged care and unmanaged cost. Perhaps typified by Dallas where we operate a hospice, unmanaged care is simply the lack of a system. Patients are left to shift for

themselves and so are the payers. With the lack of even symbolic coordination, some providers provide some services to some patients; most providers provide few services to few patients, and wasteful duplication exists side by side with gross neglect. Each part of the health care system and each provider in each part plans independently, cares inadequately, and costs soar out of control. In Dallas, for example, the diagnosis to death cost of AIDS care are roughly estimated to exceed $150,000.00, which is more than $700.00 per calendar day. As you know better than I, most American communities today provide unmanaged care for AIDS patients. Secondly, there's network care. Perhaps typified by Miami, where we also operate a hospice, the network approach to AIDS care and cost is a brokerage system. One entity or group is selected as the broker of most AIDS care dollars. That broker finds multiples of other agencies, providers, and groups to each provide some slice of the needed care for some slice of the AIDS dollar. The broker is relied upon more or less to triage patients appropriately. More or less, patients may find their way through the catalog of brokerage services. Care is more organized and perhaps more accountable than where unmanaged. Costs tend to be the same, perhaps less. Here, our network is operated by compassionate and competent people, yet there's no clear reported figure on the number of patients or the cost, though the estimates run from 500 to $1,000.00 a day.

The final alternative that I wanted to bring to your attention is that of managed care. It's the application of the hospice concept and approach to the management and provision of care, so that the manager of the care is also accountable and responsible for the delivery of that care. Hospice, as the Miami News in an article about our organization said this week, is not about dying. It's about living life fully to the end. It's about hope for a cure or even a miracle, to be sure, but hope as well for a day without pain, a place to call home, a life and a death with dignity. Hospice is a realizable hope, however, that costs can be controlled so care is not rationed.Hospice is hope until there is more to hope for. The AIDS patient and the AIDS payer should hope for no less. Thank-you.

CHAIRMAN WATKINS: Thank-you very much, Mr. Westbrook. The Commission, in setting up the schedule today, wanted to allow as many presenters as possible to come before us, and we regret very much that we're unable to ask as many questions as we would like. You're in a very important area from the Commission's point of view. We will reserve the right to come back and chat with you again, perhaps, on some of these issues, and let our

Commissioners have a chance to work with you. I'm sorry we just can't take the time now; we know this is an extremely important area.

REVEREND WESTBROOK: You asked a question a moment ago of Dr. Sparti about what barriers there were, and we have some very specific comments to make about that if you care to talk about this.

CHAIRMAN WATKINS: Would you be willing then, Mr. Westbrook, to write me a letter, as Chairman of the Commission, and I'll share it with the other Commission members, because one of the formats that we will follow will be obstacles to progress, and it's coming out more and more that this might be a useful tool for those in leadership positions to look at the plethora of obstacles that we have, many of which are self-imposed. It isn't all money and resources, as we all know, so I would like very much to have your recommendations, if your statement does not include them thoroughly enough.

REVEREND WESTBROOK: It includes some, and we can add to that.

CHAIRMAN WATKINS: If you'll write us a letter, I'll assure that all the Commission members receive that.

REVEREND WESTBROOK: Okay, thank-you.

MR. CREEDON: I think especially on this concept of managed care.

REVEREND WESTBROOK: Yes, sir.

MR. CREEDON: Managed care, very important.

REVEREND WESTBROOK: I believe that's the key, not only to the quality of service received by the patient, but to the containment of the cost.

MR. CREEDON: Right.

REVEREND WESTBROOK: The two go together.

CHAIRMAN WATKINS: It's come up before the Commission many times. We're very sensitive to that issue, and I think it's going to be one of the major elements of our report to the President. Thank-you very much.

REVEREND WESTBROOK: Thank-you, sir.

MS. GAULT: Patrick Haney.

CHAIRMAN WATKINS: We have just cancelled the break, so we can proceed.

PERSONS WITH AIDS CONCERNS PATRICK HANEY, BA, MSW

MR. HANEY: Good morning, and thank God you are here. My name is Patrick Haney. I'm a person with AIDS, diagnosed with ARC in June, 1984, and AIDS in September, 1987. Speaking with you is my attempt to make the most of a bad situation, and because I'm not sure how much longer I have to live. I'm determined to accomplish as much good as I can with what time I have left. The public believes AIDS is a problem affecting someone else, fringe groups, such as gay men, Haitians, IV drug abusers, but the public is wrong. HIV infection directly affects several million in the U.S. Indirectly, it affects us all because of its impact on medical care and cost, social services, loss of productivity, and loss of incredibly sensitive, creative geniuses, and loving human beings. It affects us all, for we are your sons and daughters, your mothers and fathers, your brothers and sisters, your neighbors, your co-workers, your fellow students and friends. We are all one.

What is the real issue here? Between the lines of all the statistics, budgets, media hype, and talk, is the real issue, individual human pain, suffering, and death. This is not a Stephen King novel; it's not a game.For those of us HIV infected, it's twenty-four hours a day, seven days a week. We can't leave our interest in AIDS at the office when we go home at night. The daily struggle of living with AIDS has to do with simply staying alive, and taking each day as it comes, wondering, "How many more days do I have left. "There's another epidemic along with AIDS, an epidemic of AFRAIDS. The hysteria of AFRAIDS is most clearly encapsulated in a cartoon many of us probably saw a while back. In it, a man is standing in front of his employer's desk; his employer says, "Wilson, I understand your sister met a cab driver who has a cousin who knows someone with AIDS. "Wilson says, "That's right. "The boss says, "You're fired. "This kind of hysteria continues to abound with AIDS, and the unfounded fears and panic are leading to incredibly reactionary responses which are getting worse.

Violence against gays has sharply increased. Oppressive laws infringing on the most fundamental human rights are being proposed and passed, and repressive social controls

such as quarantine of all persons with AIDS and the branding of PWAs' skin are being cried for, usually with no basis in medical or scientific fact. How truly sad, since the panic and fear are largely groundless and can be combatted through aggressive, dedicated education efforts. We have an epidemic of fear, hatred, intolerance, and discrimination that has gone far beyond the boundaries of medicine. Many parents, judges, legislators, educators, the general public, and even some medical professionals refuse to hear, much less believe, what the majority of the physicians and researchers are telling us.

AIDS is a political, social, and moral issue far more than a medical one. Those of us who are HIV infected continue to die, often in deplorable conditions, abandoned and alone. Like no other illness since the advent of modern medicine, AIDS carries with it stigma, shame, and a pointed finger of blame. We're seen as immoral, guilty, and at fault for being sick. We're hated, hounded, and discriminated against. Many believe AIDS is a punishment from God. Is diabetes God's punishment for sugar eaters, or hunger and starvation his punishment of the poor? Do we blame Legionnaires for Legionnaire's Disease, children for mumps and measles, or old people for Alzheimer's Disease and death? It's nonsense in these other contexts; it's equally absurd with AIDS. As someone else once said, "If AIDS is God's punishment against gay men, lesbians must be the chosen people. "Blaming persons with AIDS is cruel, irrational, and counter-productive.Headlines such as, "Even the innocent get AIDS," underscore this pervasive perception about AIDS. It's as if it's okay to get AIDS one way, but another way and it is somehow suddenly our fault, as if we're something less than human and undeserving of a dedicated, compassionate response to help. How isolated from society I have sometimes felt; how abandoned, alienated, and alone at times. The sense of urgency I feel about AIDS reminds me of the cartoon my friend John had on his kitchen wall. Two vultures are sitting on a fence and one says to the other, "Patience my ass, I'm going to kill something."

We need your help now. Americans are caring and generous people, but fear about AIDS and hatred of homosexuals has blunted this historic compassion. A massive campaign to educate the American public is vital. We need to wage a war with the goal being acceptance of all people and recognition of our common humanity. We need this country's compassion, patience, understanding, advocacy, and research grant funding authorization. And we need the basics of food, shelter, medical care, and other support services. For God's sake, we don't have time to wait any longer. Please convince the President, Congress, and the American public that we have no more time to

waste. The Constitution guarantees the right to life, liberty, and the pursuit of happiness. All we want is the chance to live. Is that so much to ask?

(Applause.)

CHAIRMAN WATKINS: Thank-you very much, Patrick. We had the privile ge of meeting Patrick and some of his colleagues earlier this week, two days ago at the AIDS Clinic under the Palm Beach County Health Department. We were very impressed with him then, and impressed with him now, and I can assure him that we are moved by his presentation to us, and we're extremely sensitive to the issues he raises. He's the kind of individual that gives us additional incentive to press on with our work on an urgent basis. We have to have the next witness now.

MS. GAULT: Jim Merriam.

PERSONS WITH AIDS CONCERNS JIM MERRIAM

MR. MERRIAM: Hi there, I'm Jim Merriam. I'm also a person with AIDS. I was diagnosed eleven months ago. I suppose that the two major things that other people with AIDS have asked me to come tell you are (1) please hurry up; and, (2) the recurrent theme that you've been hearing for the last couple of days is that while there are lots of people doing good work, there's also lots of holes in the system that people are falling through and suffering and dying because of that. I brought sort of a shopping list of things that I thought perhaps you wouldn't hear from other people, and I'd like to go through it real quickly. Probably the biggest thing the Commission can do is to say, "There is a problem; it's a huge problem; it's way out of control, and it's time to do something immediately." We need leadership from the leaders of the U.S., and you all can certainly set the tone for that by saying, as I say, "There's an enormous problem and something needs to be done." You've had some PWA involvement in the Commission. You have somebody in your office who has AIDS. I'd like to encourage you that that be expanded and continued. It's very difficult because of people being sick and such, but it's very important for PWA's, people with AIDS, to be involved in future hearings, to be involved as volunteers on the staff of the Commission, and to be involved as paid staff members.

I have a whole list of education things. One is the federal government publishes a whole bunch of brochures. Here's one on chemotherapy. There's a variety of them on cancer

treatment, heart problems and whatever. A similar thing is not done for people with AIDS. This would be brochures on how to take care of yourself. "Here's the symptoms of opportunistic infections." "Here's the experimental drugs that are used against them. "There are people that have manuals. This is put out by AIDS Project, Los Angeles, but they're all sold. There's a need for the government to get involved in that to do more in the way of brochures in self-care for people with AIDS and for people who are taking care of people with AIDS. One of the things that happens to people with AIDS frequently is that they go blind, or they're too sick to sit up and read. There's a need for the Library of Congress or a similar group to provide taped materials for people that are blind or are too sick, again on AIDS. In Florida, there's only one book available through the Talking Book Service; it was written in 1982. It talks about, "AIDS might be this or that, and there are dozens of people sick." That's the most current book available to blind people in Florida. The CDC has put restrictions on the number of brochures that are available for educational purposes, often times 25 at a time; very unrealistic. That's not even one for each county in Florida, and yet rather than saying, "Well, gee, we have an emergency and it's time to do anything we can to stop it and to help people," somebody in Atlanta is saying, "No, 25 brochures at a time." That's not realistic and it needs to be changed.

The Public Health Service videos which are supposed to be used to educate people, both general public and health care workers, are boring. I can't stand to watch them, and I'm really interested in the subject. It's an example of again making it difficult for people to get information to learn, rather than making it any easier. Again, the Public Health Service videos should be updated. You've heard again from other people this morning that there's an incredible need to staff, for doctors, for nurses, for researchers, for volunteers to take care of people with AIDS. There's a long lead time in training people, and there's not enough being done to train the people that are going to be needed in coming years to deal with the AIDS epidemic. Obviously, if it's doubling every year, we need almost to double the personnel, and yet the training is not being done. The federal government needs to be involved in that training. To pay for AIDS, one thing that should happen is to waive the two-year waiting list for the waiting period of Medicare. You've heard some of the reasons already from other people that most people die before the two years is up.

So it's critical that they get the medical care early, the intervention early. Naturally, I want to ask for more money for everything, including both AIDS drugs and for research and

testing of drugs that are used against opportunistic infections. In Florida we have a significant number of foreigners who come here for treatment. It costs a hundred thousand a piece, probably, to take care of them. It should be a federal responsibility. We're talking about millions of dollars a year spent that's picked up by local government here to take care of people from other countries that come here with AIDS. Again, it's nice that we're taking care of them, but it should be a federal rather than a local municipality responsibility. Insurance companies are now beginning to write out, add riders and exclusions to AIDS, or limitations on it, and there's a variety of insurance, not just health. As an example, my homeowners' insurance now won't cover any suits that involve AIDS. I hear people constantly that say, "Well, I had health insurance that had a million dollar cap on it, then the company I worked for changed companies and the new insurance policy will cover a million dollars for heart attacks and strokes and things, but only $5,000.00 for AIDS, or maybe a $15,000.00 lifetime cap." Again, if something is not done about that, the problem is going to be pushed off on the particularly local governments to pick up the cost. The insurance companies are wiggling out of taking care of people, and it's going to become a larger and larger problem.

At the University of Miami here, their AIDS treatment evaluation unit, to get into the system, this is for experimental drugs, you have to pay cash to go get screened, to get your blood drawn and get your chest x-rayed and whatever. They won't accept Medicare; they won't accept Medicaid. They won't accept private insurance; they don't like to take checks. Again, that's not the medical care, but the access to experimental drugs and stuff. Again, it may be something that if the federal government is already funding those programs, that you might want to say, "Well, let's encourage people who are too poor but who would like to take part in experimental programs." We're talking about $50.00 a person or something to get them in, and the federal government ought to include that. Again, the University of Miami provides free research to people if they can get into the program, but they often times don't have the money to do that. That's also true at the National Institute of Health that they will not pay for transportation and for some of the initial costs associated with getting into a program there. Once a person's in, then they're eligible for everything for free, but the problem is again for poor people in particular, that they can't get into the program. We see that here, where there's a different demographic mix that minorities, particularly Blacks and poor people, are not able to get into the research protocols, even if they can get regular medical care at Jackson Hospital.

Finally, again, you've heard about the problem with coordination. You've heard Cure AIDS Now as talking about that they're not really part of the network. Health Crisis Network is not communicating with them, and Dr. Sparti is not part of the network. There's an enormous problem with coordination and communication between groups where people are released from a hospital, for instance, before there's been a mechanism set up to take care of the person. They've been in the hospital for a month; they've lost their job; they have no money, and they're sent home in an ambulance. They can't even walk, and they're expected to take care of themselves. So there needs some better coordination that services are provided the person when they're sent home, that there's been arrangements made for food stamps, for money to turn the electricity back on, for a homemaker to go in and take care of them, et cetera.

CHAIRMAN WATKINS: Thank-you, Mr. Herriam. I appreciate very much your well thought through outline that you've given us. It's short; it's clear; and it will be helpful to us. Thank-you very much.

MR. HERRIAM: Thank-you.

MS. GAULT: Doug Segal and Ellen Bucksteil-Segal.

PERSONS WITH AIDS CONCERNS DOUG SEGAL AND ELLEN BUCKSTEIL-SEGAL

MR. SEGAL: Good morning. My name is Doug Segal. I'm 35 years old; I've been married for almost six years. I have three small pre-school children. I am a Hemophiliac and I have AIDS. But I'm one of the more fortunate AIDS victims though. I have a large circle of friends who are loving and supporting. I have hundreds of business associates who are caring and understanding. I have a synagogue that continues to welcome me and my family. I have medical insurance; I have adequate life insurance. Most important, I have a loving and loyal wife and family that will always be there for me.

AIDS is a disease that attacks a person's soul. It will physically and psychologically and emotionally suck the life out of you and those people around you. AIDS strains your self-confidence. It can take control of your life. It can consume your every waking hour, and if you allow it to, it will strip away your dignity. AIDS can do almost anything to your body. You can lose your memory; you can go blind. You can die from pneumonia; you can die from cancer. You can die from brain disorders, from tuberculosis. You can die from liver

dysfunction; you can die from kidney failure. AIDS can make you totally dependent. I am one of the more fortunate of AIDS victims though. I have a lot of people that I can depend on. A lot of people with AIDS don't. AIDS forces you to deal with your own death. Only after accepting what lies ahead can you finish your life with some sort of meaning. I'd really like to be here to watch my children grow, to guide them, to share with them. Will they even remember who I am? What will I leave behind to my family and to my friends, and to my wife?

I am one of the more fortunate of AIDS victims though. I have a lot of people who I can leave something behind to. Doctors and health care professionals become an important part of everyday life. I take medications I can't pronounce. I usually have diarrhea. I'm nauseous a lot of the time. I have colds and sore threats that never seem to go away. My energy level slowly disintegrates with every passing day.

But I'm one of the more fortunate AIDS victims though. I can afford the best private physicians and the newest medicine. Most people with AIDS can't. Education and research are vital to erasing this deadly disease. Educating those in responsible positions, such as health care professionals, school authorities, teachers, clergy, and politicians is a must if we want the masses to understand. Understand just how AIDS can and can't be transmitted. Understand just how important it is to practice safer sex. Understand a person with AIDS shouldn't be deprived of the compassion and love which are vital for a human existence. Money should be allocated directly to those persons with AIDS and their families. Money for medical care, money for medication, money for counselling, and money for something as simple as companionship and love. All persons with AIDS should receive the same financial consideration. Don't let us die because proper care and support are too expensive.

I stand here today before this Committee able to express my feelings to you; able to tell you just how horrible AIDS really is. I guess once again that makes me one of the more fortunate AIDS victims; I'm still here to tell you about it. Most people with AIDS aren't.

MS. BUCKSTEIL-SEGAL: My name is Ellen Bucksteil-Segal. I'm Doug's wife, I'm his friend, and his lover. I do not have AIDS, nor do I test positive for the AIDS antibodies. Our children do not have AIDS, nor do they test positive. We all live together in the same household. We share towels; we take showers together. We kiss and hug all the time. Our housekeeper who lives with us washes our clothes, cleans our house, cooks

our meals; she's not afraid. Our family and friends are always there with warmth and affection; they are not afraid. We are not consumed with the fear of transmission of AIDS in our family. We have educated ourselves to the facts.

I have talked to and read about countless of individuals with AIDS who are not as fortunate. Individuals who have lost jobs, friends, and even family because of the fear of AIDS. We cannot allow the ignorance about AIDS to continue. It would be as devastating to our community as it is to the victims of AIDS and those people close to them. I don't fear the transmission of AIDS to my children, but I do fear the intolerance that someone might display toward them because of lack of proper knowledge and information. It has been almost a year since Doug was diagnosed with AIDS. As our mouths hung open in disbelief, we were told to make contingency plans and hope for the best. Like robots, we called our attorney and friends and put our fears in order. How matter of fact we were those first few days. The desperation, anger, and sorrow were yet to come. The feelings of helplessness were overwhelming; we had to do something. That is why we are here today to talk openly about AIDS.

It is a disease that transcends gender, race, religion, and sexual orientation. It is a human disease that causes human suffering. People with AIDS suffer enough with the physical pain of sickness and deterioration without adding the emotional pain of rejection and isolation. We may be the first of many generations of AIDS victims, and our legacy must be to encourage programs of research and education; education to prevent the spread of AIDS, and research to eradicate every trace. Today there is no cure for AIDS.We are facing a holocaust. It is a death sentence. No trial, no wrongdoing, simply victims of circumstance.

The blood product that was infused into Doug's body to keep him alive is what is now killing him. I expected to share a long life with Doug, and now our time together will be cut short by this insidious disease. AIDS is truly a disease unlike any other. Doug carries a deadly virus in his body which can be transmitted to me through a simple intimate act of love. How ironic that that act of love that consummates our feelings for each other, can be the same act that could kill us. Our life together with our children has taken on a different meaning. Along with thoughts of death come a new meaning of life. We are now living each day as it comes, realizing that all of our hopes and dreams for the future may have been shattered, but we must live life and appreciate each day as if it was the last.

I would like to read a poem to you that I wrote to Doug when he was sick, and I call it, "A Legacy of Love." "You came into my life a wonderof a man, so bold and strong, Yet gently you took me by the hand. You shared with me your love, a passion so intense, transforming my very souland arousing every sense. Our hearts were filled with hopes and dreams, Our love was always there. But we learned together quickly how joy can turn to despair. If I must live without you, and our time together unsure, We'll find another place in time where we will meet once more. The future seems remote, yet hope for me is real. I yearn for memories we might share, and happiness we've yet to feel. How precious is our time, the future still unknown. We may never have another chance to share our love that has grown. A legacy of love you will leave to all who mourn, of hopes and dreams, lost and won, To our children, whom you adore. If I must live without you, and our time together unsure, We'll find another place in time where we will meet once more. I share with you the pain to watch our children play, Imagining the future without you showing them the way. Yet our children, they will grow, and their lives will soon reveal, Your love marked so indelibly, your presence they will always feel. In solitude I close my eyes, my dreams help me to see, The joyful and the happy way that our life used to be. One thing that we have learned for sure, of this I'm truly glad, To live each day as if it was the only one we had. If I must live without you, and our life together unsure, We'll find another place in time where we will meet once more."

(Applause.)

CHAIRMAN WATKINS: Thank-you very much, Ellen and Doug, for the very inspirational and meaningful human story. We'll continue to move; we've cancelled the break, and we must press on with our next witness.

MS. GAULT: Dr. Rigaud.

MULTI-ETHNIC GROUPS MICHELE RIGAUD, M.D., M.P.H.
HAITIAN TASK FORCE, MIAMI

MS. RIGAUD: Good morning. It would be very appropriate if we had a Haitian with AIDS to share your concerns, and I'm sure that the Committee will agree that all the people with AIDS have the same concern and needs. My name is Michele Rigaud, and today I represent the Haitian people, and I do not represent the agencies that I work for today. I was asked to talk about Haitians and AIDS. I would like to mention that by talking about Haitians, I am representing Haitians nationwide, and perhaps worldwide, not only Florida, since we are trying to

put together a corps of support for all Haitians living with AIDS and all Haitians living in the United States. The Haitian people will never recover from the stigma imposed on them through their identification as a risk group for HIV infection. Strong national and local policies remain in place because of this ethnic misclassification. Serious social issues need to be addressed by committees such as the Presidential Commission in order that educators succeed in providing an effective, positive prevention program on AIDS to the Haitian communities. The testimony being presented today is a call for a change in policies that continue to stigmatize Haitians based on this identification with HIV infection. It is a call for more a positive, productive, innovative approach in AIDS information and education for the protection of human, civil, social, and ethical rights. We will begin this testimony by identifying some serious obstacles in reaching the community.

Printed documents highlighting policies which discriminate against Haitians, among other nationals, and you have attachments of those in your package, have caused not only confusion, but raised some concerns among the health care professionals representing this community. Attempts to implement a change have met resistance largely because of these policies. The policies used by American institutions such as health organizations and hospitals have been to the detriment of the Haitian patient, who is perceived as a potential HIV carrier. Haitian patients are subjected to routine testing for HIV infection solely on the basis of nationality.

Second, another more crucial issue is indicated by the recommendations and justifications for HIV mandatory testing. As of December 1st, 1987, regardless of nationality, all immigrants applying for permanent residency will be submitted to mandatory testing under the new INS amnesty program. However, unlike Nicaraguans, Cubans, and other political foreign nationals, the Haitians will be more likely subject to further discrimination given a HIV positive result, leading to even more economy deprivation in their community. These issues represent a compilation of concerns from the Haitian community nationwide. As a Haitian-American, I recognize that irrational discrimination will increase social, political, psychological crisis of critical importance. As a medical professional and an AIDS educator, I'm overwhelmed by the challenge in providing education and counselling to the Haitian people, given these existing insensitive and stigmatizing policies. It is imperative to eliminate policies based on irrational discrimination, and develop national policies based on scientific information and medical judgment.

Finally, we believe that once these social and political barriers are surmounted, and given a more suitable, compassionate climate, it will be possible to implement a comprehensive educational program. A resolution on behalf of the Haitian Caucus was submitted to Dr. Walter Dowdle of CDC on August 10th, 1987. We recommend that these basic guidelines be followed in addressing the needs of the Haitian population as it relates to this AIDS crisis. If I have, I think, twenty-five seconds, I would like to read part of the recommendations that we addressed to Dr. Dowdle. I will not read the whole letter, but it's considering all the different aspects of AIDS in the Haitian community, which is not different than the rest of the community. We recommended to the CDC, Centers for Disease Control, that Haitian professionals be included in AIDS program development and implementation at the federal, state, and local levels;Haitian professionals be provided intensive training by the Centers for Disease Control on all issues related to AIDS prevention and control; Haitian community AIDS service organizations and community agencies be provided financial and technical support to organize an AIDS Information/Education Center at the state and local levels; Haitian professionals be actively involved in determining AIDS risk reduction strategies; Haitian input be sought in determining funding needs and allocations; Haitian representatives be appointed to the CDC AIDS office to participate in health education and risk reduction activities. The Haitian Caucus appreciated the closing statement by Dr. Mason at the time, and the resolution was submitted by him to Dr. Dowdle. You have included in your package, as I mentioned before, some facts about AIDS in the Americas, and Haitians are listed fifth among people with AIDS, as two cases per million, and no one has ever heard about Bahamians or others listed. Also, part of the Red Cross printed materials that we feel are discriminating against the Haitian population. It was brought to my attention also that Virginia, Maryland, and other states nationwide, do have the same policies and the same printed materials.

(Applause.)

CHAIRMAN WATKINS: Thank-you very much, Dr. Rigaud. We very much appreciate the conciseness of your recommendations. They're very specific and they're the kinds of things that will be very useful to the Commission. Thank-you very much.

MS. GAULT: Reverend Marcelus.

(No response.)

MS. GAULT: Dr. Capp.

(No response.)

MS. GAULT: Is Dr. Capp here?

(No response.)

MS. GAULT: Dr. Laureano.

MULTI-ETHNIC GROUPS MANUEL LAUREANO, M.S., M.D., HISPANIC TASK FORCE, MIAMI

Dr. LAUREANO: Good morning. I would like to thank the Commissioners for permitting me to address the issue of AIDS among our local Hispanic community. It is important to stress that many of us in this area have dedicated a large amount of our professional and volunteer efforts to making sure that our Hispanic community is educated about AIDS prevention, as well as stressing hope and its importance to our people, especially those infected with HIV. Without the control that hope gives the individual, we cannot expect to motivate our people to decisive action in facing this crisis.

I would like to tell you some facts about our Spanish speaking community in South Florida. We are very much aware of the over representation of Hispanics as a percentage of the total AIDS cases on the national level. In Dade County, we are 42.7 percent of the legal population, and account for 24 percent of the total number of AIDS cases. Hispanics are mainly concentrated within the major metropolitan areas such as Miami. South Florida has the third largest Hispanic population in the United States, following Los Angeles and New York. Unfortunately, these areas also coincide with the areas where AIDS has the highest incidence. The Hispanic population of South Florida continues to increase, most recently stimulated by the entrance of non-Cubans into our area. The current Dade County population of Hispanics is 869,100 people.

If we include Broward and Monroe County, the South Florida Hispanic population raises to 949,000 individuals. Ninety-five (95) percent of these individuals were born in another country, and presently are undergoing the process of trans-culturation. In order for you to get the feel of our Hispanic community, there are some things you need to know about us as a group. The Hispanic population in this area has an average age of 36.7 years. This is slightly above the Anglo White average of 35.5 years. We place high values on our

families as a social institution, which provides stability to this country's status, and on our children. We tend to retain traditional values brought along from our countries of origin. The Spanish language has a special meaning to us, and it is one of those things that allows us to retain our independent identity. In our area, 89 percent speak Spanish at home, 77 percent speak Spanish on social occasions, and 58 percent speak Spanish regularly at work.

The majority of us would like our children to become fluent in our mother tongue. As a group of people that believe in God, we depend on the church and the home to transmit cultural, ethical, and moral values. Our elders are respected and held in great esteem throughout our lifetimes. We depend on special media modes to receive our daily information. These are particularly television, radio, and print. We have worked hard, and have provided these modes in the Spanish language to our community. We are generally a very proud people that have come to this country looking for freedom and a way to provide a better life for this country for our future generations. We take great pride in taking care of our people within the context of the family and the community. It is perhaps in times of crisis that we show our better qualities of compassion and caring to our fellow man. The social distribution of our Hispanic community is quite complex. We have everything from well established middle, middle high classes, to a constant influx of refugees and migrant workers that are not yet acclimated. Yet, we are a very resourceful community where 24 percent of the heads of household have college educations. It is from here that we expect to tap, in order to help the lower disadvantaged groups which are also at high risk for HIV infection within our community, but have little means at hand to understand the fertile grounds in which this epidemic grows.

AIDS is visualized by the Hispanic community as a White gay male disease; a disease that could never affect a household where the males are to be machos and the females are to be virgins. Therefore, my community has great difficulty identifying with AIDS as a potential risk to them and to their families. There was difficulty in the beginning to discuss AIDS openly within the community because of the sexual taboos that are part of our Hispanic culture. The sexual and drug usage details must be presented in culturally acceptable terms. We have also had some difficulty attempting to make a community used to an acute illness come to understand an illness with long latency and incubation periods. They must be made to understand that risk behavior executed today may be the cause of illness many years down the line. These concepts, coupled with the fact that an

individual infected and asymptomatic may be infectious to others, are factors that fuel the spread of the epidemic in this area. We lose many lives quickly within our community because many people infected are not prepared to deal with the health care system as it exists today. Therefore, they wait until they cannot stand it before going to see a physician and enter the public health care system. So we lose many lives that could be extended and be productive.

There are added difficulties when health care providers do not allow individuals to be open and sincere about their sexual orientation or behaviors without passing judgment. This lack of trust on part of the community does not allow many health providers to be effective in disseminating risk reduction information. The reluctance on part of key members of our community, as well as some elected officials, to be associated with AIDS and its special issues just serves to reinforce the denial which exists within certain segments of our population. As soon as influential members of our community stand forward and join the forces with existing AIDS education prevention groups, we will see a shift in the general attitude of the population. As one of the few Hispanics involved in AIDS prevention and counselling, I stress that the greatest need of our community is access to accurate information about AIDS.

Our educational messages are geared to prevention. We stress no to sexual promiscuity and no to drugs. The messages are stated in simple terms, and are always made in the Spanish language by culturally sensitive individuals. Our efforts are such as to being about behavioral change. We try to provide messages that let people know that they are vulnerable. We do not want people within the community to single out and alienate any one sub-group, for any one of us can be potentially at risk for AIDS, Blacks, Hispanics, and Whites alike. We have noticed that special forums and community conferences on AIDS do not offer an appropriate way of educating the community. There is a tendency to be not associated with these for obvious reasons. Therefore, we have instituted an educational program based on mass media utilization. This provides for adequate programming to be delivered directly into the privacy of the home. The pioneer in this type of educational programming within our community has been an AM station, WQBA. There must be an opportunity for individuals to inquire about AIDS and risk reduction practices in a confidential and appropriate manner. A permanently manned Spanish hotline must be instituted in this area. Services to this regard are being provided by Health Crisis Network, even though it is hardly enough to meet the needs of the Hispanic community in South Florida. We have encountered

a genuine and culturally rooted desire to take care of AIDS patients within the family structure among Hispanics, but we have a lack of organized ways of assisting Hispanic families to do a better job or caring for the loved ones with AIDS. We must provide the opportunity for Hispanics in the area to participate in federal, state, and local levels in the development of appropriate strategies to educate and provide services to our own people. In order to curtail the spread of the epidemic, we must support, you must support the establishment of community based agencies that will deal with the AIDS problems directly. Also, try to elicit the support of the community based organizations that are already established and service minority communities. Thank-you.

CHAIRMAN WATKINS: Thank-you very much, Dr. Laureano. We have time maybe for one question, if there's any. We met Dr. Laureano the other day, very briefly, at the Health Crisis Network, but we didn't have a chance to chat with you there. Mr. Creedon has one question.

MR. CREEDON: Dr. Witte indicated in his opening remarks that 15 percent of the AIDS patients in South Florida are heterosexual, as opposed to 4 percent nationwide. In response to a question, he seemed to indicate that the reason was the high level of Hispanic population here. I wonder if you have any sense or opinion as to why it would be higher, 15 percent versus 4 percent, in the heterosexual community?

Dr. LAUREANO: As I have it understood, in Dade County we have a 24 percent heterosexual transmission rate.

MR. CREEDON: That's even higher.

DR. LAUREANO: It's mainly due to the fact that individuals that may be engaging in specific high risks behaviors, which entail sexual behaviors, are not being open enough and do not have enough confidence to reveal that they are engaging in these high risk behaviors, and therefore they label themselves as heterosexuals and stayed labelled that way for statistical purposes.

MR. CREEDON: So you think that basically the statistics may be wrong, and that a higher percentage are homosexual and not admitting to it, or bisexual?

DR. LAUREANO: Probably bisexual.

MR. CREEDON: Thank-you.

CHAIRMAN WATKINS: Thank-you very much, Dr. Laureano.

DR. LAUREANO: You're welcome.

MS. GAULT: Bruce Hayden.

(No response.)

SUBSTANCE ABUSE BRUCE HAYDEN, SUBSTANCE ABUSE TASK FORCE, MIAMI

"I would like to first break my short presentation down into two categories, while keeping in mind that I am only going to be addressing residential (24 hour a day - 7 days a week) treatment program issues. Outpatient, aftercare, day care and detoxification have another series of issues, some greater and some lesser than residential. My two categories could be classified as administrative and clinical. Because time is really limited, I will try and list only a few items under each category and try and give a short explanation for some of the sub items. Clinical: 1. Substance abuse rehabilitation is based on RECOVERY: All staff training is geared to the fact that the client can recover and regain control of their lives. The client that has tested positive for the AIDS virus at this time is looked at as having a good chance of dying from the AIDS virus. - Staff need retraining on death and dying issues - the full spectrum. - Potential impact of treating persons in a milieu setting that stresses over and over, 'You can get well.' 2. Training with staff on their own personal feelings regarding treating persons with AIDS. 3. Training with clients who will be interacting and residing with persons identified as having been tested positive for the AIDS virus. 4. Dealing clinically with family members and significant others that are related to the AIDS victim. 5. Training on how to deal with family members of clients that are residing with the AIDS victim. 6. The very important issues of when does the treatment protocol for the chemically dependent person end and when does the medical needs of the AIDS client become priority. The treatment fields desperately need help in dealing with the special needs of this population. We need money to help us to adequately address the issues and problems, but of equal importance and sometimes even more important is our need for policy, direction, and leadership on this issue.

I would like to now quickly address some of the concerns on the administrative side of the coin. 1. Due to a lack of policy and direction, programs are generating policy statements that are widely different from program to program and

district to district. - Should everyone be tested that enters your program? - If you do test, then what? - Who pays for the test? - If you don't accept the client, where do you refer to? - How do you insure confidentiality? - If words get out, what type of support can we expect from the community? - Treatment programs rely very heavily on client fees and/or donations from the community to make up our match requirement of 25 percent of all state and federal funding. Negative publicity does not help. - Insurance coverage for clients and/or staff. - Liability issues -- I don't need to express my concerns on the liability factors involved. - If staff or program knows that a client has tested positive for the AIDS virus, what is the program's responsibility? The client goes back into the community, do we inform? If the client engages in sex in your program, what then? - Should we set up a separate facility to handle the AIDS client? - If yes, then who gets referred, HIV positive only, ARC only, Full AIDS only, or all three? - If yes, then where do we put the facility?

I could go on and on, and I realize that I have probably done nothing more than ask questions or speak to concerns that you are all aware of, but the treatment field is facing another crisis. This one won't go away. The treatment field wants very much to be a big part of the solution, but we just don't need any more studies to tell us that IV drug users are at high risk. We need direction, we need leadership, and most of all we need community, local government, and legislative support in developing legislation and allocations to help us help our clients."

* * * * *

MS. GAULT: Ana Garcia.

PEDIATRICS AND FAMILY ANA GARCIA, LCSW, SOCIAL WORKER, PEDIATRIC IMMUNOLOGY, UNIVERSITY OF MIAMI

MS. GARCIA: Good morning. My name is Ana Garcia, and I'm a Pediatric Social Worker for the Department of Pediatrics, University of Miami. I've been working with children and their families who have AIDS and AIDS infection for the past five years. Seventy-five (75) percent of the families that I have worked with have been predominantly single mothers, single fathers, never married. The other 25 percent are either legally married, or have permanent partners. To better illustrate some of the points that I want to make about how AIDS is a family problem, I want to briefly describe one of the cases that we've been involved with over the past years.

In December of 1983, I was asked to go to the Intensive Care Unit on Pediatrics because a couple's baby had just died, and the child had died due to infections secondary to the AIDS process. The family didn't know anything about AIDS; AIDS was new to us, too. The mother was pregnant. It was a very difficult moment for all of them, and their problems had just started at that point. When mother delivered her second child, her second daughter, the child eventually developed AIDS related infections, and continued to deteriorate medically. The parents had a lot of difficulty accepting that they themselves were infected with the AIDS virus, and despite intensive counselling on our part not to continue to have more children because of the risks that those children would also be infected with the virus, they went on ahead and had a third and a fourth child. To get to the point, the first child and the last child eventually died of AIDS. The second child has ARC, and she's alive. She'll be four years old, and is living in a foster home right now. The third child that's a son eventually went on to test negative for the AIDS virus, even though he was positive for the presence of antibodies. In children, when they test positive for antibodies, we test them until they're about fifteen months of age, and this child was lucky enough to go on and test negative. The mother died last March, shortly after the birth of her fourth son and last child. The father was left alone to care for the two surviving children, and he did his best. He himself was very depressed, was denying any symptoms, and of course continued to deny that he had the AIDS virus. The children were eventually dropped off -- we lost them to follow up -- they were dropped off at our Emergency Room in May of this year in very poor condition.

Apparently, the caretakers that were watching the children did not care for them very well. Subsequently, the state jumped in. They were able to successfully place the little girl in a very nurturing home environment in the foster care system. The little boy also was placed in a non-medical, non-AIDS related foster home. The point of this story is that we're seeing the destruction of families. This is not an isolated incident. It's the fourth such family that I've worked with in the past five years. It's not unusual to see one of the children not affected with the AIDS virus. It's very painful to see the destruction of families. One of the salient points that I want to make is that children can be any age. I happen to work with the pediatric population, but children are 25, they're 30, 35. They affect grandparents, aunts, and uncles. It pulls a family together or it pulls a family apart. I feel that as a society we owe this particular family here the responsibility of providing the accurate prevention and education tools techniques

to insure that that son that survived that epidemic in his family, that he's not eventually going to contract the virus. In the families that we've worked with, and there are approximately 120, part of the counselling modalities that we use is again encouragement of change of behavior, safer sex practices, and obviously, for infected women, not to continue to have children.

The foster care implications of this country are incredible. A system that is not able to cope with the number of foster placements unrelated to AIDS, when you add the stressor of AIDS, they're just not ready to cope with it right now. We're lucky in our community to have Children's Home Society that is very involved in recruiting appropriate foster homes for children who have AIDS. Currently, we have five pending licenses and two that are licensed, but surely that's not enough to handle the crisis that is coming on the horizon. Thank-you.

CHAIRMAN WATKINS: Ms. Garcia, what is the situation regarding social workers like yourself in the area? What's the adequacy in terms of numbers; how are you connected into things like the Health Crisis Network? Can you give me a little feel for what the members are for colleagues of yours, how many are there; what's the need for more; what role do you play generally in the overall community?

MS. GARCIA: I network across the state, across the country, seeking out other pediatric social workers, even adult aid social workers, who are interested in this area. I sit on the Board of Directors of Health Crisis Network, and I think that's valuable in the sense of representing a pediatric population that people tend to sympathize with, but don't pay enough attention to. Professionally, there is a shortage of AIDS social workers, and part of our drive right now is to educate professional schools, social work, medicine, nursing, therapies, that, as you've witnessed today, that it's not easily transmittable; that these people need a lot of support, a lot of compassion, a lot of nurturance, in a disease that doesn't provide much of the positive soft stuff.

CHAIRMAN WATKINS: Any question from the Commissioners? Yes, Ms. Pullen?

MS. PULLEN: Who licenses foster families in Florida?

MS. GARCIA: HRS out of Tallahassee.

MS. PULLEN: Are there special licensing procedures or requirements for families that have been recruited to take AIDS children?

MS. GARCIA: The only special process is that they are oriented and educated about the disease, about transmissions, about precautions, and otherwise you provide the same loving and nurturing behavior that you would to any other child who would be in a foster care situation.

MS. PULLEN: So in terms of state practices, there are no special barriers from becoming a foster family for an AIDS child?

MS. GARCIA: No, other than that your home environment be suitable, adequate, and meet the guidelines of the state, and that you have a genuine sincere interest to have these children, and not take them in for a monetary incentive, or the stipends that are provided. Again, our staff is very involved in educating and providing this information, along with Health Crisis Network, to families that are interested in being licensed for homes for AIDS children.

MS. PULLEN: Is there full coverage of medical expenses for foster families?

MS. GARCIA: It's provided through the South Florida AIDS Network here at Jackson, since the children are followed in our pediatric clinics, they are automatically enrolled in the Network, and their total care is provided here.

MS. PULLEN: Is there a waiting list of AIDS children who have not been placed in foster families?

MS. GARCIA: There is no waiting list, per se, right now. However, I have identified that in the course of the next year, there are, I would say, about 10 families who, over the 10 families, have 16 children that would be needing foster care because these families themselves are symptomatic, and of course, we can't put a time span on how long they'll survive, but looking at the degenerative process and where they are in the illness right now, I give it more or less a year. So we'll be looking at approximately 16 to 20 children that would be needing placement.

MS. PULLEN: And you're satisfied that the Children's Home Society is working thoroughly enough to try to recruit those by the time the need is there?

MS. GARCIA: Yes. It's a new project. I'm very excited about what they've presented right now. They have a lot of energy. They're a dynamic group of people, well informed, and they know where to go. As you know, Children's Home Society has been involved nationally in foster care and adoption, and I'm very confident that they'll be able to meet the challenge.

MS. PULLEN: Thank-you very much, Ms. Garcia.

MS. GARCIA: Thank-you.

MS. GAULT: Cliff O'Neill.

LESBIAN AND GAY COMMUNITY CLIFF O'NEILL, TWN WEEKLY NEWS

MR. O'NEILL: Commission members, my name is Cliff O'Neill. I'm the news editor of the Weekly News, this state's gay and lesbian newspaper. I have also in the past worked as a facilitator of the South Florida Gay and Lesbian Youth Group.

Through the Weekly News, I've reported the discrimination, the lack of compassion, and the death that this virus has brought to my community. I've been a witness to the hope and caring of the people that have reached out a helping hand to people with AIDS. I've seen the town called Arcadia, in which a family was burned out of their home due to the irrational uninformed fear of AIDS. And I have written the obituaries for those dying of AIDS. I have stood mourning at memorial services like the Names Project, AIDS Memorial Quilt.

Through my work with the Gay and Lesbian Youth Group, I have seen young men and women jeered out of their schools and kicked out of their homes by their parents for nothing more than whom they love. Yet I have seen something else through my work with the group which may point up a major threat to the mental health and even the lives of this nation's gay youth. One in ten high school students is a lesbian or gay man, and many of the well-meaning government officials may not only be endangering their lives, but the lives of many other gay and non-gay teenagers. There's been much debate in this nation as to how to go about educating our nation's youth about the dangers of unsafe sexual activity. Many feel that teaching children to abstain from all sexual activity is paramount. That is laudable. Yet, not informing teenagers on the verge of sexual awakening about risk-reduced sex is dangerous. In my work with the Youth Group, I have seen young gay men coming out in the wake of the AIDS epidemic. These young men are gravely impacted by

the messages about AIDS they receive through their friends, their families, their schools. A number of these youths have discovered their sexuality within the past four years, yet have been confused as to how they may explore their sexuality without coming in contact with the HIV virus. These youths have come into the gay community and have asked questions. They have read literature, and they have then explored their sexuality safely. There are others, however, who are not quite so easy to reach, and it's because of them that we must think before we take such drastic measures as banning federal funding that explicitly describes unsafe and risk-reduced sexual behaviors. Many of these youths have gotten the message through the media, through their families, and through their schools, that homosexual sex is inherently fatal. Some of these young men have attempted to hold back their sexual impulses for a while, but more have, with the illusion of immortality that youth possesses, randomly and promiscuously begun having multiple unsafe sexual encounters because of these messages they have received. Others have committed suicide. With studies that show that a greater proportion of suicide attempts among adolescent males are among gay youths, can impart the message that any sex is in and of itself dangerous, a safe one to be sending our youth, or are we threatening the lives of not only our youth, but of the sexual partners they may seek out. Thank-you.

CHAIRMAN WATKINS: Thank-you very much, Mr. O'Neill. Questions from the panel? Yes, Dr. Lilly?

DR. LILLY: I'm just wondering, you alluded to the difficulties that might ensue due to restrictions on explicit education. I wonder if you could elaborate on that a little bit.

MR. O'NEILL: Well, particularly, such dangerous amendments as the Helms Amendment, which would ban federal funding from all its education programs, which would, "promote or encourage homosexual sex. "This would be tantamount to banning the federal funding for most of our AIDS service organizations, and that feeling therein that such literature would promote or encourage homosexual sex would wipe out AIDS education programs which would allow for the education of these people so as not to spread the virus further, and it's that that is dangerous.

MS. GAULT: Mr. McQuay.

LESBIAN AND GAY COMMUNITY JOSEPH McQUAY, PRESIDENT, DADE ADVOCATES FOR RIGHTS AND EQUALITY

MR. McQUAY: Good morning, distinguished AIDS Commission. My name is Joseph McQuay. I am President of Dade Advocates for Rights and Equality. I, in a way, am a last-minute replacement for Dan Bradley, Miami attorney, who also is on our Board of Directors. Dan has had AIDS for a year, and he was unable to make it today because of an illness. Stop AIDS apartheid now. Please help stop it now. A dentist in Broward last month stopped working on a man's tooth the minute he was told the patient happened to be gay; the man worked in a gay bar. The dentist reportedly said he was taking an extended vacation, and would not be able to finish the job. The Surgeon General says places of employment do not transmit AIDS. A doctor in Hollywood two weeks ago, when talking to a person with AIDS, said that he, "wouldn't stick his neck out," by treating him. The Surgeon General thinks some doctors are shirking their ethical responsibilities. A while ago, a Miami landlord demanded extra money from an estate to tent a house, fumigating for AIDS. The tenant had died of AIDS, spending his last month in a hospital. The Surgeon General says houses do not transmit AIDS. A grocery store in Miami coerced a long-term employee into transferring to another store at a lower paying job; the man merely had been exposed to the HIV virus. The Surgeon General says food-handlers pose no risk of AIDS transmission. Too many voices clamor for attention. These four incidents don't even scratch the surface. AIDS discrimination, as Dade Advocates for Rights and Equality has documented, ravages South Florida as much as the disease. There are far too many employers who fire or demote their HIV-exposed workers, far too many landlords who evict their tenants, and far, far too many doctors and dentists who refuse to treat AIDS patients. This irrational fear serves nothing but the virus. It damages the lives of sufferers. It impedes badly needed education. It destroys the human community and rends the social fabric, pitting neighbor against neighbor. It foments more discrimination and often leads to destruction. The Ray family's house would not have burned down if citizens of Arcadia had acted out of anything but irrational fear. This fear feeds on itself, much as the virus feeds on its host. We have to stop this discrimination to sidetrack the cycle of fear. And the example must come from our elected leaders, the guardians of the public good. But where is the national leadership? Where is the White House?

Recently, HHS Secretary Otis Bowen testified before Congress on the subject of AIDS. He said the federal government should not attempt to protect against discrimination at this

time. Bowen believes that the state should take the lead in this field. Well, the states have anything but a stalwart record. Taking him at his word, this only means more wasted time, more suffering, more tragedy. How many more dentists must throw their patients out of their offices with half-drilled teeth?How many more companies must fire employees with AIDS?How many more families must be burned out of their houses before Washington realizes that AIDS discrimination is increasing, not subsiding. We desperately need education to reach every corner of this country. The U.S. Government says, "We can't afford to send out the Surgeon General's report to the citizens," yet the Internal Revenue Service recently mailed pamphlets regarding new tax laws to every taxpayer in this country. I ask you: What's more important, changes in allowable interest deductions or saving people's lives? The epidemic demands no less than massive new AIDS funding; yes, a Manhattan Project. We must find a treatment, not just a vaccine for this disease. But we must first start treating 44,395 people with AIDS, Americans. We must start treating them like people with AIDS and not pariahs with AIDS. You're in a wonderful position. You, the Commission, can include one thing in your report to the President that will bring immediate relief to the AIDS community. We desperately need federal legislation banning discrimination against those who are AIDS infected, or those who have the disease. Then, one stroke of the presidential pen could banish this irrational discrimination without costing the Treasury one cent. We have to stop AIDS apartheid now, right now. Thank-you.

(Applause.)

CHAIRMAN WATKINS: Mr. McQuay, if we can have a question, please. I'd like to ask the first question. It would be very helpful for the Commission on the issue of discrimination to have some facts. What we need to know are how many active legal cases do you have, if there are active legal cases, and how do they break out? In other words, until we really understand specifically what's going on, we know there are cases out there, but we need as much specific information, and also what's taking place in the courts. Have there been precedent setting cases already?

What is either the county or the state position regarding AIDS in the workplace and discrimination because I know that we're going through some growing pains, but I think the more aggressive we can be in this area, we're sympathetic with the situation, and we want to help, but I think it would be very helpful if we could get some kind of a coordinated input to the Commission on cases of discrimination against persons with AIDS.

MR. McQUAY: Certainly. Probably the most famous case on AIDS discrimination came out of Florida a little more than a year ago. That was the case of Todd Shuttleworth, the Broward County employee who was fired because of AIDS. There is a Florida Human Relations Commission decision saying that AIDS poses no risk, and that employers should not fire any employee with AIDS; that they should try and find some other suitable employment. Court cases, that's the only one that really threatened to go to the courts, and it was settled out of court. There is no legal precedent. There's no paper trail on which we can hinge anything. We're really at the forefront of AIDS discrimination in trying to document and bring to court. DARE just started this kind of seeking program about a month ago, and we've gotten dozens of calls. A couple of those people are now seeking attorneys, and are trying to bring forth a case on discrimination. Quite honestly, it's too early right now. For so long, AIDS has been swept under the rug, and people have not wanted to come forward. It's just now getting to the point where people are coming forward. Certainly, we will continue to document this, and at some point in the future, hopefully within a month or so, we may be able to send you some sort of compiled list of what we have.

CHAIRMAN WATKINS: We would like that very much. Ms. Gebbie has a question, I believe.

MS. GEBBIE: You've already partially answered it. I wondered what the posture or role of your state Civil Rights Division or whatever label it is here in this state has been. Have they made statements?

MR. McQUAY: They've been very supportive; they have. There have been two different decisions, one affirming the first one, in which they upheld the rights of the employee to have a chance to maintain his employment. They basically said Broward County was wrong in firing Todd Shuttleworth just because he had AIDS. On the state level we have a lot of support, but unfortunately this state also saw the burning of a house in Arcadia. This state has seen examples, maybe not as well publicized, but no less heinous, of AIDS discrimination all over. It's not just Miami; it's not just Florida where this is occurring. It's happening in Iowa; it's happening in New Mexico; it's happening everywhere. That's why something from the federal level is desperately needed.

CHAIRMAN WATKINS: Mr. Creedon?

MR. CREEDON: Just a comment. You know, my impression is you can have the law, but I go back to your original statement and that is you need education because --

MR. McQUAY: They have to go hand in hand.

MR. CREEDON: It has to be both. You can't legislate against discrimination. You can legislate, but that's not going to change anything. I mean, it was illegal to burn down the house in Arcadia. The thing we need to do is to get people to understand it.

MR. McQUAY: We do need to get to the people. They have to go hand in hand, but that doesn't mean they have to be mutually exclusive.

MR. CREEDON: No. There is legislation in a number of states and it doesn't prevent it. That's the only point I'm making.

MR. McQUAY: Well, without this legislation, the education is only part of it. We have to have both, so there's no reason for us to talk about what we have to do first. I think we need both now.

CHAIRMAN WATKINS: We're going to make a commitment to you, Mr. McQuay, that we will hold hearings on discrimination and confidentiality, specifically, in January. We'll bring the Civil Rights Commissioners from selected states and from the federal government in. Because you apparently have a sympathetic ear there, I would get your information in and any other from the surrounding counties that you can coordinate with. Get it into your Civil Rights Commissioner so when he testifies -- we haven't asked him yet; this is the first time I've brought it up in open session, but we will be asking him or his representative, or her, I'm not sure who that is in this state, to come before us and give us a record of how they stand on this issue. We know it's extremely important to get on with some rational policies regarding testing and discrimination and other matters that are needed to get on with fighting the disease. We'll commit ourselves to that, if you will commit yourself and your organization and others like you to get the information in to the central authority so that when they brief us we have the latest information on Florida.

MR. McQUAY: Everything we have, you'll have.

CHAIRMAN WATKINS: Thank-you very much.

MR. McQUAY: Thank-you.

MS. GAULT: Mr. Bahlman.

LESBIAN AND GAY COMMUNITY BILL BAHLMAN, ACT-UP

MR. BAHLMAN: Good morning. Thank-you for allowing me to make some comments for you this morning. I'm Bill Bahlman from ACT-UP, the AIDS Coalition to Unleash Power and the Lavender Hill Mob, two groups based in New York that have a national impact on federal policy. I come here today with anger, and why does anger consume me? Why does anger consume so many with AIDS and the people who love them? Do you as members of the Presidential Commission on AIDS, do you understand why? You should understand that anger by now unless you have your eyes and your ears shut tight. You should know that your lack of abilities as individuals and collectively as a Commission is just a symptom of how inadequately the federal government of the United States has been in responding to AIDS. I see no brilliant men or women directing our government's response to AIDS. Not in Reagan's White House, not in the Public Health Service, not in the Centers for Disease Control, not in the National Institutes of Health, not in the Food and Drug Administration, not in the Congress, and I've met with most of them. I've heard them speak, and for the most part they make me sick.

We see their lack of direction and leadership as a means of genocide. We complain to the FDA so they put on AIDS drugs on the fast track to approval, but after two years of research with over 2,400 people enrolled in a compassionate use protocol, gancyclouir DHPG, used to prevent blindness and imminent death for PWA's with CMV infection was turned down by the FDA for approval due to a sudden lack of useful data. Why wasn't the FDA sending their agents out to meet with the drug company Syntex, which spent over twenty-five million dollars so far on this drug alone in research, coming out of their own pockets?Why didn't they send people out to the drug company to verify that the data being collected could lead indeed to approval?We find this passive approach by the FDA as another means of genocide. We complain to the NIH that there were only 442 people with AIDS enrolled in the 19 AIDS treatment evaluation units. Now we see the ATEU program has grown, but has not expanded. With 1,676 people enrolled as of September 22nd, 1987, a shocking 87 percent are in AZT studies. In New York, with only 453 PWA's enrolled, 99 percent are enrolled in AZT protocols.

Is this the best in creativeness and effort the NIH can offer? Where and when are promising treatments like Ampligen AL721, Colony Stimulating Factor, Ribovirin, Immuthiol, DHPG, Fascarnet, Antabuse, Susudic Acid, and carrision going to be tested, among others? Dr. Anthony Fauci, Director of ATEU Program justifies his almost exclusive testing of AZT by saying it's the only drug that has proven efficacy in fighting AIDS. AZT was proven efficacious by the ATC testing program. How can our research efforts be fruitful and save lives with this kind of short-sighted close-minded thinking?We find the short-sighted ATEU program as another means of genocide. We complain to the Congress, where at least they continually double President Reagan's budget proposals for AIDS funding, and we find Jesse Helms proposing an amendment to disallow federal funding for safer sex education materials that promote or encourage homosexuality, either directly or indirectly. In its homophobia, the amendment disallows the teaching of safe measures of same sex intimate companionship. The Helms Amendment passed in the Senate 94 to 2. The Congress says, "Let the queers die," and this we see as another means of genocide.

Gary Bauer, President Reagan's domestic policy advisor, and a key figure in the development of the Administration's policies regarding AIDS, and I'm sure no stranger to the members of this Commission who may very well owe their positions on the Presidential Commission to Mr. Bauer, has recently said in the October 19th issue of the AIDS Record, "I haven't seen a good case of AIDS discrimination made. "Often quoted is the burning out of the family in Florida. What is missing is that overwhelmingly AIDS children are attending schools with the knowledge of the school districts. In Florida, the decision was made that those kids should attend school. Gary Bauer hasn't heard a good case of discrimination. Being burned out of your house has got to be the worst example short of murder. There is no compassion in this kind of thinking. No letter from the President to console the family. We see this as yet another means of genocide and AIDS rages on. I wonder what usefulness your report will be, coming out just a few short months before the presidential election. I wonder what America will be able to do for Central Africa, where AIDS rages on with less health care than there is food. I'm angry that the ATEU program is not effective in recruiting PWA's, and that they tend to be racially exclusive. I'm angry about a lack of support the ATEU programs

are getting from the individual hospital boards. Many ATEU centers have inadequate staff, and not only due to lack of support from the hospital boards, but also due to the fear of AIDS. These units cannot even find keypunch operators to punch in information about these programs.

But mostly I'm angry with the Reagan Administration, through which Gary Bauer and Otis Bowen and Windom of the Public Health Service, who are in a position to command the various government research agencies into working more effectively and to finding treatments and a cure for AIDS. They are bunglers, bungling their jobs in the face of the worst epidemic we have ever faced. I call for their dismissal, as AIDS and genocide rages on.

(Applause.)

CHAIRMAN WATKINS: Thank-you, Mr. Bahlman. Drug development is one of the early key items the Commission will focus on during special hearings in January, and it would be very helpful for us if we could receive a coordinated input on this issue. We've heard from your group in Washington, and we would like to receive specific information on what you feel, the information that you have that we can bring to bear during those hearings, and try to separate the wheat and chafe that we hear from a variety of sources on this issue because it is a very important one, and we know it is. We're sensitive to it, and I can assure you that we will approach it aggressively, but we're going to need some very specific information, maybe fleshed out more along the lines of your presentation to us this morning. Would you provide that to the Commission?

MR. BAHLMAN: I can provide you with reams of data and also short reams of summaries of data on drugs that need to go through a testing process. The drugs that I'm talking about, mentioning now, they're available right now for testing. If we don't get to testing these substances now, what are we going to do with the drugs that are being developed right now? I mean, when will they get into the pipeline for testing? I don't see any answers to those questions, outside of a push from the White House. Definitely, I welcome the Commission speaking out as often and regularly, whenever you see things happening in an ongoing struggle. I know your preliminary report in December, when you hear things like a family being burned out in Florida, I wish that you will speak out as things are occurring and become a positive force, because we definitely need it on a federal level.

CHAIRMAN WATKINS: Yes, Ms. Conway-Welch?

DR. CONWAY-WELCH: Part of the frustration is the need to get coordinated information from a variety of sources. I certainly support the Admiral's request for your assistance in that. Is there a central clearing house or a central source that you access, either formally or informally, in the federal government or elsewhere, about the status of the testing programs on the various drugs? The reason I'm asking the question, is that Vanderbilt is getting ready to test Ampligen on a fast track. I know, anecdotically, that a number of medical centers around the country are in similar positions. I think that we need coordinated access, not only to what the federal government says is happening in terms of testing, but in terms of the perceptions of the community about testing, and that's the background for my question of do you have a coordinated source of data that you can pull from?

MR. BAHLMAN: Well, we're coordinating data ourselves, and we find it's like pulling teeth to get data. We're on the phone, literally, all day long calling drug companies, calling the NIH, calling the various agencies, to accumulate the data, and then trying to analyze it and work it through. We just recently got all the grant proposals for 1986 from the NIH, but the NIH doesn't want to give out all the data for 1987. Such things like the AZT, which we've seen major problems with, there are a number of doctors who don't want to prescribe it because the approval papers don't prove to quite a number of doctors that the drug is actually useful. Burrows will continue to do studies on the original people who enrolled in that trial, but that data is not made public. We met with FDA about three weeks ago, with Ellen Cooper, who wrote the approval papers for the FDA, and we're trying to get that data from her because that data is so useful, not only for doctors trying to make up their minds in terms of prescribing, but also for the individual PWA who's trying to keep up with the current research information. So we're trying to get that data, and it's hard to come by. Project Inform in California is putting together a lot of information, and they're a clearing house of data.

I'm meeting with people here in Florida who are becoming quite a clearing house of data, and we're all trying to work together. There is no national clearing house of data on AIDS related drugs that is full and all encompassing. We're using as many sources of ourselves too, and we'll gladly make those sources available to you as well.

CHAIRMAN WATKINS: Thank-you very much. We have to press on to the next witness.

MR. BAHLMAN: Thank-you.

MS. GAULT: Dr. Shuman.

INCARCERATED POPULATION HARRY SHUMAN, M.D., STATE HEALTH SERVICES

DR. SHUMAN: My name is Harry Shuman. I'm the Regional Health Services Director for the Florida Department of Corrections. I appreciate the opportunity to speak to the concerns of AIDS and HIV infections in the correctional setting. At the same time, I hope it is realized that the issues are too numerous and too complicated to be covered in the short amount of time allotted. As health care professionals within the Department of Corrections, we want what is best for our patients. At the same time, we feel a fiscal responsibility to the taxpayers in utilizing the available health services funding in ways that will be most beneficial to the health and safety of the inmates, as well as protecting the public health upon our patients' return to society.

We have begun to feel pressure from the outside to institute mandatory HIV testing on all inmates. We would like to be able to convince you that such a policy is irrational, fiscally irresponsible, and medically unsound. In his article entitled, "The Cultural Impact of the AIDS Test: the American Experience," S.C. McCombie states, "In those public health jurisdictions that have undertaken this approach, use of the test appears to function as a magical control measure. In this context the test becomes a ritual, as have many other screening tests. Its administration reduces the anxiety generated by a perception of a disease out of control and masquerades as intervention. Supporters of Malinowski's theories on religion would enjoy hearing the response to criticisms about these testing programs, which consist of statements such as, 'this is a serious disease, people are frightened, and we have to do something.' "The ELISA screening test currently employed was designed with high sensitivity and moderate specificity with the intended use of protecting our nation's blood supply. With any suspicion of positivity, the identified unit of blood can be disposed of efficiently. Human beings showing the identical positivity cannot be so easily dispatched.

The test further suffers from a lack of predictions. While it may identify those who are infected, it cannot prophesize which of those infected will go on to the disease state. We do not deny that our incarcerated population contains an over-representation of individuals from the high-risk group of intravenous drug abusers, nor do we deny that homosexual activity occurs with greater frequency in our population than in the population at large. However, simple identification of infected individuals can serve no utilitarian purpose.

In fact, such information can increase the risk of harm to these individuals because of ignorance and fear on the part of both inmates and security staff. Segregation of individuals who are HIV positive, yet are not engaging in high risk behaviors, is medically unwarranted, and sends a dangerous message to the public: that is, the concept of an AIDS colony, and may affect both the public's perception of the disease and the way to control it. And while all health care workers within a correctional setting believe in the importance of confidentiality regarding medical issues, in reality it often cannot be completely achieved because of security concerns. As health care workers, we firmly believe that education is the only viable way to contain the epidemic. At the same time we recognize that the psychological make-up of many of our inmates makes some of the usual educational materials which are based on prevention through fear ineffective. Instead we support, and ask for your support, in the continuation of specific educational programs targeted at our special population. We also request that any medical developments which prove beneficial in either prevention or treatment not be withheld from our patients on the basis of their incarcerated state.

In summary, the goals of health professionals in correctional medicine are identical to the public health goals of the population at large: primary, secondary, and tertiary prevention. We request that no "We/They" dichotomy be established when considering measures to control and/or treat HIV infections in our patients, as opposed to those in the free world. Mandatory testing, with or without segregation, will lead to medical, legal, administrative, and financial nightmares without advancing the ends of public health. I am also submitting to you a written report entitled, "AIDS, Inmates, and HIV Screening: A Rational Approach to Acquired Immunodeficiency Syndrome in Correctional Facilities," which covers our concerns in greater depth, and which is based on research from medical, legal, and public health publications. Thank-you for your time and consideration.

CHAIRMAN WATKINS: Questions from the members? Yes, Dr. Lilly?

DR. LILLY: Those who advocate mandatory testing in prisons, what are the measures that follow the identification of a person who is infected with the virus?

DR. SHUMAN: That depends on what state you're talking about. Originally, five states had decided to do mandatory testing; three dropped out and two more came in. There is no firm plan in any of them, though some have talked about segregation. Then comes the nightmare of who would staff such a facility. As you know, Florida has been under litigation for the past sixteen years about the overcrowding and the poor medical conditions in prison, and only in the past few years has a lot of headway been made. We were constantly having to release people early because we reached the cap that the court allows us to have incarcerated. If we had to identify every person and segregate them, we wouldn't have the space or the people to staff such a facility.

DR. LILLY: Well, that's all very well and good that you can't handle it now under present circumstances. If you had facilities, would it work? --

DR. SHUMAN: There's some other issues involved. If somebody is not practicing any kind of activities which would spread the disease, why separate them, why segregate them?Also, there's been a question that's come up in the legal literature about putting somebody who is HIV positive, but does not have the disease, in a group of people who are all HIV positive. May not, with repeated contact, that person's chance of developing the disease become greater?

CHAIRMAN WATKINS: What is the transitional mechanism, Dr. Shuman? We had an opportunity to talk with a person with AIDS that had come out of one of the prisons. It seemed as though that individual was dumped on society without a great deal of transitional counselling, interfaced with the appropriate network system and follow-through. It may not be the case at all, but what is the procedure, the institutional process for you to link up with the network, such as the Health Crisis Network here in Dade County, for example?

DR. SHUMAN: There is a liaison between the medical people and the classifications people that before somebody is discharged, a patient with AIDS, that those arrangements are supposed to be made. Our system isn't perfect, and I assume that

some people fall through the cracks, but it's not supposed to happen that way. If a person actually has the disease, and is not just HIV positive, or has ARC, he will only be at one institution, and that is our Northern Reception Center that has a special housing unit for people who actually have the disease. All the counselling and the arrangements with the outside agency are made there before his discharge.

CHAIRMAN WATKINS: But the HIV positive case, without ARC or AIDS?

DR. SHUMAN: Well, we don't do any testing right now, so HIV positive without anything, we're unlikely to know that information.

CHAIRMAN WATKINS: Thank-you very much, Doctor.

MS. GAULT: Ms. Volker.

MARILYN VOLKER, WOMEN'S TASK FORCE

MS. VOLKER: Admiral Watkins, and members of the Presidential Committee, I'm Marilyn Volker. I met some of you yesterday, and I still have the same laryngitis as yesterday, and I hope that you will bear with me again today. I coordinate education for the community at Health Crisis Network, which is the AIDS project here in Miami. What I am asked to speak to you today, and I thank you for the opportunity to speak to you today, is about women's concerns and women's issues. Health Crisis Network has support groups for women, and we also have a special task force comprised of women to look at women's issues in the community, and to work in terms of education and intervention with women.

What I would like to share with you today are some thoughts and concerns that women from that particular group have asked me to share with you. 1. When we begin to look at the numbers in terms of nationwide, Miami looks a little bit different. I would say South Florida looks a little bit different in terms of the numbers. The 7 percent that is usually documented in terms of national figures is higher in this particular area when we look at women and women's issues who are infected with the HIV virus. The numbers come to around 12 percent, with most of the numbers being in the IV drug using category, or heterosexual contact. One of the issues that we at Health Crisis Network take a look at it, and I would encourage you to take back to the President and to struggle with yourself, because it has indeed been a struggle for us, is how indeed do we

begin to get information to a community of women that are in all communities except for gay and bisexual men. Therefore, when we begin to look at intervention, how we do that is massive. We certainly have brochures that are out there. In looking at getting information out, probably what we do best is brochures. Brochures to the women are the least effective. They certainly like to see pictures of themselves; they certainly like to see their language. They certainly like to see information about their children. They like to see models from their community, and please may I also include that you need to also include lesbian and bisexual women when we talk about women's issues. But when we talk about getting to the grass roots, many women have the following concerns: "I do not know the organization that you're asking me to come to, and do I trust your organization?" "If I have been a disenfranchised woman from our country, do I now trust a Presidential Committee to give me my information in a way that I trust the most?" So many concerns have been, "Where am I going to get this information." "Is it going to be close to my community?" "Do I need transportation to get there," because I might be a woman who has no transportation. "Are you going to take care of my children while I get this counselling," because if I'm a woman with three, or four, or five children, and you ask me to come to be tested, to get pre and post-test counselling, to be part of a support group, to provide all of that education, I may not know you, trust you, and I may not have the means. So we ask you to please take consideration of those particular things as well.

I, as a female, may need very clear information in a brochure that you say I might risk my life, therefore I need to be using protected sex, and you talk to me about protected sex. It may mean very little to me if I do not know my body, and many, many women do not know their bodies. If part of what I deal in my life for my survival is usage of my body to maintain money for me and my children, you saying to me, "Stop your sex, or use protected sex," may not work. So I will ask you, "Are you going to provide for my survival and my family?" The images need to be very, very clear to women. The implications of the ways that women begin to get infected through drugs and sex alone have their images and their concerns for people. Drugs and women, and sex and women traditionally carry such biases and double standards, and for even women to come in and talk about being infected carries the stigma, "I have to talk about what I do sexually and what I do drug-wise," and in drug programs women come with enormous needs in terms of self-esteem, lack of communication skills, lack of support systems, and lack of networking. I may not be that woman who is able to be in a drug program because I have no one now to take care of my children if

I am in that particular program. "Will you take care of my children while I am there?" The other issue is in terms of babies and family planning. We certainly need to talk to women about those issues, but again the women ask you to be very specific and very clear. I need to hear from other women how they are surviving, how they are dealing with those issues, how they are talking to their partners. Many women will say to me, "This is the man who supports me, feeds my children, gives me a house over my roof, they support my habit for survival, and you are asking me now to stop my drugs and use protected sex."

It is not that easy. So we need and are faced with enormous challenges in terms of intervention and prevention. I would encourage you to take back to the President to begin to take a look at some very non-traditional ways of presenting information. They are probably ways that a lot of people are not going to like. They are probably ways that are going to make some people uncomfortable. I would suggest you use women on the streets in teaching other women. We suggest you use women in drug rehab programs to teach other women. They are the people that they trust; they are the people who are the models for them. The women who are also infected ask that you provide information for women who are infected as well. This is not a "them/us" situation, and they would clearly like to have some information, not just for prevention, but to help me understand when I am infected how I live my life effectively and safely and positively, and what are my resources. Thank-you for the opportunity for sharing of the concerns that the women in our groups and Women's Task Force have presented to us. Are there any questions or concerns?

(Applause.)

CHAIRMAN WATKINS: Thank-you very much, Ms. Volker. Do we have a question from the Commissioners?

(No response.)

MS. GAULT: Ms. Bohnsack-Lee.

WOMEN'S CONCERNS FRAN BOHNSACK-LEE, DADE COUNTY N.O.W.

MS. BOHNSACK-LEE: Good morning. My name is Frank Bohnsack-Lee, and I'm the President of the National Organization for Women in Dade County. The National Organization for Women has long battled discrimination against all people, both women and men. It is because of the terrible discrimination against people with AIDS that we have dedicated ourselves to ending this

tragedy. Women do get AIDS. AIDS is the leading cause of death among women 25 to 29 in New York City. Right now, the primary devastation is among gay men. As a statue in front of the Archives Building in Washington proclaims, "The past is prologue. "By studying the past, we can gain fundamental insights into consistent and enduring patterns of thought and action. In discussing AIDS, for example, it is helpful to reflect upon the social hygiene movement which existed earlier in the century. As we would learn, disease have a social construction, especially venereal disease. And this construction conditions public response. Like syphilis, many view AIDS as a consequence of corrupt sexuality. They see it as a sign of pollution and contamination. It heralds a decaying social order. Some even think that AIDS is God's punishment for a perverse lifestyle. Many think that AIDS, like syphilis, is a disease of choice resulting from a risk freely taken. Government policy is confused, reflecting enduring patterns of thought. The Surgeon General says one thing, the Secretary of Education says another. Our AIDS policy today parallels the social hygiene policy of the U.S. Army during World War II. To try to keep soldiers uninfected by syphilis, the Army could never really decide how to use their material, whether through horror stories, graphic films, for example, or to distribute condoms. The Army did both in a confused and inconsistent pattern. AIDS, regardless of erroneous structures of thought, is caused by a virus which destroys a critical component of the immune system. It is, per se, a medical issue and should not become the fodder for ideology. We cannot really deal with this tragedy until we distinguish between the medical issue of AIDS and the ideological nonsense uttered by self-proclaimed guardians of morality. The past tells us to learn; it calls us to act effectively. Let's learn from the Army's efforts, not duplicate them. AIDS, contrary to what many think, is not the result of perverse choices. Individuals struggling today with the monstrous burdens of HIV infection probably acquired it long before much was known about AIDS. With great stealth, HIV came quietly into their lives, long before anyone could raise the hue and cry. The alarm was sounded, but it was already too late for two million Americans.

Now, reflecting that hue and cry, gay men have radically altered their lifestyle. Current data indicate that the transmission rate of sexually transmitted diseases is dropping rapidly among gay men. Gay men are now an embattled community called to heroism on a daily basis, and they are meeting this monstrous challenge. They have organized massive corporations for the care of the sick. Unlike some of us, they do not ask how anyone acquired the infection. More important,

they have come to nurture each other in confronting this scourge. It is now common for one gay man to cradle another as he lay dying. They have cried their tears, a Mississippi River full of them, buried their dead, and waited in terror for the disease to strike again. For as they have realized, it will visit them again, and again, and again. As gay men have discovered their own heroism and compassion, virtues of great beauty, we have largely failed them. We debate whether the term condom can be used in polite conversation, while they stand watch at the gates of terror. In Miami, we debate using six billboards for AIDS education, while a person with AIDS, abandoned by us all, is engulfed in flames in a hospital bed. We debate about the schools, while a house is torched in Arcadia, Florida. Certainly the nation that went to the moon can do more when 25,000 of its citizens have died. Certainly the nation that reaches to the stars, can do more when another 20,000 of its children are sick. Certainly the nation that routinely wins Nobel Prizes in medicine with great vast wealth behind it can mobilize more resources to fight this scourge. Just as we triumphed in the Manhattan Project during World War II, so we must and so we shall triumph against AIDS. Our sons and our daughters are dying. No nation which allows this can endure. If this is the prologue, then the archive created by this Commission is a test of our nation's fiber, our common commitment to our shared humanity. The virus does not discriminate, neither should we.

(Applause.)

CHAIRMAN WATKINS: Thank-you very much, Ms. Bohnsack-Lee. We'd like to have the next witness now.

MS. GAULT: Dr. Gray.

EDUCATION ISSUES PATRICK GRAY, Ph.D., EXECUTIVE ASSISTANT SUPERINTENDENT, DADE COUNTY SCHOOLS

DR. GRAY: Good morning, Admiral Watkins, ladies and gentlemen of the Commission. I'm Pat Gray, Executive Assistant Superintendent of Schools here in Miami, the nation's fourth largest school system. I'd like to share with you some of our experiences with regard to three major clients of this and any public school system, particularly with the subject of AIDS. The first client of course is our students. For us, that's some 255,000 students. Our second client is our employees, and for us that's 25,000. Our third and largest client is that group constituting our parents, which in our case is somewhat in excess of 300,000. Our school system very wisely put together a task force of medical and legal experts and labor union

representatives -- we are a collective bargaining school system -- and received from that task force state-of-the-art information and accordingly adopted an aggregate of procedures which constitute a policy. These procedures were then put into effect. I might add on a personal note, I handled the first case of an employee with AIDS five years ago, long before we had any procedures, and long before there was much written, publicly, as there is today about AIDS. I remember talking to a number of physicians at the Centers for Disease Control in an effort, at that time, to try and find out what this strange disease was all about. Some two-and-a-half years ago, we discovered that some of the teachers at one of our adult education centers were teaching at an outreach center, which happened to be a county nursing home, and they were teaching individuals who were affected by some strange disease; yes, it was AIDS. So we then encountered, and that was still in advance of our school system having a policy, but we encountered that and we dealt with it.

We have today a policy in place. That policy has been prodded as they frequently are by litigation. That litigation was brought on behalf of three Haitian children who are affected, or I should say two of them are still affected, one has died. Because of that, the school system has put into place a policy which constitutes the review of a child's medical status and the acceptance of a child in the school under certain conditions. That policy was a three-part, or the agreement was a three-part settlement, with the Board, the attorneys representing the children, and the Teachers' Union, all entering into an agreement, and then very wisely putting the entire matter under the jurisdiction of a federal judge. That's a very strong procedure that we do have in place. I'd like to share with you the fact that those children who were the subject of that litigation entered our school successfully this summer, did conduct a very successful summer program, and are still successfully attending schools. I wish I could say the same thing for the teachers who are teaching them. Let me share with you some of their personal experiences. 1) 60 percent of the teachers at this particular elementary school volunteered, said they were willing to teach these children. So we did not have a confrontation as to whether a teacher would or would not be forced to teach a child with AIDS. But those teachers, and we know because we're meeting with them regularly and giving them the same kind of support that pediatric AIDS nurses get. We know because pediatric AIDS nurses are among our resources. Those teachers shared with me the fact that frequently when they walk into the teacher's lounge, other teachers get up and leave. When they sit down at the cafeteria table, other teachers get up and leave. One of them was confronted directly by a colleague who

said, "You know, if you hadn't agreed to teach these children, they wouldn't be here. "So even in a staff that has been informed and educated, and where 40 percent at least of the staff has some hesitation to be in or around or with, in an educational setting, children with AIDS, we have problems. That is a reality.

Our system is successfully implementing a comprehensive AIDS education program with those three large clients. However, I think you need to know the psychosocial reality, the actual day-to-day experience of those teachers, and God bless them, they are willing to do this. They are enlightened enough to be willing to do that, but they are encountering extreme isolation from their colleagues, and that is a reality. We are teaching children from Grades 5 to 10. I know the Surgeon General said start at Grade 3, and we certainly respect his opinion as a Surgeon, but not as an educator. We will determine whether we should begin at Grade 3, based on our experience at Grade 5, based on the receptivity of the students as we implement instruction at Grade 5. I guess we've gone the full cycle because I've gone from parents, and I have personally confronted parents in this community, many of them very, very angry in a number of community meetings, but we've gone from those parents who complained that the Board had a position under certain circumstances to place children in schools, to a point where within the last several weeks some of our teachers accused me of violating their First Amendment rights because a poorly planned program involving an AIDS victim in one of our schools was cancelled, not because an AIDS victim was part of the program, but because the presenters and the subject matter were completely unknown to the school system and the Public Health Department. I don't know if that represents a good point or not, but we are attempting to educate our children from Grades 5 to 10, and above Grade 10 through presentations of our Public Health Department. Our employees, you can't get to 25,000 employees on a one to one basis, so we have to use materials, telecasts, video tapes, and information along that line, which we do.

And then lastly, parents. We get to parents, and I would suggest that most school systems will have to do this through the only two organizations that a school system probably has, the PTA network in whatever way it exists, and the Advisory Committee network, which may be common only to the State of Florida because of a strong involvement of citizens and parents in Advisory Committees. Interestingly, I made two presentations on Monday and Tuesday evenings to what we call feeder patterns, groups of six or seven or eight schools that ultimately all feed up into a senior high school. There were announcements made that

the presentation would concern AIDS in the school system's curriculum and policy and procedures. The total number of parents who showed up at those two meetings was 9. Now, where the school system announced that it would place Haitian children into one of the schools in their neighborhood, and we conducted sessions at three Haitian schools, the smallest number of parents who showed up was 150. So that shows me at least, as an educator, that this subject is still abstract to most parents until it is believed to be hitting home. Home for a parent is where that child is attending school. We need, and I'm sure you're going to hear from a lot of people about various needs and funding and so forth, and I don't want to replicate that except to say that a public school system depends upon its public health resources in an effort to educate those three clients. Our resources are very minimal in terms of personnel, and even more minimal in terms of materials. As we look for appropriate curriculum materials, we find very little that are fully appropriate for the various different learning levels of our children. God forbid we should use some of the materials I've seen with fifth graders, although they might be appropriate for tenth graders. Most of what I've seen wouldn't be appropriate for any public school children.

It might be appropriate for some of our adult employees, but that's all. So we as a school system have a need to expand our own resources so that collaboratively with the nation's Public Health Department, the nation's public schools can join into that endeavor to reach those three clients, to reach students, staffs, and parents. In that regard, I would like to close. I have a great deal to say, and it usually takes me about two hours to talk about our procedures and our policies. I'd be very willing to respond to any questions about our experiences, our procedures, our policies, which are in effect and have been in effect for two years now in the nation's fourth largest school system.

CHAIRMAN WATKINS: Thank-you very much, Dr. Gray. We've been informed by every one of the very responsible and knowledgeable witnesses in every area we visited that you're at the heart of the weapon to control this infectious disease. We know it's critical, and we'd like to spend a lot more time with you. Unfortunately, we're going to have to move quickly through, but we'd like to open the door to the Commission from you to keep us informed of what you are doing and any thoughts you may have where the Commission can be useful in this area because we will be holding special hearings on education. We'll probably devote two-and-a-half days exclusively to that in Washington sometime later in January. So we have an open door to

you and your colleagues to make sure that we're kept up to speed on what your concerns are and what obstacles you feel that you have in progress.

DR. GRAY: Thank-you very much.

CHAIRMAN WATKINS: Thank-you.

MS. GAULT: Before we move on to the last two witnesses for this morning, I think we should let the Commissioners know what it looks like we're running into in terms of time constraints. I believe we can finish with their testimony and maybe some follow-up questions by 12:15, and then the Commissioners can grab a quick lunch. Unfortunately, we were unable to bring the lunch in here, which is what we were trying to do to save time. We'll quickly eat lunch, about fifteen minutes, and then be back up here at 12:30 to begin again. What we'd like to do then is to allow Dr. Lee to make his presentation at that time. There's a lot of problems that people are having because of travel and weather problems on the Eastern Seaboard, so Dr. Lee's presentation will be moved up to start at 12:30 and should last until 1:30. He thinks that he can finish at that point. At 1:30 we'll begin again with the hearing segment, and at that point any Commissioner who have to leave because of time constraints or weather problems at home will have had a chance to participate in the business portion of the meeting. Those who can stay then can listen to the rest of the testimony. So for our last two witnesses, Ms. Shack.

EDUCATION ISSUES RUTH SHACK, EXECUTIVE DIRECTOR, DADE FOUNDATION

MS. SHACK: Thank-you. I am Ruth Shack, Executive Director of the Dade Foundation, this community's foundation, and I thank you for the opportunity to give testimony this morning. After seven years of researching this disease and this virus, and discovering its impact on the immune system, and implementation of the treatment protocols and initiating vaccine development, it's surely time to reexamine and evaluate our educational programs and the way to effectively reach the diverse components of our community on the topic of AIDS and AIDS related issues with emphasis on prevention. South Florida is unique in its mixture of rich cultural and ethnic backgrounds. While that diversity creates a multi-tiered and multi-textured appeal of this community, it also presents specific problems when dealing with AIDS education. Education must be targeted for the various groups within the individual communities. What works for the upper-middle class mother in Kendall will not meet the needs of the welfare recipient mother of Liberty City, nor the migrant

workers in the deep south of our county. Each distinctive group within the greater community must have access to information and education and training that is relevant to their way of life and within their standards of acceptability. The need for a well-trained staff, hired from the communities themselves, is evident. Miami Haitians can educate other Miami Haitians, can gain access and understanding where the White Anglo individual might often fail due to limited language skills, or due to the simple misunderstandings of the appropriate protocol and hard to erase long-standing differences in cultural backgrounds. These problems in educating the community can best be surmounted by developing programs specially targeted and delivered by members of these groups. To avoid expensive duplication of administration, support, and service systems, a central organization, such as we have here, the Miami Health Crisis Network, could function as the home base for small neighborhood outreach programs, designed to educate, do initial counselling, and to channel those in need to the central service providers. The staff of each of these neighborhood programs should consist of persons hired directly from the community they serve who can provide training for the existing organizations with careful consideration of the special tailoring of presentations, and the initial counselling sensitivity of the community's cultural needs.

In the development of the educational programs, special attention needs to be focused on the following:Materials must be developed by each community with relevant language and graphics. Materials should not simply be translated from English, but must represent meaningful issues to each of the communities. There needs to be an inclusion of clear graphic materials, tastefully presented by the facilitators who are comfortable with a discussion of all aspects of human sexual behavior and drug usage. Educational materials need to be updated and evaluated for accuracy and effectiveness. We must consider inclusion of AIDS educational materials for persons already infected with the virus. AIDS is not a "them/us" educational experience. Many persons learning about AIDS may or may not know they are infected with this virus. For persons who do not know they are infected, materials need to be included with basic immunology information, resources for support, and the most current information about intervention protocols. And we need to provide education programs with the purpose of training the trainers that they not only include facts and examination of attitudes, but also incorporate skill developments. Miami, Dade County, and South Florida are composed of unique communities within the greater community at large. Each of these special communities add to and can gain from the greater community knowledge and progress in

dealing with this health crisis. Working together, Hispanics, American Blacks, Caribbean Blacks, migrant workers, and Anglo Americans, we can provide proper and effective education and prevention for AIDS in the individual communities, with the lasting effect on the country as a whole. That's my testimony, and I'd be delighted to answer questions.

CHAIRMAN WATKINS: Thank-you very much, Ms. Shack. Commissioners, questions?

(No response.)

CHAIRMAN WATKINS: Do you have, Ms. Shack, some recommendations or some material that we could see that you have found effective in the variety of cultural environments that you mentioned? In other words, are you already to the point where you have sampled the waters and you find that they are effective documents, and they are reaching the communities you're trying to reach?

MS. SHACK: On an Ad Hoc basis, the community has been doing that now. What we're seeking is aid in producing the kind of materials that would help us to do this formally.

CHAIRMAN WATKINS: Can you give us a cross-section of those materials, just to give us an idea of how the cultural differences are reflected in those documents on the subject of AIDS?

MS. SHACK: Well, as a quick background for Dade County, we have 40 percent of our population who have been born in other countries. Los Angeles and New York approach the 20 percent; we're at 40 percent. Everything that we do from bus systems to the dissemination of public information must be tailored for specific needs. Within the so-called tri-ethnic community, we break down into multiple communities. We're one of the largest Jewish communities within the Anglo community. Certainly you know about the Haitians, who are very different from other Bahamian Blacks, who are different from the North American Blacks, who came to Miami. Within the Hispanic community, we all think of Cubans, but of course the new Cubans are the Nicaraguans with war wounds. We have Salvadorians; we have every Central and South American community here. They all come with very separate and very different cultural mix. Everything that we do, if we're going to be effective, has to recognize their differences and work within them.

CHAIRMAN WATKINS: We're very sympathetic to that, but what I would like to do though, if you have information on AIDS that you've put out in a variety of cultural forms, is actually that information which would be very useful to us. Also, it would be very useful to our international group, under Dr. Walsh, who is working today in Geneva in the international community with World Health Organization and so forth. Particularly in Florida, it's rather unique in that regard along the lines you just mentioned. It would be very helpful for us to have linkage with you on this subject.

MS. SHACK: Absolutely. We'd be delighted to cooperate.

CHAIRMAN WATKINS: Yes, Dr. Lilly?

DR. LILLY: At one point you spoke of the need to produce materials that are tastefully explicit, and I'm wondering if the so-called Helms Amendment might have any effect on your ability to do so.

MS. SHACK: Again, we're prepared to work within whatever constraints are given us. It's imperative that we, in some way, reach people so that they understand what it is we're saying. I'm not a graphic artist; I'm not a medical doctor. I am simply a person who is interested in seeing us do something in the way of education. I'm sure that tasteful is in the eye of the beholder.

CHAIRMAN WATKINS: Thank-you very much, Ms. Shack.

MS. SHACK: Thank-you.

MS. GAULT: Mr. Lieb.

EDUCATION ISSUES, SPENCER LIEB, M.P.H., AIDS PROGRAM SUPERVISOR, STATE AIDS EDUCATION OFFICE

MR. LIEB: My name is Spencer Lieb. I work with the AIDS Program of HRS, and supervise CDC funded projects, collectively known as Health Education Risk Reduction, or HERR. These are projects in South Florida in the regional four-county area, in Belle Glade, a statewide AIDS public information project, and an upcoming minority AIDS education initiative. I also have the dubious honor of being your last scheduled speaker before lunch; I enjoy a challenge. Oral polio vaccine will reliably elicit the same protective response in just about everyone, no matter who prescribes it, no matter who administers

it. With regard to AIDS prevention, of course, the risk reduction message must often be tailored to a given culture and lifestyle, and the messenger must be credible to the audience. Otherwise, as Ruth Shack said, the information is much less likely to elicit the protective response, and the messenger may be viewed as an outsider. In Florida, AIDS has involved a somewhat broader cross-section of society than in many other states at this time. As you probably learned in the last two days of your visit, heterosexual transmission is relatively common here, as is AIDS in women and children, and minorities are over-represented among the 3,300 AIDS cases reported to date. No doubt the great majority of White, Black, Hispanic, and other Florida residents, practice personal behavior that do not place them at risk for AIDS. However, the small but significant proportion who are at risk is increasingly becoming infected, mostly due to unsafe sexual or drug abusing behaviors.

It is critical to convey a sense of vulnerability to those at risk. This is the first step in promoting change in behavior and ways to sustain that change. To those not at risk, we must convey information that will reduce fear so that rational problem solving can take place without stretching the fabric of society. Persons who voluntarily seek HIV counselling and testing anonymously through the state's network of county public health units would not be there if they did not already sense this vulnerability. Non-judgmental, one-on-one counselling has been provided in pre and post-test settings to more than 20,000 individuals attempting to adopt or sustain positive health behaviors. Counselors trained by AIDS Program staff carefully stereotyping by emphasizing the factors and behaviors that incur risk, rather than the personal characteristics of infected individuals. Confidential counselling and testing sites are now being established in all county health departments. Attendance is not dependent on word of mouth or other publicity, nor on prior awareness of AIDS and its risk factors. AIDS information and education, and counselling and testing services are offered in these settings with informed consent to interested clients. This is happening in STV clinics, family planning clinics, and maternity clinics around the state. In the past two years, the AIDS Program has contracted services with several AIDS service organizations. This year, contracts will be developed with as many as ten minority community groups, as well. Thus far, these contracts have enabled well trained professionals to reach important segments of at risk communities on a peer-oriented basis. The successful development and distribution of a survey instrument on AIDS would not have been possible without the contractual involvement of four major community based or AIDS service organizations.

Printed educational materials on AIDS are ineffective with groups having high illiteracy rates. One approach that our Dade County staff are pursuing is the development of audio cassettes with a 15-minute AIDS educational program in Haitian Creole on one side and English on the other. A staff member in Palm Beach County, as you probably know, and I think you heard about this, helped introduce a novel approach that made risk reduction counselling both palatable and digestible. Women with AIDS and female sex partners of men with AIDS were presented with vital preventative information in the context of a regularly scheduled sewing circle in Belle Glade. This past summer in South Florida, we conducted a billboard and bus placard campaign aimed at the general public. An original music and laugh advertisement was also developed and air time purchased on three popular Black-oriented radio stations. The combined campaigns have resulted in a sustained three-fold increase in calls to the Hotline. This past spring, we conducted a non-random survey of AIDS knowledge, attitudes, and behaviors among 2,300 predominantly at risk Floridians. In one question we asked respondents, "Suppose you learn that someone you have sex with has the AIDS virus, would you be sure to use condoms when having sex with this person. "Overall, more than 85 percent said yes, they would use condoms. Even among the large number who presently never use condoms, more than 80 percent would use them in this hypothetical situation.

Clearly, in our sample, the decision to use or not use condoms seems largely based on an assessment of the partners chances of being infected, i. e. their own vulnerability. Not lack of knowledge, but subjective assessments and the perceived inconvenience prevent a wider use of condoms. These risk assessments seem hard to change unless there is a dramatic increase in awareness of the level of HIV infection in at risk populations. In summary, the only way to prevent new infections and curb the epidemic is through effective sensitive education and intervention. In Florida, the unique combination of cultures and lifestyles demands the innovative approaches, some of which I have highlighted. Systematic and ongoing evaluation is essential to insure that several years from now we have not missed the boat, and that we make the necessary mid-course corrections in our strategies. Thank-you.

(Applause.)

CHAIRMAN WATKINS: Thank-you very much, Mr. Lieb. Questions from the Commissioners? Yes, Ms. Gebbie?

MS. GEBBIE: One for follow-up, and that is could you provide some estimate of your current capacity for counselling sessions and counselling testing contacts, and how that contrasts with the numbers of citizens in the state you think would benefit from that kind of personal education?

MR. LIEB: Well, the pattern is almost fixed by a number of recently funded or supplemental funded awards made by CDC. The second question is to how many individuals might actually benefit from these services. We're really getting at the question of what is that percentage of people who, in one form or another, either practice high risk behaviors or are at risk by virtue of exposure to contaminated blood in the past and so forth.

MS. GEBBIE: I know the definitions of the group. My question is at looking at any estimate you may have made of the ability of the resource to match that need. This matter is something you can answer standing here, or might be one of those things you would mail into us later.

MR. LIEB: We can respond to that. Just let me comment that it's not a stable estimate. When the media picked up on hterosexual transmission last spring, and here was also a lot of publicity about a look back program for blood transfusion recipients, that generated a very unanticipated volume, and we can't realy tell that. If things remain as they are, I think we will have adequate staffing to met the demand at present. We will be creating more demand, I hope, through our efforts, though.

CHAIRMAN WATKINS: Thank-you very much, Mr. Lieb.

MR. LIEB: Chairman, if I may make one statement to clarify a funding figure that came out earlier by Dr. Witte. I believe Dr. Primm asked this question, and that is with regard to our budget for the Belle Glade intervention project, it is a total of $314,000.00 for the first ten (10) months of the project, of which $61,000.00 comes from CDC's AIDS Surveillance Program, and the balance from CDC's Center for Prevention Services.

CHAIRMAN WATKINS: Thank-you very much. Commissioners, we must move expeditiously to the third floor for lunch. We have to be back in ou seats here at 12:30, so I'd like the Commissioners now to please move out this way, and be back in their seats at 12:30. We're in recess.

(Whereupon, a luncheon recess was taken.)

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A F T E R N O O N S E S S I O N

(12:45 p.m.)

CHAIRMAN WATKINS: We'll commence our business meeting now for the Commissioners. Our agenda item this afternoon is for Dr. Burton Lee to present his final report format concept to the Commissioners. It's the first time we've had this opportunity. The idea being that if the Commission has a format in hand, we can begin to tailor various elements of the task that we've been given under the Presidential Executive Order in some kind of an orderly framework. For example, we have the international working group already established. They need to know what format we expect their report to be prepared in, so that it can gel with the other elements that will subsequently be added to the final report. The same for financial, which is also underway. So this then will help us move towards our interim report as well, and it's extremely important that we try to discuss openly today our comments about Dr. Lee's working group effort on this format, and we'll look towards finalization of that format before our 24 November meeting, which will be focused in itself on the 7 December interim report. Dr. Lee, go ahead and proceed with your presentation.

DR. LEE: Thank-you, Admiral Watkins. I'm glad to address my fellow Commissioners, my friends, and I'm glad to address this friendly audience. The point of this organization, just to start off here, was that this is not a report to a community group, this is not a report to a mayor of some region, this is not a report to a person handling mainly reimbursement problems, this is not a report to a medical organization, this is not a report to a bunch of CEO's. This is a report to the President, and when one starts to take the roots off the multiple layers that are AIDS, one finds some very profound problems in there. It is my hope that this Commission is going to address the really profound problems that underlie this disease. The HIV epidemic is of peculiar and important interest because it does seem to reach down into the heart of our social matrix here and disturb some streams of thought which had been merrily going along up until now. I have talked to a large number of people. We've talked to some people in Congress; we've talked to the Surgeon General. I've talked to the leadership at the Institute of Medicine at great length because their medical summary for the medical recommendations on this disease is probably the best that has been done to date. Well, it is the best that has been done to date. The list of people on the organizing committee of the Institute of Medicine report is a who's who in the medical aspect of AIDS in this country. It's really a who's who internationally as well. I'm not sure that this Commission can make tremendous improvements on the medical aspects of that report.

We have talked also to people at the AMA, and they have done some enormously important work, heavily referenced, very scientific, on the medical aspects of this disease, which always break down to care, prevention, and cure. These subjects have been addressed. There's extensive bibliography in these other reports. Particular reports that I've been interested in also are some of the private institute reports, the Rand Institute, the Hudson Institute. There are summaries that have come out of the Harvard School on public health, out of Stanford on economic issues. The Treasury Department already has an extensive financial assessment of what AIDS means to this country in terms of economic impact. Now, it was my hope that we not go over and try to redo all of the best work that's been done in this country, but try to accept the best, endorse the best, and in return get their endorsement on our report. All of this material is particularly available on the medical aspects of this disease. I therefore started off by breaking this down into six major areas, and making only one of them really the medical aspects of the disease.

The first section, which is medical, breaks down, other than the lead-in, really into patient care and research. Both of these topics would be addressed in the initial medical part of this report. Of course, this is an extensive part of the report, if you look at the summary. The housing problems are brought up here. We were planning on addressing the medical aspects of the disease sequentially in the course of the disease so that we'd start off with the testing, the counselling, the diagnosis, the OPD, the hospital care, the supportive care, the housing, alternative care settings, the psychiatric problems, the terminal care, the social work problems; all of these addressed in sequence. Again, the major medical organizations in this country have done a tremendous amount of work in this area which we would be fools to disregard. It's very interesting that no matter who addresses these issues, they almost always come up in the same place. It is of interest that there are minor irregularities; there are minor differences. One of the things that interested me most was the difference in philosophy on testing between the Institute of Medicine and the American Medical Association. Both positions are very well thought out, very well outlined. One of the problems, as the Chairman of our Commission is going to have to deal with, is are we going to be presenting the pros and cons; how many conclusions are we going to come to. We are obviously going to be searching for a consensus on all these issues, and I think we will find in the medical documents, by putting them together, that the consensus is really almost there. I hope that in the medical area we can largely come to a consensus by adopting some of these reports. Colleen Conway-Welch has been interested particularly in the educational aspect.

I put a special paragraph on the retraining and education of the medical personnel that are needed that are very extensive, the counselors, the Emergency Room people, the nurses, the host of people that are needed out in a place like Belle Glade, that I think Dr. Fournier was about to address very nicely here this morning, and it was too bad to cut him off. I won't go into this in any more detail. You can read this in the outline that you have.

Obviously, a special section has to pertain to the medical aspects of research. The FDA problems are repeatedly brought up by everyone who talks to us, and I, from the cancer world, am particularly sensitive to these FDA and drug screening problems. It's a terrific area of concern in the cancer world, and it is reflected now right across the board in infectious disease. Under the medical aspects, we were just going to address the medical aspects of it under medical and leave the financial problems for a second section. I cut prevention out of medical, and we spent a long time with Roy Widdus on this particular issue. His credentials, you know, are not just that he was the Executive Director of the Confronting AIDS Report. He's also the Director of the Division for International Health at the Institute of Medicine.

I wanted to put education and public health together, we wanted to somehow link prevention, education, and public health. We decided to do it under this separate category of prevention, and this breaks down really into two major sub-categories. The first is education, and education breaks down into two major sub-categories, the first being rational understanding of the epidemic and the roots of exposure, and Cory, that's one of the places where we get into your concerns about blood banking and different roots of exposure. The other major educational aspect was behavioral change. There is a year-long study that is underway at the New York Academy of Sciences on behavioral change, with a terribly interesting group of people participating in this conference. I'm going to make sure -- well, I certainly am going to follow up on it, and hope that any Commissioners that are interested in this aspect will follow up on it with me. I have their assurance that we have cooperation at every level over there. The other aspect of prevention is the public health measures that go down the entire gamut of public health procedures when you're dealing with an epidemic. I don't think I have to go into that in detail. I should have started off by saying please do not consider that anything in this outline is anything more than a thought process. Everyone who has written a report on AIDS tells me that the formats change right up to the time of publication, and I can understand this because every one of these concerns just weaves back and forth into the other one.

Another major subheading and one that, obviously, especially in this atmosphere, is going to be one of the important things that the leaders of our government will use is recommendtions on financing AIDS care. When you look at the literature on this you see the financial considerations broken down into a million different areas approached from different aspects. I haven't seen the entire package really addressed, and under finance Colleen reminded told me, I forgot to put in reimbursement. That's hidden under insurance issues, but it's obviously much, much broader than that. Again, we thought it was interesting, and I was interested that Richard DeVos had the same idea, or maybe John Gartland put it into his head, or maybe he put it into John Gartland's head -- I'm not making any statement here -- is that again the financial aspects be approached sequentially in the course of a patient's illness so that the various levels of care are addressed. There's got to be a lot of discussion about the private and public sector, the workplace issues. One of the concerns that was repeatedly expressed to me was the diversion of funds from other worthy causes that are going into AIDS. The National Cancer Institute just lost their best virologist to the AIDS program, and there are a lot of medical organizations that have concerned good people who leave to work on AIDS issues and are not being replaced properly. The migration of PWA's is also something that's been repeatedly brought up, and confuses financial assessment of the problem, especially when you try to do it from a statewide basis. John Creedon, who's obviously very key to this entire thing, has to face this from the point of view of the various insurance and third-party payers. The fact that in Florida there's less Medicaid reimbursement than say California or New York, means that California or New York are likely -- I don't know the figures on this -- to attract more PWA's who are dependent on medicaid than Florida is. These things have to be addressed, and we have to make probable recommendations in some way as to where this thing can be broken down, state versus federal.

I'm going to skip to the legal issues next. I have been particularly interested in the legal aspects of the HIV epidemic because I think there are some very, very important underlying issues that can be addressed by getting some constitutional lawyers involved with our report. The testing issue -- mandatory, voluntary, anonymous gets into this area. The confidentiality problems get into this area. The discrimination issues get into this area. We're talking about the Fourth Amendment, the search and seizure problem. We're talking about the private rights, the civil liberties of the individual human being versus public health issues. There are some excellent treatises that have been written on some of these subjects, particularly testing; not as much on confidentiality, which is terribly complicated. I was hoping that we could come out with some really interesting recommendations, or at least an interesting assessment of some of these constitutional issues

that surround AIDS. We are also heading headlong into criminal problems as well as the complex social problem facing our society. We have heard, as we listen to people testify before us, repeatedly about people who are aware that they are HIV positive who continue to have random sexual experiences. I was disturbed actually this morning to listen to testimony about this family who knew they're both positive for the virus and continued to have children. That happens to disturb me; I don't know who else it disturbs. I have to give that social worker or that nurse, Ana Garcia, a lot of credit for being able to continue to deal with a situation like that, which would be appallingly difficult for most of us.

The problem that I would like to see us address, which will take some courage, is the liability issue. The drug companies look sometimes now at a hundred million dollars in liability costs for bringing out a new drug. They won't even touch vaccines. There are a very limited number of companies in the country now that will try to develop a live vaccine anymore because of this liability problem, and what can be done along indemnification lines or curtailing suits, cost caps, et cetera. I don't know, but I'd like to see our Commission address that.

I've put a separate section in here for ethics issues. The denial of care, the research ethics for terminally ill people, again I see a good deal of this in the cancer world. The PWA's have brought up a very good point in this double-blind randomized studies where somebody is put on a control arm, but, "Hey, I've only got 392 days to live, and I prefer not to be on the control arm." I can understand that. The problems of federal versus state legislation I've also put in here. Legislative issues are with us on the Hill now and I think that we ought to address them in some way. Increasingly, with AIDS we're talking drug abuse.

We're all very happy that Beny Primm is here to assist us with this, and Peggy Dufour makes a good point here, it's not just drug abuse but the factors underlying all epidemics, poverty and drug abuse which share many of the same factors. I have recently got to know Congresman Charlie Rangel, because he's dealing with this on a day to day basis with the House of Representatives Select Committee on Narcotics, with really very little aid and assistance from anywhere else. When you get into the drug abuse issue, you start to see that AIDS is attacking, this disease is attacking the underbelly of our society. It is attacking the area where we are weakest. When you look at drug abuse, you are looking at joblessness; you are looking at chronic, severe poverty, that we have not been able to address during the great society years. Nobody has come up with significant answers to this. As a matter of fact, I've recently been reading a book on the underclass, which actually was written up in the New York Times on the first page, I don't know if you saw it. The author comes to a very interesting gut conclusion

that the underclass really is less and less a product of race now. It's less and less a product of the welfare system. It is a product of the changing economics in the United States of America. It's a product of joblessness and subsequent hopelessness and loss of ability to deal with life. At any rate, when you get into these factors that underlie where AIDS hits here, and the drug abuse issue, you get into the illiteracy problem, unemployability problems. You get into the teenage pregnancy problem, the single parent households. You get into the chronic welfare dependency that plagues many Americans, even over several generations. All of these types of things create people that do nasty things to themselves. They inject drugs into their veins. When you have a 25-year old person who has not gone through the sixth grade, who is a drug addict, who is basically unemployable, and 70 percent of these people also are carrying the HTLV virus, in my parlance at Memorial Sloan-Kettering Cancer Center, you really are dealing with a potental terminal case at a young age. I think that I would like to see our Commission address some of these underlying concerns. When I talk to people that are involved with this disease, and involved with fighting it on a day to day basis I used the concepts they thought were important in this outline.

I've put some other things under societal; the cost to society, the crime situation. The actual statistics at Rikers Island and Greenhaven Prison, which are the two I went into, which is a maximum security prison in New York State, is that 70 percent are drug abusers, 70 percent cannot pass a sixth grade reading exam, and 70 percent are minorities -- I'm told I have five seconds, but I will keep you people quiet anyway. At any rate, I could go into this, but I'll drop it.

The last is international. We started off putting international issues under the other above chapters because they all get into international issues. In discussing this with Bill Walsh, who is head of our International Sub-Committee, we ended up putting it in both places; clearly, anything can be done with it. One last thing I was interested in doing with this report, and I hope that my fellow Commissioners will not insist that it be too dry. I would like to see a major literary figure give us a preface. I would like to have some inspiration from some of the great historical works that have been done. I read the original Thucydides description of the plague in Athens, and you know, it's just absolutely a carbon copy of what's happening. What happened in their society is just a carbon copy of what's happening in our society today. I might also add, we had a speaker who was talking about the past is prologue, and it's written on the archives of Congress. Let me leave it there. There are a million other things we could say. Oh, yes, the conclusions. The three conclusions I thought were excellent. Jim has been very interested in summarizing the obstacles to progress in this disease, and I'm in total agreement with that.

I think it's an excellent thing to put in our conclusions, a summary of our major recommendations, and perhaps some guidance for the future, which is a term stolen from the IOM report.

CHAIRMAN WATKINS: Thank-you, Dr. Lee. What we'd like to do now is let me recap for those who aren't sitting with a draft of our report format in front of them. You have given us a proposal from your working group, which has involved a number of members of the Commission. We've had one opportunity to comment. This is another opportunity in open session for the first time to take a look at this. You have acknowledgements to the organizations, you have a forward, you have a prologue, you have a table of contents, and then you break into the various groups that you talked about. You've labelled them as biomedicine, under which you have patient care and research. You have a prevention section, under which you have education, public health measures, future treatment modalities, international considerations. In fact, you have international considerations that pop into view in each one of the various areas. You then have finance, assets and liabilities, who will pay. Section 4 is societal concerns that you talked about. Legal and ethical issues is Number 5. International, Number 6, as a separate entity, in addition to, apparently, you thought it important that you pluck out certain elements of that international to apply into the other five areas we just talked about. Then you have your conclusions, which you just mentioned, bibliography, and appendices.

What I'd like to do now is I'd like to start recognizing Commissioners here to let us have their views on your draft format that you presented to us today, and to see if we can come to conceptual consensus. We all recognize, as you pointed out, that format is not going to solve the AIDS problem; we understand that. But it is an organizational approach to allow working groups to frame their thoughts in an organized area which can then be melded together to form our final report. We may find in that process considerable change to the format becomes necessary; we recognize that. I wanted to lay that groundwork to those listening to this so there appears to be some order to what we're doing and a logic train that says, "This is important," so that we can start framing our thoughts in an organized way. I'd like to open now for debate from the Commissioners on their feelings about the conceptual framework that you've laid out for our final report approach, and then let's see if we can harmonize our thoughts today and come to final agreement, recognizing we may have some more staffwork to clean up some glads to happy and a few periods to semicolons. Let's start with whoever would like to be first on the debating team here. Yes, Ms. Conway-Welch?

DR. CONWAY-WELCH: I had a couple of suggestions. I want to compliment Dr. Lee on his efforts in organizing this, and a couple of overall suggestions for consideration. It seems that under the biomedicine issue we have the current status of the AIDS epidemic and epidemiology. I'd like to make a recommendation that those topics be moved up under table of contents so that there are four items. There's definitions and terminology, historical perspective, current status of AIDS epidemic, and epidemiology as four broad introductory statements.

DR. LEE: I accept that; I think that's a good idea. Anybody else?

(Laughter.)

CHAIRMAN WATKINS: What I'd like to do is pick these up for any other debate. We'll try to take them one at a time for all the Commissioners to comment on.

DR. CONWAY-WELCH: If I can finish what I was saying because that has impact on the first one.

CHAIRMAN WATKINS: Yes, please.

DR. CONWAY-WELCH: Then in terms of consistency, for the six areas that are broken out, I would suggest that because the first one is broader even than a biomedical issue, that we perhaps label that first one care issues, and under that then would be the way it's already organized, patient care, research, international, models. In other words, strike biomedicine and substitute the word care issues, and then strike epidemiology under that because that's already been treated in a broader sense under the table of contents. Then for the other major headings, simply make sure they all, for consistency, relate to issues, care issues, prevention issues, economic issues, societal issues, et cetera. Those are my suggestions for that piece.

DR. LEE: It sounds good. One of the things I'm not sure that all the Commissioners got was really the table of contents and IOM report, which of course was going to be integral to what we were going to adopt. They have a chapter devoted to care of persons infected with HIV, future research needs, et cetera, so that was being built in there, but it can be made clearer.

CHAIRMAN WATKINS: I'd like to have other Commissioner's comments now, and we'll try to summarize. The Executive Director is going to keep tabs up here, and then we'll go back and pick them up one at a time. So if we could just move down the table here. Mrs. Crenshaw?

DR. CRENSHAW: I think that this is a very thoughtful and detailed and well targeted organizational structure. I would second what Dr. Conway-Welch said about pulling out care. I think that that's a critically important issue that deserves underscoring, highlight, and focus in a subset to itself. It seems that under that setting, research might also be made an additional category for focus because it doesn't quite properly then fit under care. The remainder of the issues as they are divided here I think are just superb.

CHAIRMAN WATKINS: Dr. Lilly?

DR. LILLY: I have no substantive changes to suggest. I think that there will be modest alterations as we go along and find that one thing works a little bit better in one place than it does another. I have no objection to the outline as it stands as a working document.

CHAIRMAN WATKINS: It's a little bit unfair I think for Ms. Gebbie just new on the Commission, but if you've had a chance to get just a general feel, we'd appreciate your intuitive comments, just having seen this for the first time today.

MS. GEBBIE: I appreciate the opportunity, and I'm a little concerned that my comments may be out of timing just because I didn't participate in earlier discussions. I have no problem with the main structure. There are some pieces underneath sections that I think slide a little too glibly over some real concerns. Let me just highlight a couple of those that I've identified. Within the section on prevention, which is at least as big a problem as that of care of the already ill, because that's what will cap the cost eventualy. I think we have to separate education toward behavior change for those people who are already engaged in behavior that puts them at risk of this virus from education for those who have not yet entered into sexual or drug use activities. This is really the education of our next generation. The educational issues are very different when we talk about that, than when we talk about how do we deal with already sexually active or drug using adults, so I think we need to be real clear in that subset. If we do that --

CHAIRMAN WATKINS: Well, as it's written, as I understand it, you find it acceptable, but you think that for highlighting purposes we've got to identify the several areas under that particular section to make clear that we're not talking about education in the eyes of the beholder. We're talking about very specific areas that we've identified that are important.

MS. GEBBIE: Yes, that's an excellent summary. The other piece is that I think within public health we have to do the same kind of thing that I've heard being discussed for the

care system, and that is look at the public health system. We have a very fragile network of state, local health departments, and their tentacles in the community that is being very taxed by this epidemic in the same way that the hospital/hospice/home care network is taxed. If we just say public health system very glibly and don't tease out that structural problem and all the burdens this epidemic has put on it, we will give people the impression that it's easy to do the prevention side of it. So I think we need to become a little more explicit and careful about the system's structure there.

CHAIRMAN WATKINS: That's excellent.

MS. GEBBIE: My other two very quick points: Within societal issues, I think, we must address the fact that this epidemic forces us to talk publicly about some issues that our society keeps trying to deny, sex and death, and that if we don't talk about the societal problem of learning to talk about and deal with those issues, we will do a disservice. I don't know whether it goes in that section, or it's woven in other places; it can't be lost. Then finally, I become very anxious when I see people pose civil liberties and public health as if they were in opposition to one another. They are not; they need not be. It is a balance of individual issues and societal issues, which if struck properly protects both halves of the balance. I want to be very careful in our choice of words so we do not falsely imply an argument where one need not exist.

CHAIRMAN WATKINS: That's an excellent point, and I think we would all agree with that, that that was not the intent, I'm sure, to put a versus, but rather to demonstrate the dilemma that often faces us when we get into that exchange because it's one of the most sensitive of the public policy issues.

DR. LEE: You're dealing with this very strongly, but that is an issue.

MS. GEBBIE: That is how it is sometimes posed. Given the perspective I bring from striking that balance every day, and having worked through this issue with many groups, I find that our choice of words in putting the issue on the table often defeats our ability to resolve it. I'm hoping that this panel will choose the right words to frame the issue so we foster resolution rather than diversity.

DR. LEE: Definitely, definitely.

CHAIRMAN WATKINS: Mr. Creedon?

MR. CREEDON: I agree with the comments that have been made thus far. I also congratulate Dr. Lee on having surfaced I think almost all of the considerations that need to be addressed. The one that may be here, Burt, which I may have missed, in talking about education it seems to me we're talking about educating our people to help prevent them from getting the disease, whether it's children or adults and so forth. I think some of the testimony this morning put emphasis on the importance of educating the public about the facts of this disease and how it's transmitted and how it is not transmitted, and that type of education, it seems to me, is essential on the question of discrimination in housing, in employment, in medical treatment, and so forth. You started out saying that the three major issues that appear in many of the other reports are care, prevention, and cure.

Frankly, I kind of like those as the major topics. This is something, as we get closer to writing a report, the emphasis will come about. I have the feeling that the societal concerns and the legal and ethical issues have to be considered under those three subjects of care, prevention, and cure individually, rather than being treated as separate entity, although maybe you have to do both; I'm not sure. I associate myself with what Colleen said. In other words, I would start out with an introduction, and do what you suggested originally, include in that introduction a recognition of what's been done so far, an adoption of much of what's been done so far, so we don't have to review it, and then move into what I think are the important areas: Care of people who are ill and how we deal with that. Prevention of disease; and the cure; the research, the vaccines for other drugs and so forth, and in that area getting into this problem with the FDA, and whether the drugs are surfacing at an early enough time to be helpful to people. Then I would then move into international and financing, and then the conclusions.

CHAIRMAN WATKINS: Dr. Primm, do you have a comment you'd like to make?

DR. PRIMM: Under the area of legal and ethical issues, I think though we talk about civil liberty, somehow I think we have a tendency to cushion or cloud exactly what we want to say without actually mentioning some of the things that we want to avert or avoid. We talk about developing strong advisory groups, for example, so that civil liberties are looked out for. I think we ought to talk about homophobia; I think we ought to talk about racism. I think we ought to talk about sexism because we all know these things exist, and if we sort of couch them in the way we have covered them, I don't think that we will focus on them quite as much as we should in order to bring every American into cooperation in this epidemic. I think that's really an important issue here getting people's cooperation. I want to

compliment you also. I was not here, of course, as you formulated all of this, Burt, but I think it's really wonderful. Any way that I can help you ongoing now to further transform it into a document that we will all be proud of, I will certainly assist you.

CHAIRMAN WATKINS: Ms. Pullen?

MS. PULLEN: Well, I'll probably have some more reactions after I've had more time to look at this and sift what we've heard today into it. One of the things that I don't think you hit head on here, though maybe you have and I just missed it, that was brought out today is this issue of case management and coordination of care. Not simply taking various segments of the delivery system and saying, "Are these segments operating and available," but also how do the patients get linked with these segments in the most appropriate and cost effective and health effective manner.

CHAIRMAN WATKINS: Dr. SerVaas?

DR. LEE: That's good. I didn't put that in there. I'm trying to --

MS. PULLEN: Our deliberations are dynamic as well as the disease is.

CHAIRMAN WATKINS: We have to move right along. I need Dr. Servaas' input here.

DR. SERVAAS: I'll be brief. Dr. Lee, I think you've done a tremendous job. I know how much work you've put into this, and I was privileged to work with you on some of it, and thank you for including these things from all of us. The only thing I could add right now is when you talked about it not being dry, I think that would be really nice if --

DR. LEE: Not what?

DR. SERVAAS: Not being dry. The report you said would not --

DR. LEE: Oh, not being dry, yes.

DR. SERVAAS: When you mentioned historical perspectives and epidemics and plagues, could we add Paul DeKruif to the syphilis epidemic of 50 years ago, which was also a sexually transmitted disease, and all of us in medicine are aware of all of the similarities of the problems. If we could get something from Paul DeKruif, the medical writer, something out of that into our historical perspectives, I think it would help make it less dry.

DR. LEE: Yes.

CHAIRMAN WATKINS: I think that we can, Dr. SerVaas, lean on the task that we have from the Presidential Executive Order, item number 4, which is to submit the entire history of infectious diseases in the United States, and from that perhaps glean some thoughtful points harking back to Dr. Lee's Thucydides example that would be very catching and very important in making this come alive. I think we have a good basis, an historical and very sound basis on which to make such a statement, and I would recommend that we include that, so that we don't just put in an appendix that says, "This is the history of infectious diseases," but rather we infract from that a view that the Commission can use to give this some life.

DR. LEE: This historical perspective, the reason I wrote it this way, this is actually pretty much the title of what, as Cory pointed out to me, the Hudson Institute is going to do. They're going to spend the next six months or so doing a very comprehensive review of this. I look forward to reading it and incorporating many of the really excellent treatises, in part, say, in our report with attribution, staggering it through, so that we present a unification of many of these ideas throughout the country, and throughout all of the various efforts. I want to include this guy Gosten for instance, on his legal writings on testing; nobody said it any better of whom I am yet aware.

CHAIRMAN WATKINS: I'd like to now, if we can, and then we can have any additional comments, but we have to move right along, so I'd like to have the Executive Director summarize what's been proposed here to see if we can come to general consensus that with minor adjustments along the lines suggested here; I hope we can agree in concept to the format, so that we can begin our planning effort for the next meeting, in which we'll move aggressively into the near-term interim, rather than this longer-range final report.

MS. GAULT: The only major structural change that's been suggested is to divide up the biomedicine section. If someone would correct me if I'm wrong, I want to make sure that I have that, because most of the suggestions have been to flesh out essentially what Dr. Lee already has in other areas. I think we can do that by getting specific recommendations aside from maybe just the immediate reactions of the Commissioners. The most important thing to decide right now then, or to confirm, is Dr. Conway-Welch's suggestion to move the epidemiology to the table of contents, and create patient care as the first substantive topic.

DR. CONWAY-WELCH: Let me pass this down to you, Polly.

MS. GAULT: And then, and this is where I need a little bit of direction, to pull out research as a separate issue. What was the Commission's intent on that? That was discussed, but nobody --

CHAIRMAN WATKINS: There was no proposal that I know of in the Conway-Welch proposal to pull out research, but rather to title the section care issues, and leave research in; at least that's the way it came out. There was no proposal to extract research.

DR. LILLY: I think one of the problems with this proposal is that it does do a disservice to research, which is a major aspect of what needs to be done. A great deal has been done; a great deal must continue to be done, and if we bury it as a sub-section under patient care, I think that --

DR. LEE: I think if we pull out patient care, we should pull out research.

DR. CONWAY-WELCH: I don't think I --

MS. GAULT: Dr. Crenshaw did make that recommendation that research be pulled out.

DR. CONWAY-WELCH: Can I make a suggestion? We may have a chicken and the egg issue. Research may fit better under the various categories, or it may be better to pull research out as a category, and then have sub-categories under that. Could we agree in principle that as we get into the report that whatever way is most manageable is the way we'll do it?

CHAIRMAN WATKINS: Well, let me make a proposal that we not put research everywhere; that we pull research out at this point, as we should pull international out, as a separate issue. If we want later on to dissect those sections into the various elements of the report, we can do that simply. I think it's better now if we can agree on the format then that would be care and research. In other words, we're adding a new category, so to speak. We're going to seven categories, and then if we decide later to mix them up, we will. I would think we should also apply that to the international area for consistency. At this point in time, we don't need to make the decision of whether we should parsel international into all areas. Let's decide that on the merits of the international report to us from Dr. Walsh. Is that in agreement, generally, with the other members?

DR. LEE: I think it's better.

CHAIRMAN WATKINS: We'll agree to that then. Go ahead, Madam Executive Director, and read the rest.

MS. GAULT: The rest of the issues then we'll flesh out, the staff will flesh out, and then distribute for the members for their comment, but they range from things like financial/economic issues. Dr. Conway-Welch made a suggestion that these things be looked at as issues, and clearly stated as that. Mrs. Gebbie made quite a few suggestions and so did everybody else, so I think the best thing for us to do -- we're now talking about sub-groups; we're not talking about major areas, so we'll flesh those out, and those will be ready for everyone to take a look at on November 24th, and you all can actually choose the wording, so that I'm not putting words in your mouth right now.

CHAIRMAN WATKINS: Well, I'd like to task the Commissioners though specifically that made those recommendations to get into us in a week your subset insertions to clarify those issues. I think the ones that Ms. Gebbie, Dr. Primm, and others came up with are very important, so let's get those into us. Let's don't leave it hanging loose here today. We need to move on this thing, and I'd like to get them in -- what's today, Thursday -- we want them in hand next Thursday, your recommendations for insertion underneath the various sub-groups, because I think they will help in our 7 December report to the President, which I would hope we would let him know the basic concept and the format that we intend to follow, so that others reading the report will know that we're sensitive to the sub-issues inside and we're not trying to disguise anything under some kind of poor wording that tends to raise questions in the mind of the readers of whether or not we're really concerned about specific issues inside those broader words.

DR. LEE: Also, we have two new Commissioners here. On public health issues, I mean, you phrase it any way you want to. You're the public health expert. I hope that Beny will really be helpful on the chapter, that part of the IV drug issues, and how he would like them phrased in that report; the terminology you would like used.

CHAIRMAN WATKINS: Absolutely. Yes, Dr. Primm?

DR. PRIMM: When she talked about the table of contents, she only mentioned epidemiology to be pulled out as was suggested, but there was another thing, the current status of the --

MS. GAULT: Sir, I was looking at another document; we'll move that up then, too.

CHAIRMAN WATKINS: That will be moved up in addition.

DR. PRIMM: So there were four issues there.

MS. GAULT: Right.

CHAIRMAN WATKINS: I'd like to propose then, without having to repeat all this, I think we have a good consensus, so I'd like to hear a motion from the floor that we adopt the Lee document as modified here today in open session agreement.

DR. LEE: So move.

MS. GEBBIE: Second.

CHAIRMAN WATKINS: All in favor?

COMMISSIONERS: Aye

DR. LEE: Thank-you very much.

CHAIRMAN WATKINS: Yes, Ms. Pullen?

MS. PULLEN: Just to clarify, the effectiveness of the adoption of that motion is to set this forth as a working plan, not to set it in concrete as the report outline?

CHAIRMAN WATKINS: That is correct.

MS. PULLEN: Thank-you.

CHAIRMAN WATKINS: It's put forth as the currently accepted working plan for the Commission. We will always entertain recommended changes as we move downstream, but we have to give the financial and international working groups already established this format, and we have to frame our thoughts for the 24 November meeting in which we're going to be discussing our initial report to the President, and much of this will be in our minds as we write that report, so that we're consistent on the interim, as well as the final report, to the extent we can. Let's proceed then with the remainder of the agenda.

MS. GAULT: Okay. A few people came in late for their groups, and maybe we can try and get them right now and see if they're here. Is Pastor Marcelus here?

MULTI-ETHNIC GROUPS WISLER MARCELUS, PASTOR, HAITIAN LUTHERAN SERVICES, BROWARD AND DADE COUNTY

REVEREND MARCELUS: Good afternoon, ladies and gentlemen. It's really an opportunity for me to be here with you. My name is Reverend Wisler Marcelus from the Haitian Lutheran Services Protestant Voice, Inc. Our proposal is to provide help and informations to all Haitian in the sounding communities. First of all, I would like to explain briefly what we are doing at the Lutheran Haitian Services. We care for the Haitian people, that's why we always provide services like child care, health services, education, and referral services. But recently, our Haitian community center decided to reach the whole entire Haitian community by providing a strong education concerning the AIDS epidemic in Creole as well in English for a better understanding and research in the Haitian care.

I want to tell you also I was born in Haiti, and I'm living in the United States since 1980. But today I don't want to stand up here as I'm used to do in the community to talk about the Haitian problems, such as housing problems, employment problems, or immigration problems. But today I stand here on the behalf of my people and other unfortunate people who have been affected with the disease AIDS, not excluding those who have loved ones that have lost their life to this deadly disease. As you all know from studies and statistics, it is well known that AIDS kills no one because of their creed, color, or character. People from all walks of life are affected. No one should be denied the needed people. A human being is a human being, regardless of origin and background. The only way to conquer this disease is by the people coming together as one, forming organizations, and setting up funds for people, and again I stress people who are standing with a need. I have noticed when a person from a poor or bad environment is affected, no one seems to care, but these people are not equally treated. My concern is really in the particular area and the particular point, and also my concerns is when a celebrity is affected, then funds are raised, the whole high officials in high places come out to help. It is a good opportunity for me today to say I really want to see with every one of you today justice for all people. Remember we are all God's people. Let's care and roll up our sleeves and get to work. Thank-you very much.

CHAIRMAN WATKINS: Thank-you very much, Reverend Marcelus. Any questions from the Commissioners?

(No response.)

CHAIRMAN WATKINS: Thank-you very much, sir.

DR. PRIMM: One question.

CHAIRMAN WATKINS: One question from Dr. Primm.

DR. PRIMM: Have you had difficulty in joining the network here in the Miami area with your people, and if you have, what has that difficulty been?

REVEREND MARCELUS: The difficulty is the language barrier. This is the most important situation between us and for us and for the people. I think that's the reason why the enforcements for a better understanding, a better research will really be a good point, if we can focus on that particular point.

DR. PRIMM: May I suggest something to you, Reverend? I attended and received my medical school degre from the University of Geneva in Switzerland where everything was in French, and I had never studied a word of French until I got to that institution, so I understand your dilemma. What I did was to make myself a part of everything that I could be invited to, and I went there, and even though in many instances I didn't understand, there came a time when understanding and comprehension just became more clear to me, which was nine months later. May I suggest to you that even though there is a language barrier, that you send a representative to these organizations that have indicated to this Commission that they have reached out. Sometimes it is very difficult for them to find someone from your community who they have invited there to help them, and that you send someone anyway, and that there will be an understanding, and you must insist upon an understanding of your lack of the knowledge of the language and so forth, until such time as you are an integral part and are included and not felt to be excluded.

REVEREND MARCELUS: Well, I think really it's necessary to be included, you know, in that system because as I said as human beings, and I think it's really an opportunity to consider and to know exactly we are all human beings, and we are a part of this new system, and that's why in any way we can do something in order to avoid some problem later, lack of education, you know, so I think it is very clear, you know, to get together and stand up in a way and as soon as possible to see how we can resolve this dilemma.

CHAIRMAN WATKINS: Thank-you very much, Reverend Marcelus.

MS. GAULT: We have a witness who's going to substitute for another, and we understand he's under severe time constraints. Dr. Eisdorfor, would you like to come forward, please?

RESEARCH ISSUES DR. CARL EISDORFOR, DIRECTOR, THE CENTER FOR BIOPSYCHOSOCIAL STUDIES OF AIDS, UNIVERSITY OF MIAMI

DR. EISDORFOR: I'm Dr. Carl Eisdorfor. I'm the Director of the Center for Biopsychosocial studies of AIDS at the University of Miami. I'm substituting for Dr. Szapocznik, who was originally going to substitute for me, but I was due in Washington yesterday so I'm here today. I know I have five minutes so I'm going to read much of what I have to say, most of which may be redundant, but I think it's worth emphasis. AIDS is not simply an infectious disease of viral ideology. It has profound psychological and social consequences. Indeed, your very existence is a recognition of that latter point. It needs to be emphasized though that the transmission of the virus is largely behaviorally mediated, and we desperately need intensive efforts to understand how to maximize our impact on those very behaviors which are acting to transmit and exacerbate the disease.

Secondly, the virus can and does affect the central nervous system, more or less, directly. I'm hedging because there's some equivocation. However, it can and does produce dementia, not only secondary to the adventitious infection of the brain because of the collapse of the immune system, but HIV is now clearly able to produce a dementia before any other symptoms of the disease are present. The existence of a dementia, which I've described as a primary AIDS dementia, and which has now been accepted by the CDC as a form of AIDS, has very profound and schizophrenic like symptoms that are present in many AIDS patients; indeed one or another of these probably in all patients. Indeed they're present not only in the AIDS patient, but in the HIV infected individual, and we've now discussed the worry well those groups that are at high risk for getting the infection. Again, we need much more by way of mental health intervention, including psychiatric care, not only on an in-patient basis, but on an out-patient and community care systems basis.

Fourth, families need help. I'm talking about biologic families, and what I would call cultural and social families. Very often, we're able to provide help to the patient. There are no resources available outside of volunteer efforts to provide the desperately needed help to families that are often impacted as psychologically as is the patient him or herself. Fifth, staff. Staff have been extraordinary. Volunteers have been extraordinary. We're carrying the burden of this, but the risk

of burnout is high. We've known that it's very difficult to work with patients who have this kind of disease, who are looking at imminent death, where there's a lot of ambiguity, without staff burnout. I would hope that in your report you would address the need for help for the staff in order to continue their care to provide the patient. And by staff I don't only mean doctors, nurses, social workers, and so on; I also mean volunteers. The volunteer community, in my opinion, has made the difference between being able to barely contain this disease and the potential for a disaster. IV drug users need particular help. This is a group which is even more marginal in their impact on society and their interaction because what they're doing is inherently illegal and we at the same time need to understand the enormous impact of this, particularly now, on heterosexual transmission. A particular problem that has to be addressed also is the problem of minority groups. Often in our haste to do something, we ignore such crucial issues as belief systems, the belief in how diseases are transmitted, and how they're impacted, and how in fact they can be cured or reversed, and we see this every day -- the miracles that medicine can provide unfortunately don't extend to this disease right now -- and language.

I was pleased to follow our representative from the Haitian community. We ignore these issues because they're more expensive to do, doing translation, back they're translation; making culturally relevant input is important. There is an emerging base of knowledge that I think has unique importance here. It's called, for lack of a better word, or mainly because scientists like to use complicated words, psychoneuroimmunology. The data clearly demonstrate that depression, anxiety, and the catecholamines, those hormones mediating stress, lead to alterations in the immune system -- this is outside of the AIDS population. They clearly negatively affect immune competence. Since most of the people we're talking about have anxiety, depression, and are clearly under stress, we need a lot more research in this area -- this is a basic research area -- more in the mental health disciplines, perhaps, but this could influence the course of infection and disease. In fact, that's one of the foci of our project here.

Finally, full circle, only to stay within the five minutes. While I very much support the need for more basic and clinical immunologic and virologic research, and certainly community care programs, I pray that the very significant basic and clinical issues in mental health and psychosocial mediators not be overlooked in your deliberation. Over the past several years, the mental health community has become so disarticulated in many parts of the country, as to be substantially compromised and I desperately fear about our ability to deliver what is I believe the essential care needed by this important group. Thank-you very much.

(Applause.)

CHAIRMAN WATKINS: Thank-you very much, doctor. I wonder, do you have some time? I know you're pressed, but maybe we have a question here because you're touching on an area that I think some of the panel members are vitally interested in. Yes, Dr. Crenshaw?

DR. CRENSHAW: I want to thank you for your comments, and I think it's absolutely critical that we help to recognize and to take care of the mental health of our mental health care takers because their well being is impaired with the emotional drain and the stamina required to treat this disease. The type of training, support, and care for that, do you have any concepts or things that you think can be implemented rather quickly to be helpful because we're so short on personnel, and yet this is something that must be done or we'll be even shorter?

DR. EISDORFOR: Yes, thank-you. I think there are a number of strategies that can be employed relatively rapidly. One is the use of group approaches, supportive groups, organizations like the kind of -- a good example is the ADRDA, the Alzheimer's Disease Related Disorders Group, which splits its efforts between concern with research and community support groups. I think the role of the mental health professional, social workers, psychiatrists, psychologists, could be to act as counsel, consultant if you will, to groups like this and develop support. I think with the help of this Commission, as we stop hiding this problem under the rug, or whatever it is we're managing to hide it, and make it a disease that the country as a whole must confront, indeed the world has to confront, I think we'll be able to do to AIDS what I think that group, frankly, as done for Alzheimer's. It was a disease of senility nobody wanted to touch, and now everybody knows the disease; we're saying, "Yes, my mother does have it." I remember in the early days I worked with that disease and nobody would admit that anybody in their family had it. I think we've got to get away from that nonsense. I have to compliment you on your concerns about the whole issue of being able to talk about death and sex. I think we must, and I think that's part of this paradigm of throwing light on it, and finding ways to support the non-patient care, because as the care giver goes, so goes the patient.

DR. CRENSHAW: I agree with you, and I was disturbed when I was talking in San Francisco to some of these care takers and they had tried support groups within their own facility and found that they weren't working well because of the incestuousness of the work relationship, and people didn't want

to be as candid as they could. I would appreciate so much, since you've obviously given this a great deal of thought, for you to put in writing to us these recommendations, and in particular any areas or examples you know of where it is being done successfully, and what's working and what isn't.

DR. EISDORFOR: My pleasure.

CHAIRMAN WATKINS: Dr. Conway-Welch?

DR. CONWAY-WELCH: I wanted to share a moment of frustration with you. You mentioned the mental health care givers of psychologists, psychiatrists, and social workers. In fact, I feel very strongly that Masters prepared nurses in the area of psychiatric nursing can also lend support.

DR. EISDORFOR: Mea culpa, mea maxima culpa.

DR. CONWAY-WELCH: That's not why I'm saying it. The problem is training monies for all levels of graduate education of nursing come out of the public health service division of nursing except for psychiatric nursing, which comes out of NIMH, which has cut all training monies. I only find what you say validating the fact that there is a role for psychiatric nurses that is not being acknowledged, and that funding for a long time now has not been available, so even their acknowledgement of their contributions is falling by the wayside. DR. EISDORFOR: I would support that indeed. Operationally, we do involve -- as a matter of fact, probably the group we involve the most in terms of numbers is psychiatrically trained nurses. But again, can I underscore again, all of the training funds in NIMH simply don't exist.

DR. CONWAY-WELCH: Exactly. DR. EISDORFOR: I mean, we're all in the same boat.

DR. CONWAY-WELCH: Yes, I agree with you. **CHAIRMAN WATKINS:** Can we impose on your class for one more question, Dr. Eisdorfor?

DR. EISDORFOR: Sure.

CHAIRMAN WATKINS: Dr. SerVaas?

DR. SERVAAS: I wonder if you can tell us how we might help get information to psychiatrists throughout the country, because I've spoken with a lot of psychiatrists who don't understand what you've just told us. Richard Price, Dr. Price, who told me a few months earlier that 25 percent of his patients

first present with brain problems, Alzheimer's like or MS or something like that. How can we reach the psychiatrists throughout the country because a lot of psychiatrists with whom I've spoken are not aware of that. I have a question for you, too: Are you afraid that we're missing diagnosis on these people when they come in?

DR. EISDORFOR: To answer the latter one first, I have no doubt that we're missing diagnoses, mainly because of the way we approach the patient, and who's seeing the patient. We've seen enough of them to be able to go back and say, "Oh my God, we missed it then," and we've seen the New England Journal of Medicine had an article on the patient diagnosed as Alzheimer's who turned out to have AIDS, and we've seen other instances like that, so I think the documentation for the latter point is there. To address the first point, which I think is a very key problem, the whole issue of how do we educate not only the public, but the professionals. There are really several ways to do it. The easiest way, probably, and I can't speak for them, is that a lot of psychiatric education, most of it through the federal government, is supported by the NIMH. An initiative on their part which would enable people to set up continuing professional education would be important. Secondly, direct reaching out to the American Psychiatric Association, you know, I have one of those union cards, and putting them on the spot in terms of what is APA doing is very important. I know the American Psychological Association -- I'm a member of both clubs -- has a task force on AIDS, and I believe now the other APA, the psychiatrists, are considering it. I think if we set up some goals, if we said, "Okay, if you come up with a way to disseminate the information, we will help support it, and this is a professional responsibility," I think that would do it. Finally, and certainly not least, medical societies around the country, through the state and national medical associations do it. I will tell you we had the first program of the Southeast Psychiatric Association last month, and we spent two hours going into detail on this fortuitously, but we're only one of three centers nationally supported by the NIMH; it's ours, San Francisco, and they just funded one in New York, and there's a lot of country between New York and San Francisco.

CHAIRMAN WATKINS: One of the ways, Doctor, and we're going to have to close on your testimony here, that we'll link with you, if you don't mind, is we're going to bring one or two representatives of the American Psychiatric Association on our advisory groups. We have a team of five to seven skilled clinicians in a variety of areas, health providers and so forth, who will consult with us so that we can give proper attention to your particular area of interest because I think it's unique in terms of the absence of addressal of the important issues, and the early identification of cases. We want to let you know that so that you'll have a friend in court, if you will, that we can

link on a continuing basis with you, and get all of the input from you along the lines that was recommended here.

DR. EISDORFOR: I publicly pledge any help I can possible be.

CHAIRMAN WATKINS: Thank-you very much for coming.

DR. EISDORFOR: Thank-you.

MS. GAULT: Dr. Chitwood.

RESEARCH ISSUES DALE CHITWOOD, Ph.D., IVDA'S ISSUES

DR. CHITWOOD: Good afternoon, and thank-you for the opportunity to be here. I'm here representing colleagues and myself who are working primarily in the area of research with intravenous drug users on the question of HIV infection and HIV related disease. In the few minutes we have, I want to let you know what we're doing and point out to you what some of our real concerns are. We're trying to take a comprehensive approach to the problem in South Florida, doing this in this way:

1) We're currently determining the prevalence of HIV among IV drug users, both in treatment sample and in street sample. One word of caution I'd like to make is there are lots of numbers that seem to float around about what the prevalence rate is among IV drug users. It is not the same across the country. It varies considerably. Some of the earliest reports that came out, which cited numbers approaching upwards to 70, 80 percent, were based upon ELISA data, not upon confirmatory Western Blot data. Those numbers are high. Probably New York has the best data because they've been doing it the longest, and the published data, anyway, in working with colleagues there in joint projects indicate closer to 50 percent or 50 percent plus. We're also working on incidence to determine the number of new cases among intravenous drug users who initially test negative. We need to keep very clear that we're looking at prevalence existing cases, what's the extent, and then what is the rate at which individuals who are negative are becoming positive. We need to get a handle on this to really see how rapidly it's progressing.

The third thing that we're doing is we are right now beginning to implement an intervention program to change the behavior of IV drug users who are on the street, and we're accessing Emergency Room, criminal justice, and street network populations, and evaluating that approach; we're using two approaches. We think it's essential that we use basic epidemiologic data and profiles of people who are seropositive and attach that knowledge that we gain to our intervention strategies. As Dr. Eisdorfor indicated, working with IV drug

users, working with any drug users, means we're working with a population that is described as a deviant population, although I don't necessarily use that term, but are involved in illegal activities. I think we have to in our intervention, 1) take a careful look at the adequacy of treatment, and make it available for people who want to get into treatment. We have to take a very active role in going out and enrolling, bringing people in to treatment, and we're developing a central assessment center to do that. But there are a number who will not enter treatment. We have to make a decision, and our decision is not to write-off individuals who won't go into treatment. We have to have an aggressive indigenous worker outreach program to IVD users on the street to people who are not necessarily shooting drugs at the time. This involves some conflicts for some people between encouraging illegal behavior or illicit behavior. I would like for you, because you're in the position to really take a careful look at it, and I'm glad that Dr. Primm is here to spearhead this, take a careful look at our laws concerning how we deal with IV drug use. You can look at the question of in many areas being illegal to have paraphernalia, to have needles on one's body, and the relationship between the likelihood that people will therefore not carry sterile needles. Since we know the major route of transmission for drug users are dirty needles, we've got a tension here and we've got to address that very carefully.

A couple of points to let you know that we're observing here, and our data won't really be -- we're just about at our six-month state collection point, at which we'll be doing our analysis, is that the crack problem, cocaine problem, if you will, some people feel that crack is causing individuals to stop shooting, and in some instances this is true, but we're also finding individuals who are shooting crack, who did not use to shoot, who have begun to shoot opiates in order to manage the high. So the crack connection involves a number of issues, and may actually bring some people into the IV using population. We have looked carefully, or are looking carefully at the relationship of prostitution and drug use. In our cocaine studies that we have conducted during this decade, we have identified about a quarter of the men and women involved in prostitution for the express purpose of obtaining funds to buy drugs. Our studies of looking at prostitutes itself are showing that a majority of women who use opiates are heavily involved in prostitution. This has been increasing in this decade in our area. Also, IV drug users have a lot of infections which are unrelated to HIV initially. One of the real care problems, real care concerns is that IV drug users come for treatment, not for prevention, but in order to stay alive. So they show up at the Emergency Room not because they have a small abscess, but because they don't want to lose their arm. They show up at the ER not because they're not feeling well, but because they passed out and someone brought them in.

The whole process of the way in which one seeks and receives care is a problem in trying to deliver services. We have to be aggressive; we do not have time to waste. We have to coordinate what we're doing in Miami with New York and San Francisco and Chicago, across the country, and we are working to do that, but I would urge you, in your recommendations for funding and so on, to link researchers together so that, for instance, with our incidence studies, it's easy to find prevalent cases, but it takes longer to find incident cases, so link our studies so we can pull our incident cases for our studies, much like we do in our cancer research with the groups that work together around the country, so that we can get answers more quickly, and not spend the time that we don't have to waste. I think, in closing, the one thing that I want to say is if we really want to impact IV drug use, we're going to have to talk about stop using drugs, but beyond that we have to talk about, for those who use drugs, stop shooting, and if they won't stop shooting, use new needles, and if they won't use new needles, teach them how to clean needles. This is something that we have to do if we really are serious about impacting the spread of the virus among IVDUA's.

One last phrase or statement: There was some years ago a Rabbi in Miami who wrote an article, and I remember the story that he wrote, and I want to use it quickly. It's about a Rabbi centuries ago walking in the woods and finding the heart of evil beating, and he decided that he had a chance to destroy that heart by crushing it, but he heard the cry of a human being coming from that heart, the cry of a child in this case, and he realized that if he crushed the heart, he'd kill the child, kill the person. The moral of that for him was that one had to fight evil from afar. Let's make sure in fighting the heart of evil, the virus, that we do not crush the people who we're trying to protect. Thank-you.

CHAIRMAN WATKINS: Thank-you, Dr. Chitwood. Any questions? Dr. Primm, I think you might have one.

DR. PRIMM: I have a question and that is that we made a number of visits, as you know, to organizations, and we were told that if someone is found to be HIV antibody positive that may be in drug treatment, that they are discharged summarily from that particular program. Can you comment on that? And one other question: Are there waiting lists in the State of Florida for admissions to drug treatment programs, and if there are waiting lists, what programs are they; are they chemotherapeutic programs, or are they therapeutic communities, or what?

DR. CHITWOOD: There has been a concern, and this question gets raised quite a bit, the question of exclusion if one is HIV positive. That has happened in the past. To my knowledge, right now, that is not the rule in most programs, and

I do not know of any that are currently doing that. In our research we do not disclose when we're collecting data in treatment programs; we do not disclose test results to anyone other than the person we test; and we maintain confidentiality completely. In terms of waiting lists for treatment programs, I don't have the exact numbers, but there are definitely waiting lists. If one can afford it, we can find treatment, but for people who do not have insurance, third-party payment, or not able to pay, it's difficult to get into some of the programs, particularly in the residential programs and drug-free programs of that nature.

CHAIRMAN WATKINS: Thank-you very much, Dr. Chitwood.

MS. GAULT: Dr. Scott.

RESEARCH ISSUES GWEN SCOTT, M.D., PEDIATRIC ISSUES

DR. SCOTT: Good afternoon. I'm Gwen Scott; I'm a pediatric infectious disease specialist, and I've been working with children with HIV infection since we identified the first cases at Jackson Memorial Hospital in 1981. Certainly in looking at the problem nationally and locally, the numbers of children are increasing at a steady rate. As of September, 1987, there are 574 cases that were reported nationally in children under 13 years of age. The majority of these cases, approximately 78 percent, were due to perinatal transmission; in other words, from an infected mother to her infant. When we talk about perinatal transmission, we include transmission in utero, across the placenta, as well as at the time of delivery due to exposure to infected secretions from the mother. Postnatally, there may also be exposure by ingestion of infected breast milk. Other causes of infection in the child under 13 years of age include blood or blood product transfusions from infected donors. In the 13 to 18 year old age group, causes of infections are much more similar to adults. Nationally, about 160 patients in this age group have been identified. Of those, 48 percent are homosexual or bisexual, 22 percent have hemophilia or a coagulation disorder, 6 percent are from blood transfusion, 6 percent from IV drug abuse, and about 3 percent from heterosexual spread. Unfortunately, this 13 to 18 year old group tends to be a forgotten group. They seek medical care less often, and much less is known about the incidence of HIV infection in this group than probably any other group. HIV infected children have been reported from 34 states, but about 70 percent of them reside in either New York, Florida, New Jersey, or California.

Recent national statistics again differ from that in adults in that about 54 percent of children with disease are Black, 25 percent are Hispanic, and 21 percent are Caucasian. With relation to Dr. Chitwood's report, about 70 percent of all

cases of pediatric AIDS can be related to drug abuse in either the mother or the father. What's the typical profile of a child who is perinatally infected with AIDS? Well, typically, that child lives in a large metropolitan area, usually in the inner-city, and comes from a lower socioeconomic background. That infant is frequently Black or Hispanic, and at the time of presentation of disease is usually less than 2 or 3 years of age. Certainly, 80 percent of these children are diagnosed within the first three years of life, and about 50 percent of them may die within the first two years of life. There certainly are some children that live for longer periods of time, but the majority of children with perinatal disease still have a very poor survival. The disease differs from that in adults in that some illnesses, such as Kaposi's Sarcoma are very rare in children, but common in adult males. Whereas diseases like lymphoid interstitial pneumonitis are very common in children and rarely found in adults. In Miami, and I think we parallel many of the other larger cities in the country such as New York and Newark, we saw our first case of pediatric AIDS in 1981. At that time we identified about five cases that year. In the past year, we are identifying one new case per week, and project that we will see about 60 cases newly diagnosed with clinical disease in 1987. Our population in Miami is a little bit different from those in other cities. 95 percent of our children are Black, with the remainder being Hispanic or Caucasian. The major modes of transmission in the parents are either through heterosexual contact or through drug abuse. We are presently following about 100 children as out-patients, and have about 10 children at any one point in time hospitalized. For us, the networking program is extremely important because some of these children develop chronic lung disease and must go home on oxygen or respiratory therapy. Many of them have heart disease and require multiple medications.

The Visiting Nurse Association has been invaluable in keeping these patients as out-patients, rather than having them constantly as in-patients. I think that pediatric HIV infection is really unique, and will offer some insights into the disease that the adult disease will not. However, we have major questions that still remain to be answered. The natural history of the infection in children is not yet fully described, and the mechanism of perinatal transmission from mother to infant is not well understood. We still do not know the portion of infants that are infected in utero as compared to those that are infected at the time of delivery. This information is extremely valuable because there may be different treatment options available for a child who is infected at the time of delivery, and one might utilize a high titered antibody to HIV in combination with either antiviral drugs or a vaccine in an attempt to prevent infection in that infant. A similar model is presently quite successful in preventing Hepatitis B infection in infants, and might be utilized also in this infection as well. We also don't know

what proportion of infants born to HIV positive mothers will be infected, or what factors influence transmission to the infant. Also, we have a much more difficult time making a diagnosis in an infant, since if the mother is seropositive for HIV then the baby's serum will also contain antibody to HIV because of passive transfer of that antibody. Therefore, the antibody testing alone cannot determine whether or not that infant is infected. Since this antibody can persist for many months, some children require follow-up up to 15 to 18 months prior to being able to determine their HIV status. So the research efforts need to be directed toward the development of laboratory tests that will simplify diagnosis in the infant. If children are to be saved from this devastating disease, then infected children must be identified early, preferably before the onset of significant clinical symptoms, and treated. At present, there are Phase 1 treatment protocols with Azidothymidine (AZT), and Ribovirin nearing completion. However, the results of these studies are still preliminary, and Phase 2 drug trials are being planned. But I think that drug studies in children have really lagged behind those in adults, and the urgency to treat this population is no less than it is in adults because the morbidity and the mortality is as high. I think that we as pediatricians feel that new drugs need to be made available to children as soon as safety is established so that we can proceed early on in treatment protocols with efficacious drugs. I'm sure that Ana Garcia has discussed some of the other unique psychosocial problems that go along in dealing with children and families, but I think that some comment should be made about the medical care for these children. They may require frequent, multiple, and prolonged hospitalizations, and the model of a medical care team, including not only physicians, but nurses, social workers, physical therapists, respiratory therapists, developmental specialists, are very critical. I think that research is the key to this disease. Great strides have certainly been made since its first description in the early 1980's. I think that the main research areas of interest lie in, as I said before, the development of diagnostic tests for the neonate and young infant, studies of the mechanism of transmission from mother to infant, further understanding of the natural history of disease in infants, and a better understanding of the path of physiology of the disease in different organ systems, such as the lung, the central nervous system, the kidney, and the heart. It's also important to determine the risk of infection to an infant born to an HIV positive mother. Little is known or understood at this point about transmission by breast milk. The real hope for these patients lies in the development of effective antiviral drugs and a vaccine. I think that these research areas are a priority. It's critical that funds are allocated, not only to do the research, but funding for development of research facilities is also critical.

Drug studies need to be instituted early in children, and treatment programs should be targeted to the neonate and prevention or modification of disease in this group by treatment of the mother during pregnancy or the newborn infant. I haven't said anything about patient care dollars. I think you've heard a lot about that today, but children with HIV are work intensive. I think that model programs need to develop for working with families, for their care, education, and counselling of families with HIV infection, and I think that we need nationwide educational programs that are targeted to all ages. I think that these definitely need to be supported by our national leaders. I thank you very much for this opportunity to present these issues to you today.

CHAIRMAN WATKINS: Thank-you, Dr. Scott. Questions from the Commissioners?

DR. PRIMM: Mr. Chairman, I just have a comment. I just really want to commend Dr. Scott on her very complete submission to this Commission, and also on her testimony, and certainly for her terribly enlightening visit last night. I just was so very, very impressed, and I won't forget you, Doctor.

DR. SCOTT: Thank-you.

CHAIRMAN WATKINS: You've impressed us all, Dr. Scott, during our tour of the ward and your very professional presentation to many of the members here who understand the language a lot better than I do, but I got the feeling that you're one of the unique wonders in the nation in this area. It is one that we have to be very careful, because they don't come and testify before us, that we don't forget them in the process, and we won't. As we told you before, we want to maintain the linkage with you down here with the Commission. You have an open door to us. We may have another question from Dr. Crenshaw.

DR. CRENSHAW: I agree with you that the 13 to 18 age group is really getting overlooked. They're not old enough to make the independent decisions without all sorts of obstacles, and they don't have the finances if they're concerned, and they're not educated enough to be concerned where perhaps they should be. You've given this a lot of thought. Could you give us some recommendations on how to better understand the extent of infection in that population and how to better access, reach, and help?

DR. SCOTT: I think that perhaps one way to deal with at least education in this area is to develop peer groups that will go out and educate their peers, because I think that many

times adults going into a high school and educating is not as effective as a peer group educational system. I think that we need as physicians to involve not only the pediatrician, but also the adolescent specialist, and I think that we still have work to do in terms of educating pediatricians who care for adolescents, and adolescent specialists in larger centers about their great importance in terms of dealing with these issues with their teenagers. So I think one job that we have to do is more education for physicians, and then also more information put out to adolescents to make them aware of how AIDS is transmitted and how they can protect themselves, perhaps by peer education rather than physician or other modalities of education.

DR. CRENSHAW: Thank-you very much.

CHAIRMAN WATKINS: Thank-you very much, Dr. Scott.

MS. GAULT: Dr. O'Sullivan.

RESEARCH ISSUES MARY JO O'SULLIVAN, M.D., OB/GYN ISSUES

DR. O'SULLIVAN: Good afternoon, and thank-you very much for the invitation to address the Commission. It's kind of a hard act to follow Gwen Scott, but since Gwen Scott gets many of her patients from us, let me go on and talk a little bit about us. I'm the Director of Obstetrics at Jackson Memorial Hospital, and have gotten into working with AIDS patients primarily because of the babies and then tracking them back and finding out that the mothers were additionally positive. I think one of the very important things, at least from the point of view of our activities in counselling patients, it is extremely important, and I think this is something that has been sort of alluded to in several different ways and even brought out, but needs to be reinforced, and that is the fact that until we understand the population that we deal with, why they do the things that they do, and how they think, it is going to be extremely difficult to accomplish a great deal of what we have talked about here today. We have to understand where they culturally come from, what kind of background they come from, and that is hard for many people sitting in this room to do as we grew up in our little middle class environments for most of us, and have never lived in an inner-city, or drug-infested environment, or rat-infested home, or transported from one country to another, from a different culture and a different language background.

I think this is a vital issue in how we counsel our patients and how we deal with them. To go on from there is that, as Gwen pointed out, we have very little understanding about the incidence of HIV infection in the population in general, and since 7 to 8 percent of AIDS patients are women, we really have almost no understanding of the incidence of HIV infection in

women in general, especially in even in women of the younger reproductive age group as already been brought out here today. So one of the big things I think that's important is to determine what is the rate of HIV infection in various population groups. The second thing brought out by Gwen was the risk of perinatal transmission, and we do know that women do transmit this infection, but they don't do it with every pregnancy; they do it with one and not necessarily with another. What increases the risk of transmission in one pregnancy as contrasted to the other, and is there a way to make the diagnosis of a utero infection, that is infection which has already been transmitted prior to delivery?

So the techniques need to be developed in order to do this. Some of that is now already in place by virtue of things like umbilical blood sampling done transabdominally, but the technical ability to grow the virus is extremely difficult. Of course, just to look at HIV antibody is not good enough, so we need some other way of being able to make the diagnosis with ease on very small samples of blood. We also need to understand the impact of this infection in women, but in pregnant women. It is not known, for example, based upon the immunological changes that normally occur in pregnancy whether 1) the pregnant woman is more susceptible to infection; 2) whether in fact progression of infection is more rapid in these women because of their pregnancy; and 3) whether their long-term survival rate therefore is decreased because of the presence or the absence of a pregnancy. So that long-term studies need to be done on those women who are already infected. We need to know also not only about the risk of utero transmission, but as Gwen brought out, what is the real risk of breast feeding. There has been several cases reported in literature, at least two to three, about the potential risk of transmission due to breast feeding. Culturally, for many people this is an extremely important part of maternal/infant bonding, and if we take this away without real proof that in fact this significantly increases the risk, we divorce the mother to some degree from her child. We need to establish infection relatively early in pregnant women, and by establishing the co-factors or the risks of transmission, could begin to look at the possibility of drug intervention, not necessarily therapy, since we don't have any, but drug intervention even perhaps in pregnancy to at least if not protect the infant against infection, at least allow the neonate a better quality of life for a longer period of time. A great deal needs to be known about the immunological changes of pregnancy alone because again this is a whole new area, and what those changes really are, what's normal, what's not normal, and how HIV really affects that, and whether those changes can be some way modified and in turn affect the risk of transmission in utero.

We need to know what's different about the fetus in utero when he contacts the infection, whether it makes any difference if the infection is transmitted early in pregnancy or late in pregnancy, and why the fetus when he's born with the infection has a much shorter survival than does the child who contacts the infection as a result of blood transfusions or in some other ways. I think inherent in all of this insofar as counselling is concerned is understanding the population we deal with. Thank-you.

CHAIRMAN WATKINS: Thank-you, Dr. O'Sullivan. Could you take one question from the Commission? Dr. Primm?

DR. PRIMM: I have a question, and that is you spoke of drug intervention during pregnancy for HIV positive mothers, I guess, to influence the progression or course of the disease in the infant. Can you elaborate on that a little bit?

DR. O'SULLIVAN: No, I can't.

DR. PRIMM: Were you postulating?

DR. O'SULLIVAN: Well, I think if there were a drug that were available that we could utilize, there might somehow affect the transmission of infection in utero, or protect the baby to some degree, so that the quality of life for that infant after it's born might be better for a longer period of time. The only way we're ever going to find that out is by first determining what's relatively effective in the neonate, and then trying that in the terminal part of pregnancy.

DR. PRIMM: Thank-you, Doctor.

CHAIRMAN WATKINS: Any other questions?

(No response.)

CHAIRMAN WATKINS: Thank-you very much, Dr. O'Sullivan.

MS. GAULT: Dr. Marchette.

RESEARCH ISSUES LISA MARCHETTE, Ph.D., NURSING ISSUES

DR. MARCHETTE: I appreciate the opportunity to address you today. I'm Dr. Lisa Marchette; I'm an Associate Professor at the University of Miami School of Nursing, and I'm the Nursing Research Coordinator at Mt. Sinai Medical Center in Miami Beach. From my nursing research on AIDS and from my career in nursing for the last ten years, I've found several things about AIDS that have been particularly worrisome to me and that I want to share with you today. The first is something that was touched on in a

broader sense by Dr. Eisdorfor, which has to do with the feeling of health care providers towards people with AIDS. It's a particularly strong problem in nursing due to the very bad problem of the nursing shortage. There's a very bad problem of nurses who are available and willing to care for people in any area of nursing or in any kind of facility, and the enrollment of nursing students has been down for a long time. It seems to be showing that the nursing shortage will be there for a long time. The problem of the nursing shortage is heightened with the increase in the number of people with AIDS that nurses are asked to care for because of the strong feelings that nurses have, and of course, I'm generalizing, but I've seen in literature and in my own practice at Mt. Sinai and other institutions, and through the Hotline at Health Crisis that there are a lot of health care providers, there are a lot of nurses who feel very strongly about caring for people with AIDS, and also feel very strongly about mandatory testing for HIV for all people who are admitted to a health care institution.

In addition to the education that's needed in order to demonstrate that some of their feelings that they have are based on inaccurate information, of course we still need the support groups that were mentioned before, and also I think that the strong leadership from CDC and OSHA and JCAH and from hospital administration is needed to continue to protect the health care providers, but in addition, to protect the confidentiality and the quality of care that's delivered to people with HIV infection. Health care administrators need to continue to insist that people who, especially I should be speaking for nurses now, that nurses continue to care for people with HIV infection, and that confidentiality is maintained and that testing is voluntary. Another important need in nursing is research on the alternative or non-medical therapies that are used by people with AIDS. There are a lot of treatments such as nutritional changes, meditation, yoga, relaxation, visualization, therapeutic touch, acupuncture, homemade medicines, positive thinking, vitamins, aerobic exercise, and medicinal herbs. The list goes on and on in the literature of therapies that people are using that nurses need to be aware of, and that the health care system in general needs to be aware of with regard to why people use those; what kinds of people are satisfied with what kinds of therapies; and which ones seem to be the most effective for what kind of patients. Also, more funding incentives and support are needed for education of nurses at the Baccalaureate, Masters, and Doctoral level, and of course increased and frequent continuing education programs so that nurses can be informed about AIDS when they complete their education and continue to be updated.

Last, I commend the NIH National Center for Nursing Research and several nursing specialty organizations for making AIDS nursing research the highest funding priority for their nursing research dollars. The National Center for Nursing

Research in NIH needs more money that can be earmarked for AIDS nursing research. Nurse researchers have a unique contribution to make to the AIDS knowledge base. The needs of people with AIDS are very nursing intensive and scientifically sound studies need to determine the effect of traditional, as well as innovative, nursing methods to help these people.

CHAIRMAN WATKINS: Thank-you very much, Dr. Marchette. Questions from the Commissioners?

DR. PRIMM: Do you have difficulty, Doctor, in finding nursing personnel that will work with AIDS patients in institutions here in Miami?

DR. MARCHETTE: I think that with nurses as well as physicians and other health care providers who have been surveyed, most say that given a choice they would rather not care for a person with HIV infection; that they are very worried about contracting it themselves or giving it indirectly to their loved ones. I think that most administrators do not give health care providers a choice as to whether or not they will care for them, but still the tension is there, morale is down. There is friction within the organization when discussions come up that make it seem as though it's up for discussion as to whether there should be mandatory testing of all patients with it written all over their chart that they're HIV positive in order to protect the health care providers. I'm sure that you've already covered mandatory testing of health care providers with the Commission before. I feel that nurses who would like mandatory testing of health care providers are going to be at more risk for getting infected because the people who test negative then will be treated in such a way that they will let their guard down and be a little bit less strict in their infection control, and therefore be caring for a person who actually is carrying the virus in a way that they might contract the virus from that patient. There also has been discussion of testing all health care providers. We hear rumors all the time of hospitals that are thinking of testing all their employees in order to decrease their hospital insurance. Of course, nurses on the whole do not want to be tested, and do not want to have their employment contingent on being tested, so the whole idea of who is going to infect whom is a highly tense situation.

CHAIRMAN WATKINS: Dr. Conway-Welch, you had a question?

DR. CONWAY-WELCH: Dr. Primm asked the question.

DR. PRIMM: I was wondering one other thing and that is the incentive to overcome some of these difficulties. In some places people have been offered financial incentives. What do you think about that as a resolution of some of the problems that you just laid out?

DR. MARCHETTE: Well, financial incentive has been seen as a solution to the nursing shortage for a long time. I think that financial incentive helps to a great degree, especially considering that nurses do make less than a lot of people who have the same amount of education. Also, I think that incentives for caring for a particular kind of person might help, but people have to feel comfortable about their work, and that's probably a greater incentive or a greater consideration when people choose their work than is their financial reimbursement. I think that that would help in a lot of cases where nurses are underpaid.

CHAIRMAN WATKINS: Ms. Gebbie, one more question and then we'll have to move on.

MS. GEBBIE: We heard this morning from the Florida Medical Association that they'd asked the Nursing Association to join with them to get educational materials out to all providers to try and decrease some of the lack of information that may be contributing. Are you aware of that effort; is that working, or is that so new that it's not yet been --

DR. MARCHETTE: I'm a member of the Florida Nurses Association AIDS Task Force and there are several educational programs and pamphlets that have been made available to nurses. I feel that they are educated to a great extent but that their emotions are the thing that they are trying to deal with now and still deliver quality care.

CHAIRMAN WATKINS: Thank-you very much, Dr. Marchette.

MS. GAULT: There seem to be two people that have particular time constraints in the next two panels, so we'll call them up right now. Leon Kelner from the U.S. Attorney's Office. Following Mr. Kelner will be Terrence Collins, so if you could be ready then also.

LOCAL/STATE GOVERNMENT REPRESENTATIVES
LEON KELNER, U.S. ATTORNEY'S OFFICE

MR. KELNER: Mr. Chairman, thank you for taking me out of order. I must say in looking at the agenda I feel a little bit out of place and a little bit puzzled why you've asked me to testify. When I look, there's only one other lawyer, and that's probably a good thing if you want to get something done, and I'm the only one from the law enforcement community. As you are aware, I am the U.S. Attorney for the Southern District of

Florida. As U.S. Attorney, I am responsible for the prosecution of all federal crimes in the Southern District of Florida. Because of a variety of factors, my office handles the largest serious criminal caseload in the United States. Approximately 50 percent of that caseload is narcotics related. As you informed me in your invitation to me to come here, there is a high correlation between IV drug abuse and the spread of the AIDS epidemic. As a result, I think that we probably share the same frustration, dealing with an intractable illicit drug problem. My office deals with the problem from a very different perspective. We deal with it from the supply side. Law enforcement agencies that are assigned down here deal with the importers, the distributors, and those people who facilitate the flow of narcotics through South Florida.

I want to emphasize that South Florida holds a very unique position in drug trafficking. Approximately 70 to 80 percent of the cocaine and marijuana imported into this country comes from this district. The vast majority of this illicit trade does not stop here, but rather, the drugs are shipped from here for distribution throughout the rest of the country. As a result, those of us in law enforcement in South Florida, be it at the federal, state, or local level are working at a critical juncture in the drug trade. We are trying to stop these drugs from reaching the distributors who in turn sell it on the streets of our cities. What we have done with the limited resources we have in federal law enforcement is to focus on the cartels that have been responsible for the importation of much of the narcotics introduced into this country. We have also focused on the people who assist the movement of the drugs into this country, be they corrupt foreign officials who provide safe refueling stations, professionals who launder the drug proceeds, or state, local, or federal officials who are corrupted by the extraordinary sums to be earned in the drug trade.

Additionally, because we, South Florida, is the first landfall for much of these drugs, it is also the place where the United States Customs Service and the U.S. Coast Guard has focused its interdiction effort. I could go on and describe the large number of significant cases that have been made in South Florida. I could also describe to you the substantial changes that have been made in the drug laws to assist law enforcement in the prosecution of violators. However, I must tell you even with the great strides that we have made on the supply side, the fact remains that this country still faces an enormous drug abuse problem. I've been at this since 1982 in this office. The reasons that this district does a land office business in narcotics prosecution, the reason that in the last fiscal year law enforcement in South Florida alone seized in excess of 30,000 kilos of cocaine, and the reason that more and more illicit drugs are being cultivated is the extraordinary demand that we have in this country for these narcotics. My job would be a hell of a lot easier if we could reduce or eliminate demand. You must

remember that traffickers are motivated by greed, and the enormous amounts that the American people are willing to pay for drugs is what motivates them. Doing away with demand removes these traffickers' incentive. Equally important, as you must all be well aware of, the societal cost from drug trafficking has been and is continuing to be well documented. The cost in terms of the breakup of families, the collapse of successful careers, the impact on the quality and cost of manufacturing are all givens by now. What I am now learning, and have learned through this Commission and through what I've read in the newspapers is that we have another cost, the spread of this virulent disease. What we all have to focus on, and for something that I do not have an answer for, and something that I am very frustrated about, is how to deal with the demand side. I'm not only referring to the lack of space, be it bed space or clinical space, to deal with people who are already addicted, but we must try to find the answer of how to stop people, especially our children, from experimenting. How do we stop them from taking that first step on the road to addiction, because quite frankly, that in my mind is the key question, because we have to stop our children especially before they reach the level of addiction.

I tell a story about what I do for a living, and why I do it, and one of the things I tell people is that I'm really selfish; that what I'm trying to do -- I'm a big golfer and I really love it, and that's one of the reasons why I like South Florida, and when I retire I want to spend my remaining years on the golf course, but however, I can only do that if there is a new generation that's going to take care of business, is going to take care of teaching the young, is going to take care of government. If our young are fried on narcotics, who's going to be running the ship when I want to play golf, and in that sense, I'm selfish. I want to have a good life, but in order for me to have the good life, I have to make sure my children are not infected. I was told that I'm limited. Lawyers have a big problem with five minutes, but I really didn't have anything else to say, except I believe it's within your mandate, it should be if it isn't, to try to come to grips and answer that most difficult question of how do you deal with demand. Thank-you.

CHAIRMAN WATKINS: Thank-you, Mr. Kelner. I can assure you that it is in our mandate, and that it is one of the top issues, in fact will be the subject of our forthcoming set of hearings in mid-December that will be focusing on drug abuse and its relation to AIDS. Any quick questions from the Commission members? Yes, Dr. Lee?

DR. LEE: I have a million questions, but I'll just tell you that I think you're a hero, and that the people like you that I have met in New York, I take care of some of them, are the heroes in our society because you're dealing with one tough bunch of bastards out there.

MR. KELNER: I thank you very much, and on behalf of the hundred lawyers in my office I thank you.

CHAIRMAN WATKINS: Any other questions?

(No response.)

CHAIRMAN WATKINS: Thank-you very much, Mr. Kelner.

MS. GAULT: Terrence Collins.

LEGAL/ETHICAL/ECONOMIC STRUCTURES
TERRENCE COLLINS, M.D., CHAIRMAN,
WORKGROUP ON AIDS & FLORIDA STATEWIDE HEALTH COUNCIL

DR. COLLINS: Thank-you; I appreciate your taking me out of order. I'm Dr. Terry Collins; I'm an Associate Professor of Community Medicine at the University of Florida, and also Chairman of the Statewide Health Council's Task Force on Aids. This afternoon, I'm testifying on behalf of the Statewide Health Council. The State Health Council was established by Florida law to be an advisory council on matters of health planning to the state's Department of Health and Rehabilitative Services, insurance, and community affairs, and to the Governor, and to the state legislature. The Statewide Health Council has been concerned with the affects of AIDS on the health care delivery system and other aspects of society for several years, and has recommended actions in the areas of public education, testing, confidentiality, concerns in the school system, insurance, discrimination, and some workplace issues. Today I was asked to speak briefly concerning the Statewide Health Council's position on the issue of insurance. As a general premise, access to appropriate health care is contingent upon access to some component of the health care financing system, be it private insurance, either through group or individual policies, or a public payment mechanism, such as Medicare, Medicaid, or in some states programs specifically established to meet the needs of the medically indigent who do not qualify for these other programs. Without a payment mechanism, access to the appropriate quality health care is difficult to obtain unless the health care facility or agency is prepared to assume the cost of treatment as part of its bad debt or charity care. Though estimates may vary, private insurance has paid for approximately 45 to 60 percent of the care of HIV infected patients. Faced with the prospect of rapidly escalating costs, the insurance industry is seeking ways

to better screen individual applicants, assess risk, and price premiums accordingly, or refuse insurance to high risk applicants.

At the same time, state legislatures and insurance departments are considering regulatory methods to insure continued access to the health care through private insurance. The use of AIDS related tests and inquiries into the test history of applicants for insurance has raised considerable controversy. The insurance industry notes several arguments supporting its use of these two procedures in the underwriting of individual life and health policies. These include the issue of fairness to all applicants, the reliability of the ELISA-ELISA Western Blot Series, the increasing percentage of HIV infected individuals who go on to develop AIDS or ARC, adverse selection, the threat of uncontrollable financial liability, and the basic principle on which the insurance industry is based, determination of risk. Advocates for HIV infected individuals, on the other hand, argue for the prohibition of testing based upon such arguments as the discriminatory use of the test, concerns over confidentiality, and possible adverse effects on employment, housing, and other facets of life, diminished access to the health care delivery system, disincentives to voluntary testing programs, and general public policy concerns and the predictability of HIV related testing.

The Council recognizes the validity of many of these conditions, and has adopted and recommends to you the following policy components: The determination of HIV seropositivity should not be used as the basis for adverse underwriting decisions on an individual's application for insurance of any type, including health and disability for conditions that are not related to the HIV infection. Involuntary termination of insurance coverage for a person who is diagnosed with AIDS or ARC under the context of a pre-existing condition should be prohibited. Testing for the purpose of obtaining individual life, health, and disability insurance should not be prohibited by law, but this type of testing should be restricted to the use of the most accurate series of tests, which is currently the ELISA-ELISA Western Blot Series. Guidelines should be developed so that the industry's use of this test is applied in a non-discriminatory fashion, that is required uniformly of any applicant whose medical history indicates that there is sufficient and appropriate reason for requiring such a test; that this test will be administered only after informed written consent of the individual to be tested; that the test must be accompanied by appropriate counselling; that the results of such a test will be strictly confidential, delivered to the person individually and in person; and not be included in industry data banks. Testing for the purposes of group insurance should not be permitted. Since current public health measures to deal with the spread of AIDS depend heavily upon the voluntary testing program,

the benefits of which have never been questioned, and because information obtained from inquiry into an applicant's prior test history may have limited accuracy, inquiry into the prior AIDS related test history of an applicant for insurance of any type, either during the application process, or during an investigation conducted by the insurer or an insurance support organization on behalf of an insurer, should be prohibited. Legislation should be undertaken to insure that the confidential information concerning HIV infected persons that is held by insurance companies and insurance support agencies be protected from third party access, including subpoena, or any other method of discovery, except under rare and very specified circumstances. Federal legislation should be enacted to prevent discrimination on the basis of AIDS or HIV seropositivity in employment, housing, school admission, public accommodation, and the procurement of goods and services. The ability of the insurance industry to use AIDS related tests for the purposes of individual health insurance will inevitably result in an increasing number of individuals who cannot purchase private insurance to cover the expenses of their health care needs.

The Statewide Health Council makes the following additional recommendations: The establishment of risk pools, such as those already developed in 11 states, including Florida, should be encouraged through federal legislation and funding so that individuals unable to obtain conventional insurance can provide for their health care needs. Eligibility requirements should be structured so that any HIV infected individual is immediately eligible for enrollment. Federal incentives should be developed to encourage studies by the states to determine the feasibility of implementing a program of subsidies for premiums and/or deductibles to individuals participating in such risk pools. Losses to state risk pools should be shared by all health insurance providers, including those who are self-insured who are currently exempt from participation because of the Employee Retirement and Income Security Act of 1974. As a final comment, it is obvious that the care and treatment for those infected with HIV is going to be costly and that both the public and private sectors will bear a significant share of the costs. What is unresolved is the proportion that each will share, and whether areas that have been affected the most by the AIDS epidemic will share a greater burden or that the costs will be more evenly distributed within the individuals states or in the nation. More than ever before, the federal and state governments must take an active leadership role in developing a comprehensive and integrated plan to deal with all aspects of AIDS; a plan that directs the anger of the nation and our state towards the disease rather than its carriers. Thank-you.

CHAIRMAN WATKINS: Questions from the Commissioners?

(No response.)

CHAIRMAN WATKINS: Thank-you very much, Mr. Collins.
MS. GAULT: Dr. McCartney.

LEGAL/ETHICAL/ECONOMIC STRUCTURES
JAMES McCARTNEY, Ph.D., GENERAL ETHICAL ISSUES

DR. McCARTNEY: Mr. Chairman and members of the Commission: As a resident of Florida, I thank you for holding your hearings here today in Miami, and look forward to this opportunity of presenting some thoughts for your reflection. My name is Father James McCartney, and I am the System Ethicist for the Allegany Health System based in St. Petersburg, and Director of the Bioethics Institute at St. Francis Hospital here in Miami. I'm also adjunct Professor of Moral Theology at St. Vincent dePaul Regional Seminary in Boynton Beach, Florida, and a Professor of Jurisprudence and Ethics and Social Policy at St. Thomas University Law School. I am also a member of the Clergy Advisory Committee of the Health Crisis Network, a local agency which serves persons with AIDS and their families and friends. In my remarks I will focus on seven areas where I believe the federal government has responsibility to provide both leadership and funding. These include research, education, compiling epidemiological information, assisting other governments, ensuring care, providing housing, and balancing privacy rights over against protection of public health.

First, research: We all know the overwhelming statistics that are currently used in projecting the AIDS crisis for 1991. We know that in the United States alone it is estimated that over 270,000 cases of full-blown AIDS will have occurred by 1991, and over half of these persons will have died. We know that at least 1.5 to 2 million people are currently infected with the HIV. We know that while the cost of care is dropping, nonetheless we can safely say that it costs between 10,000 and $15,000.00 a year for the average care of someone with full-blown AIDS. We must now add into this another $8,000.00 per year for those on AZT or Retrovir. All this information puts a tremendous burden on the federal government to try to find both a cure for and a vaccine to prevent this disease as quickly as is humanly possible. Thus, the National Institutes of Health should provide funding for basic research in virology, with a special focus on retroviruses that will help understand the physiological mechanism of HIV even better. The NIH should also be empowered to conduct clinical trials as expeditiously as

possible on new antiviral agents with the hope of inhibiting virus growth and eventually bringing about a restoration of the immune system. I believe we must see controlling HIV as the number one health priority for years to come.

Education, Number 2: The federal government must continue under the direction of the Surgeon General to provide effective, timely education about the cause of AIDS and its transmission. This should be done in cooperation with state and local governments, but should also include such tactics as paying for television time during such widely viewed shows as football games or the Cosby Show, or shows like them. The very effective advertising that the military has developed over the years could be a very good model here. The government has a responsibility to provide information about all the different ways in which the spread of AIDS can be slowed and stopped, even while pointing out that some methods are more effective than others.

Third, compiling epidemiological information: The Centers for Disease Control must continue to compile epidemiological information about the disease. Therefore, the federal government should require that all HIV positive persons be reported anonymously to the CDC for epidemiological tracking. The CDC should also develop other relevant statistics which will help us understand the spread of the disease and those most at risk.

Fourth, assisting other governments: Because AIDS is a world-wide pandemic, the United States has a moral responsibility to assist other governments in coping with this disease. This can be done by sending the latest research information to other government-based health agencies for their use. The United States should also build into its foreign aid budget funds which will help foster basic care of people in those countries most afflicted, especially in Central Africa and the Caribbean.

Fifth, care: The federal government, through grants and contracts, must ensure the possibility of treatment for all HIV positive persons, and not allow the market to allocate resources as is done in other areas of health care. Access to basic health care must be seen as a human right, and not as a commodity, since we are talking here about unbelievable suffering and debilitation. The federal government must do all in its power to make sure all the citizens of the United States receive a basic decent minimum of health care, especially in the context of AIDS.

Sixth, housing: One of the most urgent needs in this region, and I suspect in others, is adequate housing for those who are in the last stages of AIDS, and who need round-the-clock support, without the aggressive type of care usually rendered in

hospitals. What I have in mind in this regard is something similar to an in-patient hospice care facility. While I believe this is primarily the responsibility of local and state governments, nonetheless the federal government could help in this endeavor by providing funds, possibly through the Department of Housing and Urban Development, to initiate some of these projects and to promote the very efficient, cost-effective philosophy of hospice care in the rendering of terminal care.

Seventh, balancing privacy rights over against protection of the public health: The federal government, as well as other levels of government, must constantly be weighing personal privacy rights over against the protection of the public health. In this context, I will offer four concrete suggestions for the moment: A) The federal government should regulate insurance companies so that they cannot refuse insurance for persons who are HIV positive. We must make sure that there is some safety net provided for HIV positive persons, otherwise the care for these persons will be paid directly through the tax monies used for indigent care. B) The federal government must enforce legislation which prevents job discrimination on the basis of HIV positivity alone. I believe the federal discrimination statutes in this regard are adequate, but the Justice Department must be instructed by this panel to enforce these statutes efficiently and fairly. C) The federal government should enact legislation to protect doctors nationwide from liability when they communicate HIV positivity information to an at-risk sexual partner. This is one case in which I believe personal privacy must yield to the rights of third parties not to be harmed. Right now there is much confusion among physicians as to what is their ethical and legal responsibilities in this regard. D) The federal government, while it has the right to screen persons entering military service for anything whatsoever, including HIV positivity, also has the obligation in this context to ensure privacy and confidentiality of those tested. This has not always been the case. The Commission should do all in its power to ensure that those who have information about the HIV status of military recruits or anyone else whom the federal government tests, use those results in an ethically responsible way. Strong and effective legislation should be enacted to prevent the disclosure of this information to unauthorized persons.

In closing, I would like to thank the members of the Committee for allowing me to present this testimony. I will include with this transcript the recent pastoral letter on AIDS issued by the Bishops of Florida. I will also include a section of, "Aids in South Florida: A Plan for Action," issued by the Health Council of South Florida in April of 1986, namely the fourth section on legal and ethical dilemmas, on which I worked as a member of the task force established by the Health Council. I'd like to thank you all for being with us today.

CHAIRMAN WATKINS: Thank-you very much, doctor. Do we have some questions from the panel members? Yes, Dr. Conway-Welch?

DR. CONWAY-WELCH: This is an information-seeking question. If anyone else in the room can answer it, I would appreciate it as well. Is it correct that when patients are involved in hospice care and are receiving support from the federal government through one of a variety of mechanisms that they can only be on drugs that control pain; they can't be receiving radiation or on AZT or any other more aggressive therapy, meaning that if AIDS patients are in hospice care they then are not able to continue receiving AZT?

DR. McCARTNEY: As far as I know, and if anyone knows more they can add on to this, but first of all, hospice care is only covered by Medicaid, not by Medicare. Even the Medicaid coverage is very limited, so my guess is that you're correct. Does anyone else have any --

(No response.)

DR. McCARTNEY: I know the amount for funds for hospice care are very, very limited. They've tried to develop some pilot projects to see the cost-effectiveness of hospice care, but as far as I know, there's no widespread funding of hospice by the federal government.

DR. CONWAY-WELCH: The reason I ask the question is that I've had conversations with people on cancer therapies who are not able to receive radiation or any continuous drug treatment in a hospice.

DR. McCARTNEY: That would make sense to me. Hospice Care focus is on care of the terminally ill, and I would imagine that by their own philosophy hospices would be restricted from these types of funds.

DR. CONWAY-WELCH: That certainly seems to open up another crack in the system, in addition to the others we know about.

CHAIRMAN WATKINS: We'll pick that item up, Dr. Conway-Welch, specifically in the staff, and we'll get out a piece of paper to all the Commissioners on it to try to answer that question. Thank-you very much, Dr. McCartney.

LEGAL/ETHICAL/ECONOMIC STRUCTURES
JOHN SFORZA, EXECUTIVE DIRECTOR, FLORIDA HEALTH COALITION

"I have been asked to address this Committee on the economic concerns of employers. We all recognize the impact AIDS has on the very fiber of our society. Not withstanding those issues, I will address only the economic concerns of employers faced with a public health problem, fast becoming a corporate health and economic problem. Employers are presently attempting to cope with the financial and administrative toll of AIDS; a toll which we count in human misery, death, and dollars. AIDS is a worldwide problem. Here in the United States, Florida ranks third behind New York and California in the number of AIDS cases. So we are on the frontlines against an enemy with the potential of affecting the quality of life so severely that each of us will be affected whether or not we contact the virus. The Miami Herald reported earlier this spring that, 'No one knows the total cost of the problems in Florida.'

It is true that costs will vary from patient to patient, but the July 30th issue of Medical Benefits reported that the Centers for Disease Control places the total cost, from diagnosis to death, in the range of $60,000.00 to $100,000.00 per patient. These costs reflect the typical hospital treatment for the entire course of the illness. These are direct costs to an employers health care plan.

Other costs can be assumed to emerge which can be defined as direct or indirect. These include, but are not limited to: Health care insurance premiums. As employer plans experience AIDS related expenses costs are going to increase, perhaps so much so that smaller employers may not be able to provide health coverage. Life insurance coverage usually provided by employers will also have a serious effect on the cost of doing business, and some will question the value of providing traditional employer paid group life insurance for their employees. Disability benefits, whether they are insured plans such as LTD or salary continuance plans sponsored by employers, will be affected by the potential or prolonged absences of the victims of this disease and their family members. Temporary replacement or productivity losses will result in loss of revenue to all businesses. These are just a few of the direct costs associated with the business community. Other costs do exist which will have a negative effect on all businesses; they are the indirect costs.

These include, but are not limited to: Employee education costs associated with the prevention of AIDS, as well as the costs associated with safety information regarding AIDS in the workplace. Public relations costs, regarding public safety of the product, a concern shared by all food processing and distributing businesses. Marketing costs of products. Our

society is changing; as the fear of AIDS ends the so-called sexual revolution, advertising costs will be affected. Uncollected health care costs associated with uninsured AIDS patients will be passed on the insured population via increases in treatment fees charged to insured or paying patients. These are just a few of the business community's concerns. If employers are going to survive this potential national disaster, there must evolve a coordinated federal, state, and local response to manage health services and the health financing crisis posed by the escalating AIDS epidemic. The assessment, development, and implementation of a comprehensive service delivery system for care of AIDS patients in a cost effective manner must be achieved. Additionally, insurers and employers who are hit especially hard by AIDS claims must be able to protect their solvency through an AIDS insurance pool. Lastly, while the medical community is working hard to find a cure and vaccine to eliminate this terrible disease, government and business should focus their efforts on prevention. Prevention can be accomplished through educational programs. Government is needed to sponsor large scale preventative programs and as a main source of information, business is needed to sponsor localized preventative programs. But this is very costly to the business community. An extra tax incentive should be offered to the corporations that provide AIDS prevention programs for employees and dependents and the community at large."

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MS. GAULT: Mr. Berger.

LEGAL/ETHICAL/ECONOMIC STRUCTURES
DAVID BERGER, PRESIDENT, SOUTH FLORIDA CHAPTER, AMERICAN IMMIGRATION LAWYERS ASSOCIATION

MR. BERGER: Good afternoon. My name is David Berger, and I'm the President of the South Florida Chapter of the Immigration Lawyers Association. The American Immigration Lawyers Association was established 40 years ago. We have 2,700 members, and we are engaged in the representation and assistance of aliens and corporate entities who are appearing before the Immigration Service and related federal agencies. I will talk today about the impact of AIDS testing on immigrants. For many years, potential immigrants to the United States had to undergo medical examinations. 50 years ago we were most familiar with those who were turned down for glaucoma and tuberculosis. In 1987, the issue is AIDS, and the Immigration Service is in step with the needs of society.

I'd like to discuss that today, and the impact on the immigrant community. Since July 8, 1987, all aliens must undergo a clinical examination for symptoms of AIDS. In three weeks, effective December 1, '87, all aliens must take a blood test,

which would be the ELISA and the Western Blot. A positive readout makes any and all immigrants inadmissible to the United States. There are three settings you have to examine when you're considering immigrants, and you're probably familiar with them. The first is the legalization program, the amnesty program of the Immigration Reform and Control Act of 1986. An individual who has been in the United States since before 1982, or is a qualifying agricultural worker, can obtain permanent residence, the green card, upon showing eligibility under the statutory provisions. The person, in conjunction with that application, would have to submit a medical examination form. The second setting is an individual who is applying for permanent residence under the ordinary provisions; it's called Adjustment of Status. The best example is marriage to an American citizen, a person came in as a tourist and they want to become a permanent resident. They too must take a medical examination. The third category is the immigrant visa applicant, that is an individual who is applying for admission to the United States as a permanent resident, and is submitting such application to an American Embassy or American Consulate outside the United States. Outside these three categories, you also have visitors to the United States. We receive approximately one million visitors to the United States each year. The conventional proposals to deal with aliens who have tested positive are very clear. A legalization applicant, upon positive testing, would be immediately arrested and removed from the country.

There is a problem, and that problem was recognized in June, 1987 by Senator Simpson, one of the proponents of the bill. The problem is in the confidentiality provisions of the legalization section of the Immigration Reform and Control Act. The confidentiality provisions create a problem because if a person is found AIDS positive, that information cannot be given to any other federal agency, and that person cannot be deported because his application for legalization is denied. Ordinarily, confidentiality was not looked at as a serious issue by the immigration service. They felt that anyone who was denied legalization should be let alone, and that was the intent of Congress because Congress wanted the underground alien community to come forward, and Congress promised this community confidentiality, so as to draw those out of the woodwork. To date, less than 900,000 aliens have applied for legalization which expires in May, '88. Estimates were that as many as four million would apply. The immigration service said it estimated two million would apply by May. So right there we have a very serious problem because legalization applicants who are HIV positive cannot be removed on that basis alone because of confidentiality. The Immigration Service is now presenting this problem to the appropriate bodies in Congress because it is a serious problem and it was overlooked by Congress. One of the issues is whether or not the alien can be turned over to one of

the state's agencies, and that issue again is under consideration. As to the matter of adjustment of status, which is a permanent residency process in the United States, you have the same problem. If a person appears before an immigration officer and he is HIV positive, you would think that the person could be arrested and deported on the spot. It doesn't work that way. This is a democratic country, and our system of immigration is the most liberal or amongst the most liberal in the world. That person is denied the application but is not taken into custody.

If the person were taken into custody, they could bond out, and eventually go back into that underground community. The immigrant visa applicants and visitors are in a different category. They are not yet in the United States, so you could say that upon positive testing, no exceptions, they would be excluded from admission to the United States. Because of the complexity of these issues, the American Immigration Lawyers Association has drafted a proposal, and the proposals address these areas in legalization, adjustment, and some immigrant visa cases. The National Organization of AILA would propose that the person would be allowed to stay or enter in the United States, but would be required to undergo counselling and education. In other words, the person would not be arrested and deported, but the person would be allowed to stay under the humanitarian provisions of the law. The proposal is based on the argument that the deportation of infected individuals would increase the global nature of the disease, and would be an affront to the world community. One of the issues that has been raised is whether or not all visitors to the United States should be AIDS tested. Now with one million visitors per year, it has not been seriously considered, although Canada is currently seriously considering the issue. In summary, the immigration laws provide for the exclusion of aliens who are infected with a contagious disease. They also provide for the exclusion of aliens who are likely to become a public charge. The immigration laws however are humanitarian in tone, and they emphasize the unification of families. The exclusion or deportation of infected aliens is an issue which must be carefully analyzed before an overall policy is implemented. In this analysis, we must not only consider enforcement and economic factors, but also the human and global facets of this issue. Thank-you.

CHAIRMAN WATKINS: Thank-you very much, Mr. Berger. Dr. Lilly, do you have a question?

DR. LILLY: Yes, or a comment, basically. I've been very interested in this issue, and for particularly in the category of individuals seeking legalization. One thing I'm surprised you didn't mention because it's always been a puzzle to me is the likelihood that many, if not most, of those individuals who do turn out to be HIV positive in fact acquired the infection

here, and that hypothesis for which there's a good bit of support that in fact this nation is a net exporter of HIV infection. I'm wondering if that has any influence on what's going on.

MR. BERGER: That is why the National Organization of the American Immigration Lawyers Association prepared this draft which I have submitted today, with the understanding that the incubation period can be as short a time as six months, and these individuals have been here since before 1982, so they obviously contracted it here, and we would again be contributing to the overall export of the disease. That is a major problem, and we understand.

DR. CONWAY-WELCH: Will we be receiving a transcript of that draft, or a copy of that draft?

MR. BERGER: I have presented the draft today, and I believe copies are being made.

DR. CONWAY-WELCH: Oh, okay, thank-you.

MR. BERGER: We are trying to disseminate our comments throughout the agencies in Washington. We have a conference tomorrow in Washington, D.C., the Second Annual Capitol Conference, and we will be meeting with members of the Congress to address these issues.

CHAIRMAN WATKINS: Could you answer a question on does the law address the issue of deportation to what country, because in some cases the countries to which he or she would be deported have their own laws that preclude individuals entering that country with HIV positive tests, so the question is how do you solve that dilemma?

MR. BERGER: That's a serious problem because if a person is already in the United States and is arrested by Immigration, they can only be deported to their country of nationality. If their country of nationality has such a law, they cannot be deported. For example, you have Marial Cubans that are in Chrome right now, the Chrome Avenue Detention Center. The only reason they are there and not in Cuba is because Cuba will not accept deportees who are Cuban nationals. Those, however, who are in what they call an exclusion category, in other words, you arrive at the airport at JFK and you are found excludable, can either be sent to from whence they came, whichever country they originated at, or to their country of last residence, or their country of citizenship, or any other country in the world which would accept them. But again the problem is that if a country does not accept an infected alien, they stay here.

CHAIRMAN WATKINS: But does the current law allow any consideration to this regard, or is it so rigid that we end up on the 1st of December with some extremely serious problems like that facing us right off the bat, and will they only be solved in litigation, or is there some thoughtfulness going into possibly modifying the laws to take some of these things into account? AIDS obtained in the United States clearly, not able to go and be deported to the nation of origin, can't come in the United States, what's the resolution?

MR. BERGER: There are large Immigration Service detention facilities throughout the country, the most well-known is in Oakdale, Louisiana, and it is a huge facility, millions of dollars have been put into it. What the Immigration Service may be considering, and which Senator Simpson alluded to, would be some type of quarantine and/or detention centers at the worst. We are in a situation where if we cannot deport the person, that person remains in our community and the Immigration Service can work with public health and quarantine the person, but these matters will be tested in court, there's no question. However, we are trying to resolve the matters before the agencies and of course the United States Congress.

CHAIRMAN WATKINS: Thank-you very much, Mr. Berger.

MR. BERGER: Thank-you.

MS. GAULT: Mr. Sammone.

LEGAL/ETHICAL/ECONOMIC STRUCTURES
JAMES SAMMONE,AIDS COALITION ENDOWMENT

MR. SAMMONE: The text of my speech is towards the end of the statements you've just received. The other thing in the front there is a project that we are working on at the AIDS Coalition, and there are numerous typographical errors, and I hope you will excuse them. We're just a little volunteer organization and we have to get typing wherever we can. I don't know if you guys are as tired as I am; I can use a little nap. I want to address this Commission both as the President of the AIDS Coalition Endowment and as an HIV infected person so that the Commission will view my statements not only as an organization, but as an individual who has been affected with a life-threatening disease. We want you to see us as people, not statistics. We are your sons and daughters, your nieces and nephews, your bank teller, your grocery packer, your clergy, your health care worker, your military, the guy that used to pump your gas, now you have to pump it yourself, and your neighbors. We realize that those facts are frightening to some people, and that is why it is of paramount importance that this Commission make the statement that this disease is not transmitted through casual contact. That should be your number one educational

goal. It is only through this leadership that the American public will not react hysterically, but in a rational and compassionate way. They look to you now for that statement; please make it. Once that leadership step has been taken, it will then be important that some specific measures to end this epidemic be enacted. We believe that this Commission need recommend to the President and to the Congress that a state of national health emergency exists and that extraordinary measures need to be taken. We want you to feel our sense of urgency, but not write us off as terminal. We fully intend to live with this disease. We take the responsibility for our own health, and to do whatever is necessary to stay alive, and we will do so. That is not a statement of the desperate few, but of the determined many.

We are seven years into this epidemic which this government did not want to speak about for so many years because of its sexual nature that has been alluded to by Dr. Crenshaw, and I appreciate that. For that reason, many thousands have died unnecessarily. We will die no more. With the inception of this national health emergency we will in effect declare war on AIDS. We must take that declaration as seriously as our last declaration of war during World War II. In that state of war, extraordinary measures such as this country had never seen took place, the most secret of which and the one project which ended the war was the Manhattan Project. We ask you now to endorse the New Manhattan Project on AIDS, as has been advocated by the human rights campaign, and which the AIDS Coalition Endowment endorses. The Manhattan Project brought together the most learned minds of its time in an effort unsurpassed in history. That is the kind of leadership that we need now from you to combat this health crisis. We believe that unless this project is not undertaken in short order this epidemic will far exceed the Black Plague in international proportions. We also believe that you know that, and now the American public does also.

The project need appoint one head, as with Oppenheimer during World War II, to develop and initiate a national strategy with government agencies, the FDA, the CDC, the NIH, the Public Health Service, and others directly responsible to that person. It is imperative that this appointment should come from the health care community and be an AIDS expert, not another political appointment. The time for politics is over. It is time for the bureaucratic haggling and disagreement to end. We are doing the dying while you are doing the arguing. This project is what is needed. We are experts like no others have ever been. We need an expert such as Dr. Mathilde Krim or Volberding to head this project. You may not agree with their politics, but you must agree with their expertise. We hope that this appointment will be made from a joint committee of Congress to avoid any more political appointments that waste the valuable time that we may have left. Time does not permit me to go into

specific pharmaceutical problems that I really would like to talk about because I wanted to keep to your time limit. Hopefully, some of those problems will be remedied by that project, so that's why I also didn't really go into it. But I hope that you will ask me some questions about that area. Thanks.

CHAIRMAN WATKINS: Thank-you very much, Mr. Sammone. We had a presentation earlier this morning from a person with AIDS -- I'm trying to find the name right now -- Patrick Haney. We asked him to submit to us the issues regarding the various drugs that he mentioned to us that need some expeditious review, and you said you didn't have time here today. I'm sure you know Patrick Haney, so maybe you could get with him on his submission to the Commission as we asked to expand further on his particular proposal so that we can take them under advisement.

MR. SAMMONE: Some of the things that are important that really need to be done quickly are not just pharmaceutical problems. Some of them are just ideas like the idea that this disease can be rendered non-infectious. Every other retrovirus can be, why not HIV? The thrust of research could possibly be put in the wrong place. We believe that with either a combination of drugs that we may be able to become non-infectious.

CHAIRMAN WATKINS: Dr. Crenshaw, you had a question?

DR. CRENSHAW: I was just going to say that with ideas on that order and others that you haven't had a chance to share with us today, please write them up and submit those too, and we'd be glad to review them. I think that one of the things we're finding with all the people that we talk to interested in research is the manner in which the studies are selected and how they can be better evaluated in advance and the funding delegated in the most appropriate --

MR. SAMMONE: The protocols that don't put 50 percent of people on a placebo for nine months at a time as with Ampligen. The reason that that study is not going ahead is because you can't get subjects to be in it. They'd be a fool to get in a study for nine months and take them off AZT.

DR. CRENSHAW: Do address all of these things to us with anecdotes like that in writing; it would be appreciated.

DR. CONWAY-WELCH: Part of my question this morning had to do with the frustration of trying to get out some coordinated information regarding the problems that you're suggesting, not only with the pharmaceutical problems but some of the other ideas to which you alluded. I would also appreciate it if you would give us your perspective of recommendation on protocols. I don't have all the information at my fingertips at the moment, but I do

know that with at least one of the Ampligen studies there are provisions made to break the code and bring people off the placebo study onto Ampligen at various times through the testing period that as I understand it would not take nine months to complete. I would be very interested in the pros and cons that you would see regarding those concerns.

MR. SAMMONE: I could tell you that very quickly. What the protocol calls for if someone starts to become very sick, they will be taken out of the test group and put back on AZT. Now if you just substituted AZT as an active control, and tested the drugs against each other, even the FDA has said that that would still be a valid test.

DR. CONWAY-WELCH: Can you give us that particular perspective and information as part of what you would submit?

MR. SAMMONE: Absolutely.

DR. CONWAY-WELCH: That's the kind of information that we're anxious to receive. MR. SAMMONE: This other information that you have is about the many other pharmaceuticals that are available through the underground. People are going to take them; people are going to use them; and it would be a real waste if we didn't collect that data. That's what this other project is about.

DR. CONWAY-WELCH: And this other project has a home with the University of Central Florida's Department of Medicine?

MR. SAMMONE: There are people from the University of Florida's Department of Health -- it says medicine and that's not correct -- and they have an AIDS Task Force of the University of Central Florida. The people on the task force will be involved in it plus we're getting statisticians and computer people to set up the program for input and output so that we do have -- it's not as if it's a project of the University. They are helping us out. I also recently got a guarantee from a major Central Florida attraction, that I can't tell you who it is, but I'm sure you can guess, and everyone in town said I would never get anything from them for AIDS, and they are going to underwrite our Scantron sheets, which is a quarter of a million Scantron sheets because they are monthly and that would be $35,000.00 through Scantron. Also they're going to underwrite 50,000 of our brochures to the tune of about $10,000.00.

DR. CONWAY-WELCH: Part of the concern I think, at least speaking for myself as a Commissioner and perhaps for others, is that there are a variety of this kind of thing going on around the country as a response to what people feel are problems from the federal response. I hope that one of our roles is to be able to collect this information and to provide some

structure for it. We need it; we need you to give it to us.

MR. SAMMONE: We will structure it. We will put it together. We hope to have 20,000 people who are using other pharmaceuticals and food supplements and whatever filling out these sheets, and we will provide it to you.

DR. CONWAY-WELCH: That's what I'm asking. MR. SAMMONE: Also CRI in New York will get it and also a research group here in Florida. We would like everyone to look at the data independently. We don't have a problem with that. We could use a little money. It would be a lot better if we could have PC's to coordinate with the 200 groups around the country that we're going to be working with. You know, we're talking about a lot of people and a whole lot of data; that's why it must be computerized on Scantron.

DR. CONWAY-WELCH: I guess what I'm asking is is there a proposal or is there a document that summarizes the --

MR. SAMMONE: That's it (indicating).

DR. CONWAY-WELCH: Is there something with more detail than this though?

MR. SAMMONE: Not a working -- you mean like a working administrative kind of --

DR. CONWAY-WELCH: Yes.

MR. SAMMONE: No, there is not.

DR. CONWAY-WELCH: Will there be?

MR. SAMMONE: Absolutely, there will be.

DR. CONWAY-WELCH: Could you share that with the Commission when that --

MR. SAMMONE: Sure.

CHAIRMAN WATKINS: Thank-you very much, Mr. Sammone, we must move on

DR. LEE: Can I add one thing, Admiral?

CHAIRMAN WATKINS: Yes

DR. LEE: Mr. Sammone, I've heard this Manhattan Project idea, talking to the people who are in control in Washington and talking to the people who are not in control in the rest of the country. It's tough for us to come, at least it's tough for me to come to grips with that because a Czar does

things that you don't want. Pluralism in medical research is really the best way it's done. I'm not still sure that a Manhattan Project with one person controlling it, which leads to so many of the things that the PWA community is complaining about, is the answer. Please think more about that, and talk to your friends about it, and come back to us with more thinking on that because that's something that I think we ought to try to think about more.

MR. SAMMONE: Well, as you know, Mr. Oppenheimer was not well liked on the project, but he did direct it. I think that it was at another one of your meetings, or it might have been this morning, someone said something about a dual heading, and I mentioned both Dr. Mathilde Krim and Volberding. That would be fine; we would love it.

CHAIRMAN WATKINS: Thank-you very much, Mr. Sammone.

MR. SAMMONE: Thank-you.

(Applause.)

MS. GAULT: Mr. Jacobs.

LEGAL/ETHICAL/ECONOMIC STRUCTURES
GARY JACOBS, HEALTH MANAGEMENT INSURANCE

MR. JACOBS: Thank-you all very much, and thank-you for inviting me. My name is Gary Jacobs, and I'm President of a company called Health Management. Our firm works in the innovation and design of cost containment programs for the federal government, the state government, and the private sector. I have to stay within my time frame, so I'd like to just read through my comments, and if you have any questions, I'd be glad to answer those. The cost of AIDS treatment in our society has created a myriad of conflicting options to the payer system, providers of health care services, the patient, and the patient support system. It has caused employers, insurers, politicians, governments to react to the sensitive nature of the disease itself, along with the costs associated with it. As a payer system both in the public and the private sector begin to respond, it is clear that humane, cost-effective care is necessary. Morally, each of us has rights as people of the world community to be treated fairly, equitably and honestly as we live on this earth. Florida is in a unique position, state of the third highest incidence of AIDS, to rally its public and private resources to battle this raging foe.

As the public sector became the initial focus of concern, we are now beginning to see the response of mainstream corporate America. Initially, education, training, strategic

planning has begun in the workplace as a first step. Effective case management of PWA's coupled with the above tactics will be necessary weapons to allay the fears of employers and build collective strength among purchasers, underwriters, and consumers of health care services. The insurance industry must implement programs and benefit plans in conjunction with the employer's response at the workplace, as well as with government at all levels to effectively deal with this problem on a more global basis.

Herein lies the challenge facing mainstream America: On what terms will employers and their underwriters cover the cost of AIDS treatment? What are the legal issues confronting testing and its relationship to insurability? What will be the response of our state legislators and insurance commissioners in insuring coverage, designing policies and plans that are effective to cover the issues at hand? How will the public and private sector systems devise creative payment solutions? Florida traditionally has been a low benefit area, as has many states in the South. Collectively bargained health coverage is less pervasive in Florida than it is in the more traditionally unionized areas of our nation. Additionally, dependent coverage is usually assumed by the employee, thus forcing a decision, a very important decision of whether or not to cover one's own family. If one elects not to cover the family, the potential cost of care will be borne by our public health care system and our institutions. Florida also does not have one dominant carrier, as many states in the South do not have. Thus, we have hundreds of carriers, hundreds of different competing health plans from insurance companies to HMO's to PPO's all competing for business. In the competition for business we have found that there are restrictions. There are retroactive denials of coverage, and there are pre-existing clauses rationally designed to contain cost and lower risk. Yet risk protection cannot become a solution. Risk management, through carefully developed treatment protocols and payment policies, must be implemented in order to contain the cost of AIDS care. Insurers of all kind must enact case management methods, consistent with current medical protocols, in order to provide humane care in the most cost efficient ways possible. Effective case management techniques may also cause our political and insurance institutions to change rules, policies, and laws which presently restrict care for AIDS to more costly settings under Medicaid and major medical policies.

Under Florida's Medicaid system, without a federal waiver, PWA's that qualify for Medicaid coverage can only access providers and services presently covered under our state Medicare program. The same exists for treating AIDS as any other illness under our major medical plans within our state. This prohibits reimbursement for less costly alternatives, and tends to use expensive in-patient care as the system of choice because it will

be reimbursable. Zoning at the local level must also be re-examined to foster the development of group living environments for AIDS patients. They must also be designed in conjunction with their payer systems, so that payment will be received so these will become viable organizations. Reimbursement for such services must be achieved so that lower cost facilities can be developed for this specific population. Coordination through community-based networks of licensed facilities, and I think licensing of these facilities is going to be important also as we grow in the area, must be implemented so that on a county by county basis, all residents will be assured of the availability of treatment. Counselling must be an integral part of care from the point of pre-testing on to insure the emotional health of our people. Through this approach we can build community based treatment networks as managed care prototypes, which will serve to care for their own residents within their own communities, with payers assuming their responsibilities and rights so together as a common community we can face this tremendous challenge. An additional comment, if I may, and Representative Pullen, I know in Illinois there's some unique activity going on in your state level, but my people have been working diligently to put together rapidly organizational structures for case management of PWA's to meet the jargon and needs of the insurance industry and the Medicaid payer system, specifically here in Florida as a prototype. I would be happy to make these available to the Commission, and I also have a lot of recent case studies that we have done in South Florida where savings can be achieved by implementing some of the protocols. I thank you very much for the opportunity to address you.

CHAIRMAN WATKINS: We would like to take advantage of those inputs to the Commission, Mr. Jacobs.

MR. JACOBS: Thank-you very much.

CHAIRMAN WATKINS: Any questions from the Commission members?

(No response.)

CHAIRMAN WATKINS: The next witness then.

MS. GAULT Representative Gordon.

LOCAL/STATE GOVERNMENT REPRESENTATIVES
ELAINE GORDON, MEMBER FLORIDA HOUSE OF REPRESENTATIVES
LEGISLATIVE TASK FORCE ON AIDS

REPRESENTATIVE GORDON: Good afternoon. Thank-you for the invitation to speak with you today. As a member of the Florida House of Representatives from Dade County, I welcome you to our community. As a member of the Legislative Task Force on

AIDS, and the Chair of the Appropriations Sub-Committee on Health and Social Studies and Criminal Justice, I underscore our commitment to work with you to develop a strong and effective national policy to stop this terrible disease. My presentation today will focus on three areas: Where Florida has been legislatively on this issue; The objectives and activities of the Legislative Task Force on AIDS; And then some recommendations. The Florida Legislature first passed AIDS related legislation in 1985 when it established statutory authority for the alternative testing sites. Since 1985, 30,000 Floridians have been anonymously tested at these sites, and approximately 12 percent have tested positive for the HIV antibody.

In 1986 we realized we needed to address the public health aspects of AIDS, as well as other sexually transmissible diseases, and we passed a comprehensive rewrite of our outdated venereal disease statute. This law, which seeks to strike an appropriate balance between the rights of the individual and the need to protect the public's health, strengthens provisions relating to confidentiality, and to reporting, investigating, examining, and treating sexually transmissible diseases. Our law has become a model for other states with Illinois recently enacting an almost identical version. Also in 1986, we passed a law requiring those who have been arrested for prostitution to be offered an antibody test, and those who have been convicted to be given the test. In 1987, Florida witnessed a phenomenon experienced in other state legislatures. Numerous bills relating to AIDS were filed. Most of these bills were referred to the Committee on Health Care, on which I serve, of which I am a longstanding member. Because of the importance of the AIDS issue, and the need to have a thorough discussion of the various AIDS related proposals, the House formed the Legislative Task Force on AIDS.

The Legislative Task Force on AIDS is made up of 11 members of the Health Care Committee. Membership is bi-partisan, and represents a cross-section of political ideology. The purpose of the Task Force is threefold: To receive and evaluate testimony on a variety of AIDS related issues; To act on various individual member bills, which have been referred to the full committee; And to draft legislation as a proposed committee bill on AIDS.

In preparation for 1988 legislative session, the Task Force has already met to discuss the health care delivery system and treatment related concerns, efforts to educate about AIDS, policies concerning school children and school employees, and issues relating to counselling, testing, and confidentiality. Future meetings will focus on insurance, discrimination and employment related concerns, and public health measures. Although it is too early to represent to you a consensus on the

approach the Task Force will take concerning legislation, I can share with you a sense of the Chairperson's direction. First, we see the need for further implementation of a comprehensive and coordinated statewide education effort. Second, we must continue to encourage voluntary and anonymous testing. Third, we must require that anyone who receives an antibody test be offered counseling and follow-up services. Fourth, in order to encourage testing and treatment, confidentiality must always be guaranteed. Finally, strong non-discrimination laws, particularly in the areas of education, employment, housing, insurance, and health care must be enacted. I notice that the federal proposal did not address insurance, and I'm sure you've heard from many of us here today that that is a very important issue that we want addressed. As part of any statewide effort in these areas, we recognize our responsibility at the state level to act responsibly and responsively. In addition to the substantive legislation we have already passed and expect to enact in the future, Florida has authorized substantial expenditures for AIDS. For instance, for fiscal year 1987/'88, we appropriated approximately 12.5 million dollars for AIDS. However, we also firmly believe the federal government must also show a stronger degree of leadership and a fuller commitment of its financial resources. Several specific recommendations for federal action come to mind. The importance of education cannot be overemphasized.

We should expect no less than an approach which treats this disease in a clear, straightforward manner, unencumbered by religious or political overtones. Since one of the primary ways this disease is transmitted is through sexual relations, we must provide education in a frank and open manner, even though some may find such discussion discomforting. Furthermore, this educational effort should involve indigenous, community-based groups who have the expertise and experience to reach the broadest range of our citizens. We need a national position and policy on testing which underscores the limited, and in fact, counterproductive value of compulsory testing. Too many people view mandatory testing as a quick fix, when in reality it is a no fix. In 1986, Florida repealed premarital blood tests, and before we undertake mandatory tests of any kind, such as we have now for syphilis and TB and others, those are diseases that can be cured. What do we do if we mandatorily test everyone? What do we do about those people? What we need to do first is to have enforceable anti-discrimination laws, confidentiality, counselling, health care, housing, et cetera. We cannot just mandatorily test these people, find out that they are infected, and then just say, "Good-bye, you're on your own."

We also have to address the fact, as we did when we repealed the pre-marital blood test, what happens when a test is negative, then there is a sexual encounter that night, and the person is infected the next day. The cost of the mandatory

testing is enormous, and the State of Florida, for one, is not prepared to underwrite that cost. The federal government must address the widespread discrimination faced by people with AIDS. As a state legislator, I can appreciate the current debate as to whether anti-discrimination laws are best left to the states to enact. I believe at the very least we need minimum federal standards that states would have to meet or exceed. My remarks today are from the perspective of someone who has been involved in the substantive and fiscal aspects of this issue. Additionally, as a Task Force member, I have heard much of the testimony you have and will receive. I truly appreciate the magnitude of your efforts and commend you for your diligence, and again offer to you the cooperation of the State Legislature and particularly our Task Force.

(Applause.)

CHAIRMAN WATKINS: Thank-you very much, Representative Gordon. Questions from the Commissioners?

(No response.)

CHAIRMAN WATKINS: I think it would be very helpful to us, as you continue your deliberations in the Florida House of Representatives in this area that you keep us in mind as a point of contact.

REPRESENTATIVE GORDON: Most certainly.

CHAIRMAN WATKINS: We have just been briefed on the various pieces of state legislation that now exist throughout the country. We were informed by the Task Force that presented that to us that several years ago, three years ago, there were 40 pages dealing with AIDS. There are now three large volumes, and growing very rapidly. The question is the degree to which state laws are consistent with each other; how well these laws are coordinated with the work of the state territorial health officers; the degree to which state laws can satisfy some of the concerns now expressed by the Congress in the 54 draft bills on these various issues; the degree to which the federal government versus state government should relate to each other on these issues.

There's so much activity in this areas right now, and with the press of business on Capitol Hill, there's some question in my own mind, and this is my own personal belief, that those bills up there may not come to fruition in quite the right way, and quite the timing that may be useful, so I think there's still confusion as to the relationship between state and government roles to play. I think that because we've been here and because we've had presentations from people like yourself and other members of the state legislature, we would like to have the

benefit of your deliberations as you face some of these tough issues. It would be helpful to us as we begin to have hearings on confidentiality and discrimination, that we know we're at the heart of some of the obstacles that we've talked about earlier to progress.

REPRESENTATIVE GORDON: I would certainly be very happy to share that with you. In fact, I'm anxious to share that with you, as well as ongoing recommendations that might surface as we are having our deliberations. For instance, one fiscal aspect is that the federal projections are that there is going to be greater and greater amounts of federal dollars for research at the federal level as the rest of the money starts to decrease, that is direct care, et cetera. Also, that the major part of research is going to be done at the federal level. I think that since timing is of the essence, we have to get a little bit more liberal about allowing some creativity and innovation for research at the state level too. There is nothing where it is written in stone that the only people that know anything about how to research a cure or an anti-infection medicine exists only in Washington, D.C. or at the federal level. I think that there are resources out there that ought to be tapped because the more people working at it I think the sooner we're going to arrive at a solution.

CHAIRMAN WATKINS: What I'd like to suggest, if it's all right with you, is perhaps you have a contact person in your own office that can deal with our contact person on the staff, just so we keep that liaison alive, and we'd be the beneficiary I think of any things that are coming out of the state legislature down here just on a timely basis, so we could watch it. Would that be something that you could do for us?

REPRESENTATIVE GORDON: Yes, absolutely. I would probably give you several; some that would be at the Tallahassee level, and then some at my local office level, so you can find us wherever we are at any time.

CHAIRMAN WATKINS: Thank-you very much. Would you provide that to one of us?

REPRESENTATIVE GORDON: I certainly will. My assistant happens to be with me here today and I'll have her do it.

CHAIRMAN WATKINS: We have one more question from Dr. Conway-Welch.

DR. CONWAY-WELCH: I know that California introduced a drug bill, or, "a drug bill," that allowed California, the state, to make some decisions about the availability of certain drugs for testing. Is there similar kinds of interest of that in

Florida? Are you approachable by groups who are interested in that? Could you comment on that?

REPRESENTATIVE GORDON: We are approachable. My comment is where are the dollars going to come from. The State of Florida is 49th or 50th in the provision of social services and health care in the states. I don't know if you are aware, but right now we are in the throws of extremely painful debate as to how we are going to find resources in the future to support all of the issues related to the fastest growing state in the country. So because of that restriction on the amount of money we can spend and where we can spend it, our priorities simply don't provide us the opportunity for that kind of innovative treatment modality. That's why I said if we could get help from the federal government, at least to be able to just match some money from the state, and of course a hundred percent federal funding is always better, but our state is now just addressing this crisis. As you know, we're third in the country. We are a gateway for immigration, illegal as well as legal, and our resources are being strained. I don't think we're going to see that very quickly.

DR. CONWAY-WELCH: There are avenues for introduction, but it's a problem of resources?

REPRESENTATIVE GORDON: Exactly. I think we are open to anything that is not only legal, but also has some efficacy in order for us to address this problem. We are all very, very concerned. There is a lot of misinformation. I'm sure you've read about the problem in Arcadia with the two boys that were kept out of school. You know, there is panic, and because of it inappropriate kinds of bills are being introduced. At the same time, a lack of opportunity and resources to be able to provide education, appropriate education statewide too. We are open to all of those avenues, provided we don't further strain our budget.

DR. CONWAY-WELCH: So the issue in part is new dollars.

REPRESENTATIVE GORDON: In all, in a hundred percent, it's new dollars. Philosophically, we are willing to do it all. It is a hundred percent the issue of where will we get the money to do everything we would like to do. We have wonderful, tremendous resources, and educated people, trained people, people who have become experts in this field over the last several years. You've heard from them today. We are very, very willing to tap those physical resources, but we don't have the fiscal resources.

DR. CONWAY-WELCH: Thank-you.

CHAIRMAN WATKINS: Thank-you very much, Representative Gordon.

MS. GAULT: We have two witnesses that are remaining, and we'd like to get adjourned by about 4:20 if we could so that the Commissioners could catch their planes, the ones that are trying to go east, or go northeast, so could we now have Sylviane Kaufman? The last witness then will be Dr. Larry Capp, who was scheduled to go on an earlier panel, so if he could be scheduled to go next.

LOCAL/STATE GOVERNMENT REPRESENTATIVES SYLVIANE KAUFMAN, ACTING DIRECTOR, METROPOLITAN DADE COUNTY HEALTH SERVICES

MS. KAUFMAN: I'd like to thank you for this opportunity to appear before you today to speak about Metropolitan Dade County's involvement in addressing the AIDS crisis in this community. Metro-Dade County government recognized the seriousness of AIDS and its potential impact on this community dating back to 1982. The county's Health and Human Services Committee was concerned and committed to responding to the AIDS issues and fully supported all the efforts by our county departments. The county's early participation began with the initial planning efforts of the Health Council of South Florida, and with the development of the AIDS Network of South Florida, and this role continues today. The county's Department of Human Resources, Office of Health Services, and Jackson Memorial Hospital actually constituted the original AIDS network in this community. The Human Resources Health Center, which is a 150-bed superior rated county owned and operated skilled nursing facility, pioneered the provision of skilled nursing care to AIDS patients in 1982, when no other nursing home in the nation would accept AIDS victims. This community-based resource allowed the discharge from Jackson Memorial of AIDS patients who qualified for skilled nursing care. Appropriate treatment is provided in our nursing home at one-fourth of Jackson's Hospital Medicaid rate. Initially, Human Resources Health Center responded to the medically needy and indigent segment of this population with the allocation of two beds, using existing resources and staff. As demands grew, and in order to relieve further pressure on Jackson, the bed allocation gradually increased to 4, 6, 8, and currently 12 beds for AIDS patients. These beds operate at 100 percent occupancy, and on any given day there are 12 to 16 patients inappropriately occupying hospital beds at Jackson, waiting for placement to our nursing home.

Human Resources developed a treatment and staff education program that has received national recognition and has been used as a model throughout the country. It is still the only nursing home accepting AIDS patients in Dade County. In order to defray the additional costs of caring for these very sick patients, the Office of Health Services aggressively sought

and was awarded a special Medicaid rate from the state, which is roughly double the usual Medicaid per diem rate. The county recognized the need about two years ago to expand the total AIDS beds capacity to 30 beds, which was in keeping with the AIDS Network plan and the Health Council's plan. To accomplish this goal, the county successfully lobbied for state funds and was awarded 2.3 million dollars in this last legislative session to construct a 30-bed AIDS unit at the Human Resources Health Center. Architectural plans are being developed right now, and the anticipated project completion date is July, 1989. The operating expenses, however, will be included in Dade County's operating budget. In addition to the skilled nursing services at the Health Center, the Department of Human Resources, through its Office of Health Services, provides home health care, including skilled nursing and homemaker services, medical management of diagnosed AIDs cases in our correctional system, social services, counselling, community education, in-service education for health care providers, and advocacy. Medical detoxification, assessment, referral, and residential care to substance abusers with AIDS is provided through our Department's Office of Rehabilitative Services. Emergency financial assistance and independent living facility arrangements are provided through our Office of Emergency Assistance as part of the AIDS Network's residential care component. The county has played an active role in nationwide research which has been funded by the Centers for Disease Control.

The State Department of Health and Rehabilitative Services, State Health Office, and the Dade County Public Health Unit have been conducting a study on the transmission of human immunodeficiency virus among prostitutes in Miami. Over 95 percent of the women enrolled in this study have been recruited from the county's Department of Corrections and Rehabilitation at the Women's Detention Center. Project staff have been supported by Metro-Dade's Office of Health Services, Prison Medical Services Program personnel without any cost to the state. The county's Community Action Agency provides 20 meals a day to AIDS victim in the community through a private sector agency, Cure AIDS Now. We anticipate this to be an ongoing service to AIDS victims. One of the most recent Dade County government mandates was that AIDS education be provided to all 22,000 Dade County employees. The county manager, with full Commission approval and support, formed the Metro-Dade AIDS Task Force. The county's personnel department has coordinated this effort with input from the fire and police departments, labor unions, the county attorney, Affirmative Action, the Department of Human Resources, and Handicapped Services. The Task Force has developed a Train the Trainers Program on AIDS, with the major kick-off the week of November 16th. All county departments will have selected staff trained in AIDS education, who will in turn train all the departmental employees.

In addition, printed brochures on AIDS in English and in Spanish will be provided to 22,000 employees. Posters have been designed and 500 will be distributed to all county locations throughout Dade. Brochures and posters will contain numbers to call for further information on AIDS. Each pay check issued next week will contain the statement, "AIDS - GET THE FACTS." Continued information will be provided through articles in Metro-Dade Today, which is our bi-monthly county publication, through new employee orientation sessions, and through management seminars. Much has been accomplished in the last six years as health care providers and community leaders have struggled to address the AIDS public health epidemic and its impact on Dade County. Dade County has stretched its resources to the limit in attempting to be responsive and will continue to do so. Although current effort is necessarily concentrated on those already affected by the disease, we firmly believe that uncensored and widespread awareness and AIDS education and prevention programs are probably the most cost-effective means of arresting the spread of this disease over the long term. We believe that Metro-Dade County's massive undertaking in AIDS service delivery and education demonstrates a committed county government in the war against AIDS. I thank you for your attention.

CHAIRMAN WATKINS: Thank-you very much, Ms. Kaufman. Questions from the Commissioners?

(No response.)

CHAIRMAN WATKINS: Ms. Kaufman, do you believe that the health services that you can deliver now and even those with your additional facility being improved will match the projected demands against those services? In other words, are you closing, staying the same, or falling behind in terms of your projected needs as the infectious disease begins to explode along the lines that we've all be told?

MS. KAUFMAN: Well, in the initial planning, the consensus in the community was that 30 beds would be sufficient, but that was two to three years ago, and now we realize that if the increase continues that it would be realistic to expect 40 to 50 beds as being necessary. However, we have designed our facility. It is going to be licensed for an additional 30 beds, but these private rooms are designed for double occupancy, so our potential is to accommodate 60 if that becomes necessary.

CHAIRMAN WATKINS: And will that be adequate then in relationship to the prospectus?

MS. KAUFMAN: Some five-year projections that we did that would carry us through 1992 indicated that it's possible to have 50 to 60 people requiring skilled nursing care. We also anticipate, with the other services in the network in this community, Hospice and Visiting Nurse Association home care and so forth, that those resources will also expand to offset some of the patients that now go to our nursing home facility. If there were more resources in the community, they might not even have to go there. DR. PRIMM: Did I understand you to say that you do some funding of Cure AIDS Now for Meals on Wheels; was that my understanding?

MS. KAUFMAN: One of our county departments provides the meals on a daily basis. They are picked up and delivered by Cure AIDS Now to AIDS patients in the community.

DR. PRIMM: I see.

CHAIRMAN WATKINS: Yes, Ms. Gebbie?

MS. GEBBIE: One of the roles local government often plays is to make certain everybody gets into the system. What is your sense of satisfaction or dissatisfaction -- I know this is a hard question -- that all of the interested groups in the county, either concerned about treatment or thinking they have something to offer to the service system have access to one another, to work on issues or to develop better services?

MS. KAUFMAN: I feel good about it having been involved for probably over the last six years. I think the potential is there, and the mechanisms are there, either through the various Health Council committees or through the AIDS Network and through the County Commission, which has hearings and their Health Services Committee, and any group in the community can come forth and does to try to link up with us or with other agencies. Sometimes they don't. I guess in my experience I've seen a diversity in where the majority of the health providers in the community and planners are going or attempting to try to go with AIDS, and perhaps sometimes some groups having different ideas and wanting to go along on their own. We welcome them to join us and to try and come into the plan and expand it, and perhaps there are some smaller agencies or individuals who would rather take a leadership role and have the rest of the network follow along with them. I think this is in the minority and rare. I think it's pretty open between the Health Department and the school system and everybody is meeting with everybody else, it almost seems, continuously.

CHAIRMAN WATKINS: Thank-you very much.

MS. GAULT: Dr. Larry Capp.

MULTI-ETHNIC GROUPS LARRY CAPP, Ph.D., METRO MIAMI ACTION PLAN

DR. CAPP: Good afternoon. I appreciate the opportunity to address the Commission and to represent the Black community in terms of the ethnic issues and our concerns with respect to the AIDS crisis in our country. I am both a clinical psychologist and a public administrator. I serve as Executive Director of the Metro-Miami Action Plan, which is an organization that was developed several years ago to provide a catalytic process through which a broad range of activities would become directed towards the improvement in the quality of life of the Black community here in Dade County. Disparities in quality of life have been identified in several areas. I'm here today to speak about a disparity in the area of health and human services that our community and our organization is very much concerned about. You've heard all sorts of statistics, many of which are very alarming, especially alarming to the Black community. When we read that 37 percent of all AIDS cases in Florida are Black; that nationwide, 25 percent of all AIDS cases are Black; that 57 percent of all women with AIDS are Black; that nationwide 66 percent of all children with AIDS are Black. We learned from Dr. Scott earlier that in Dade County, over 90 percent of the youngsters with AIDS are Black. That represents a major disparity that we are very much concerned about. It leads us to ask a question:

Why does that situation exist, and do the resources that are being used to address this problem address this particular high risk population? My organization and the Black community is extremely concerned that there is a lack of sufficient educational outreach efforts directed towards the Black community. We feel that in the absence of a medical solution, the only effective way to halt the epidemic is to discourage the behaviors which place people at risk. This will require a very special effort targeted at the Black community, and we have to use non-traditional mechanisms because we're dealing with a non-traditional problem. We feel that if you're going to contain AIDS in the Black community, you've got to have information that's targeted to that community in a language that's understandable and in presentations that reach the community that is at high risk. We're talking about a grass roots level health education effort. We're talking about an effort that would involve intensive outreach by sensitive staff persons, and by this we mean a staff that's willing to go out into the community and all of its neighborhoods. Not all of the social gatherings in the Black community are like the weekly sewing club that was talked about in Belle Glade. We need people

who can go into some more difficult situations and provide information about AIDS. My organization searched far and wide to find out what was being done to target the Black community with respect to the AIDS problem. We found two brochures that talk about AIDS in the Black community that has the statistics that I mentioned earlier. These have been the only things that we've found that impact the Black community that show any effort to tailor a campaign for the Black community where so many of these cases are disproportionately found. We think that's inadequate. We think the resources are not meeting the need in terms of health education in the Black community, and it's clearly evident. We are not finding that agencies are spending 66 percent of their budget on health education in the Black community, even though 66 percent of the children with AIDS are Black. We don't find them spending 57 percent of their budgets to reach Black women, even though 57 percent of the women with AIDS are black. We feel that we need to have more dollars directed in this direction. You have to reach those persons who either cannot or will not even read these brochures, if these brochures are located in places where they happen to congregate and gather. These come from downtown in my office, and not a lot of the people that we need to reach visit downtown offices on a regular basis. We need individuals and organizations who have credibility in the Black community, who have the courage to go out into the pool halls, into the street corners, to reach the prostitutes, to reach the IV drug abusers, the kinds of people who don't read pamphlets, the kinds of people who don't come to workshops, the kinds of people who don't read newspapers, the kinds of people who don't have access to television, and when they do have television they don't watch the kinds of documentaries that speak to this issue and this problem.

A very special effort is needed, and we realize this is a difficult task. It's a task that cannot be accomplished through volunteers. It's a task that you can't rely upon the churches to accomplish. It's a task that's going to require some sophistication and some skill, although not necessarily four-year college degrees in order to accomplish the goal. You're dealing with an issue that touches to the very intimate parts of human life when you speak about sexuality, but it's one that's very important, and we need to overlook some of the niceties and begin to deal with the issue in a very, very frank and a very direct fashion. We need to look at the psychological barriers that prevent from acquiring the necessary information, that cause people to deny and avoid access to the information. We've learned from the anti-smoking campaigns that just providing factual information alone is not enough. It takes more than just that. It takes special efforts, and we're dealing with a life-threatening situation here, and we need to treat it as such. We need to direct the dollars to the community that is at risk. The Black community feels that we are being neglected in terms of health education, and we need people who can come out and

communicate to the folks at the grass roots level who do not have access to the conventional kinds of mechanisms. In the interest of time, I'm going to stop there. We are also concerned with the housing issue and the availability of housing for AIDS patients as a second major concern of ours. Thank-you.

CHAIRMAN WATKINS: Questions from the Commissioners?

DR. PRIMM: I would like to ask you how would you go about reaching that segment of the population in the Black community that you referred to that cannot be reached by conventional methods, in the pool halls, in the bars, et cetera, where drops on the corner might be for intravenous drug users; how do you propose that? You also had in your handout an idea about funding of houses, I would imagine hospices that are culturally oriented. Do you have places here that would be receptive of the formation of such houses in the minority neighborhood, in the Black neighborhood?

DR. CAPP: I think so, but let me answer your first question initially. There are organizations in the Black community, they are Black private non-profits community-based groups that have a great deal of credibility, that have delinquency units that they call street workers who go out and work with the dropouts under the trees and on the street corners. These kinds of organizations have the ability to employ individuals who may merely be high school graduates, but have the ability to relate to these people on the street. They represent organizations that have credibility and are respected. When they go into these non-traditional social environments, if it's a pool hall, if it's a bar, they will have the ability to feel comfortable, which is going to allow them to relate and provide information to individuals who otherwise would not receive that information. It takes a special kind of person. Often times, we're talking about having Black people go into these communities, and not all Black people will go into some of the places I'm talking about, not all Black social workers and not all Black psychologists will go into some of these places, but there are people who will, and people who do, and who will address these needs and concerns. In terms of the housing issue, my organization feels that we need to develop funding so that families can provide care to AIDS victims in their homes. If it's the breadwinner who develops the disease, then obviously the income into that family and the kinds of financial supports that they've had in place are not going to be there.

Rather than attempting to build a hospice on every corner, we need to look at trying to help those families that want to maintain that person at home to do that for as long as humanly possible. There are no programs, other than the traditional welfare programs at this point, that will allow them to do that. I think in responding to this special need, we need

to look at that, and not always look at building a new bed outside of the home in order to deal with this problem because that's much, much more expensive.

CHAIRMAN WATKINS: We noticed, Dr. Capp, during going through the Health Crisis Network, they were still building up their staff and we did not see Black representation there on the staff, and Dr. Primm picked this up as we went through. I just wonder if that is an obstacle for you not to have in the Health Crisis Network itself representation on the staff from the Black community.

DR. CAPP: That's definitely a problem, and it's definitely a concern of our organization. We feel that you need to have that broad based sensitivity, especially when the statistics and the numbers tell us that you have such a huge problem in the Black community.

CHAIRMAN WATKINS: It wasn't that their intent was not to, don't misunderstand me, but we had the same problem you have, the percentages are high and it would seem that there would be heavy focus on having Black representation there early on. I hope that there's going to be some mechanism to be able to help that situation improve in the very near time frame, at least this was a general observation we had.

DR. CAPP: We certainly hope so. At my organization, we have a Health and Human Services Action Committee, and within that committee we have a sub-committee on AIDS. We're going to be sponsoring our own workshop in order to bring in the churches and volunteers and the fraternal organizations to see what they can do. We know there is a limit to what any voluntary group can do, and certainly there's a role for government, there's a role for the community-based organizations, and we have to put some dollars behind it if we're going to have the maximum impact. We share that concern, and we're not just complaining about it; we're doing something about it. We want to join hands with all the local organizations and pull them together in a coalition, and we will join their coalitions in order to address this problem.

CHAIRMAN WATKINS: Dr. Capp, we're going to have to terminate because we're not going to make our aircraft, and we appreciate very much your candid thoughts and your piece of paper that we'll take with us and take under advisement with our Commission.

DR. CAPP: Thank-you.

CHAIRMAN WATKINS: If there are no objections from the Commission members, I would like to make a closing statement, unless you have any other statements, and adjourn the meeting. Any other comments from the members?

(No response.)

CHAIRMAN WATKINS: I think I can speak for the whole Commission that we've had a productive three days in South Florida. We've heard from literally hundreds of people, most of whom live with the AIDS crisis on a day by day basis. We've been to Palm Beach County, and Broward County, and now Dade County, and we've been very impressed with the leadership, with the sense of urgency, and with the incredible dedication of the many people who work in this field. The visit has been very helpful to the Commission, both as we focus on our thoughts for our interim report to the President on December 7th, and as we set up our remaining schedule for the next few months. In particular, we've heard witnesses comment over and over again expressing their great concerns on care issues, hospice and home health and the like. In addition, we've also been told time and time again about the concerns at grass roots levels, about drug development, and why has it been so slow. So we look forward to continuing our dialogue with everyone we've met here in South Florida in the last few days, and we thank all of you very much as we proceed in meeting our own very awesome mandate to the President. Thank-you very much.

(Applause.)

CHAIRMAN WATKINS: This meeting is adjourned until 24 November.

(Whereupon, the hearing was adjourned at 4:30 o'clock, p.m.)

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APPENDIX

TESTIMONY

Task Force on AIDS

John J. Witte, M.D., M.P.H.
Acting Assistant Health Officer for Disease Control

FLORIDA DEPARTMENT OF HEALTH AND REHABILITATIVE SERVICES

November 12, 1987

CURRENT AND PROJECTED CASES

Florida has consistently ranked third in the nation in the cumulative number of reported cases of acquired immune deficiency syndrome (AIDS). The United States cumulative case count by October 12, 1987 was almost 43,000. Florida cumulative cases of the disease number 2,919 (as of October 1, 1987) or approximately 7% of the nationwide count.

The Department of Health and Rehabilitative Services has maintained good surveillance of the epidemic in Florida since 1981. Projections made by the State Health Office in February 1987, show that the Florida cumulative case count will continue to double approximately every twelve to fifteen months. Florida expects as many as 4,000 cumulative cases of AIDS by 1988, 8,000 cases by 1989, 16,000 cases by 1990, and 32,000 cumulative cases of the disease by 1991.

These grim projections cannot be averted. The virus that causes AIDS is slow to claim its host. Persons infected with the human immunodeficiency virus (HIV) may show no signs or symptoms of illness for 5-7 years on the average, and up to 10 years or more in some cases. Consequently, most persons in Florida and the nation who will be diagnosed with AIDS between now and 1991 are already infected with the virus.

Persons diagnosed with AIDS represent only a fraction of the problems associated with the epidemic. The Centers for Disease Control (CDC) in Atlanta estimates that there are from 2 to 10 persons who suffer from a lesser illness, AIDS-related complex (ARC), for every diagnosed case of full-blown AIDS. Florida may have as many as 29,000 persons currently suffering from ARC.

The Centers for Disease Control (CDC) also estimates that an even larger number of persons are infected with the virus that causes AIDS and currently show no signs or symptoms of illness. CDC estimates that 50 human immunodeficiency virus infections exist for each reported

case of AIDS. In Florida, that translates to more than 145,000 persons infected as of today.

Seventy-five percent of the Florida cases have been reported from the southeastern counties of Palm Beach, Broward, Dade, and Monroe. Nevertheless, AIDS is a statewide problem. Forty-seven (70%) of Florida's 67 counties have reported one or more cases of AIDS. There is no reason to think that any county will be spared a case of AIDS in the next few years. As with all other sexually transmissible diseases (STD), the occurrence is widespread because of the population mobility and specific personal behaviors. Moreover, the AIDS virus is efficiently spread through intravenous drug abuse, unlike other STDs.

National data show that the AIDS epidemic has disproportionately affected minorities. Twenty-five (25) percent of the cases reported nationally are black persons and 14% are hispanic persons. In Florida, the corresponding percentages are 38% black and 12% hispanic.

Florida differs in other significant ways from the national averages. Four (4) percent of the nationwide cases have been reported as heterosexual persons. Fifteen (15) percent of the reported cases in Florida are heterosexual persons. Ten (10) percent of Florida's heterosexual cases are among persons who have immigrated to the state from Central Africa or the Caribbean where heterosexual transmission of the virus is thought to play a major role in the spread of the disease.

Other numbers are also grim! Florida has reported the third greatest cumulative number of cases of AIDS among children. Like other states, 83% of the children with AIDS in Florida were born to mothers who were infected with the human immunodeficiency virus.

In summary, AIDS cases in Florida have been reported from a broad cross-section of the population. Homosexual and bisexual males, intravenous drug users, heterosexuals, and children of many race and ethnic groups are casualties of the epidemic in Florida.

FILE COPY

TESTIMONY BEFORE THE PRESIDENTIAL
COMMISSION ON HIV EPIDEMIC
NOVEMBER 12, 1987

Linda S. Quick
Executive Director
Health Council of South Florida

The Health Council of South Florida, Inc. is a voluntary, not-for-profit corporation serving Dade and Monroe Counties in Florida. The Councils' purpose is to provide effective health planning for the area and to promote development of health services, manpower, and facilities which meet identified health needs in a cost effective manner. Our Agency has provided this kind of leadership in South Florida since 1968. In October 1985, the Health Council of South Florida began a massive and concentrated effort to assist Florida in their efforts to address the impact of AIDS.

Initially, the Health Council Board of Directors authorized the establishment of an Ad Hoc Committee on AIDS to develop a plan. The Committee, with 35 members, was an effort to assure representation and participation from affected parties, political and social leadership, and those segments of the health care community actively involved in South Florida AIDS efforts. Nearly 50 people were put on the interested party list, receiving notices of meetings and offered an opportunity to participate. The first three meetings were spent on orientation, education and issue clarification. The plan chapters and content areas were selected. The Ad Hoc Committee members and interested parties were asked to serve on four work groups identified earlier by the full Ad Hoc Committee and representing chapters in the plan: public education and information; care and treatment; legal and ethical dilemmas; research and prevention. Discussions were lively and emotions often high as the struggle for

priorities, direction and exactness of expression took place at workgroup meetings. Surely, completing and preparing the written Plan for full Committee and ultimate Council adoption belies the effort and emotional energy committed to the planning process.

The planning process and the Plan that resulted in April of 1986 was not complete. AIDS is a dynamic disease and does not lend itself to absolutes. Even as the 150 people engaged in the plan development process asked questions, studied the issues and available data - new reports were being published, new treatments being pursued, and unfortunately new cases were being diagnosed. In the year and a half that followed many positive things have also happened and the Health Council of South Florida is proud to continue being an active participant in these plan "implementation" processes as well.

Most importantly and in a large part as a result of congressional actions, the Care and Treatment portion of the Plan is currently being implemented. In Dade County, this effort is characterized by the South Florida AIDS Network - a federation of service providers centered and administered through the University of Miami Medical School/Jackson Memorial Hospital, with participation from Visiting Nurses Association, Hospice, Health Crisis Network, Dade County's Human Resources Health Center (nursing home), Florida Department of Health and Rehabilitative Service and an ever-widening circle of care givers for persons with AIDS, persons with AIDS related conditions and those already having tested positive for HIV Antibodies.

This Network operates with a complex combination of federal, state and

private money. Similar, but smaller treatment networks have been development in Broward and Monroe Counties - as well as in West Palm Beach. The goal, of course, is to link all of southeast Florida with a sophisticated and accessible care and treatment system that is in position to provide humane and appropriate services regardless of the stage of infection or ability to pay.

Still missing, but services for which new funds and programs are being developed, are: residential facilities for adults and children, specialized care of addicts (IV and other drugs) with AIDS, programs addressing the interface of mental health and AIDS care, and efforts to reach minority group members at risk for AIDS.

As part of this implementation process the South Florida AIDS Advisory Committee was formed and funded in part by the Robert Wood Johnson Foundation and the Health Resources and Services Administration of the US Government.

The Committee was organized by the Health Council of South Florida to effectively mobilize and coordinate the whole community to address and resolve the non-treatment issues surrounding AIDS, as well as to provide advice and coordinate assistance to Dade, Broward and Monroe Counties care and treatment networks. There are currently 32 members on the committee from the tri-county area that has a population of approximately 3 million.

As part of its advisory function the Committee is very active and has itself

adopted the following goals.

- Continue the community dialogue around AIDS begun by the Ad Hoc committee during the planning process;

- Undertake additional AIDS related plans and projects that may be required in the future, including annual review and update of the current plan;

- Encourage and nurture Plan related implementation efforts taken by other community agencies and organizations;

- Fulfill a leadership role in continuing efforts toward a community-wide approach to AIDS information and education;

- Serve as the community-wide advisory board to the Public Health Trust and its subcontracted agencies as required for receipt of foundation funds;

- Provide requested advise and information regarding AIDS and related issues to all South Florida residents; and

- Seek and expand sources of funding for AIDS related projects.

To this end, as planning is an ongoing process the committee will continue to update as well as add additional chapters to the current plan within the next couple of years. This past month, a policy on HIV Testing was adopted and presented to the Florida legislature for its deliberations. One member

of the committee, Citicorp Savings of Florida, has even begun what we hope will be a common practice of private industry funding with a generous $10,000 donation to the Health Crisis Network. And with a $100,000 appropriation from Florida's legislature, the SFAAC has just begun conducting an objective data gathering and analysis effort to help the State evaluate the use of funds earmarked for SE Florida. The Committee is also talking about the best way to include Palm Beach County with the development of an even broader regional AIDS Plan for South Florida. Part of this effort has taken place through an informal Consortium for AIDS Related Education Services (CARES) and its efforts to implement the public information and education chapter of the original Plan. And in the past 9 months, the Statewide Health Council (a consortium of Florida's eleven local health planning councils like HCSF) has published two extensive policy reports addressing AIDS in the public schools, AIDS and insurance, and related discrimination. Dr. Terrence Collins, Chairman of the SHC's work group is on your agenda later today.

Finally, the opportunity to address distinguished members of the President's Commission would be wasted if we did not point out the Health Council of South Florida's concern over State and Federal legislation. This year's policy statement of the South Florida AIDS Advisory Committee is attached. As you listen to my friends and colleagues today you will come to understand that South Florida is, thanks to a sound plan, prepared and progressing, if not perfect. We are united, if not always unified, in our efforts to support research, disseminate accurate and honest education, and assure humane treatment in the work place and in the health care system. But as I told Senator Chiles in August, "AIDS kills, and, because people are dying, the country is frightened. We must not let our fear be of other people. We must concentrate the country's anger on the virus - not its carriers. We must

understand that this public health dilemma is a public policy dilemma as well." And, you - our President's own Specially selected Leaders must lead! Florida's own leadership will walk and work with you, but the nation needs real leadership. No group I've addressed in the past two years has a clearer opportunity or obligation to provide it. Thank you.

FILE COPY

FLORIDA AIDS PROGRAM

Summary

Cooperative Agreements for Federal Funds

Item	Funding Cycle	Amount
Surveillance	12-01-86 to 11-31-87	$ 338,187
AIDS Prevention Activities	05-01-87 to 04-30-88	$1,552,344
AIDS Prevention Activities	09-29-87 to 04-30-88	$1,950,704
AIDS Prevention Activities (Belle Glade)	05-01-87 to 04-30-88	$ 61,502
HIV Study in Children	09-28-87 to 09-27-88	$ 114,937
	TOTAL:	$4,017,674

Prepared by,

Joyner Sims, Ph.D.
AIDS Program Administrator
Disease Control
November 9, 1987

ORIGINAL

AIDS AND HEALTH MANPOWER NEEDS:

By:

Arthur M. Fournier, M.D.

A generation of physicians were trained and matured in an atmosphere of complacency: Beginning with the discovery of penicillin, and spurred by the development of antituberculous medications and various vaccines, we operated under the assumption that the major infections diseases could be either cured or eliminated through vaccination programs. Although we all hope that a cure or vaccine for HIV infection is just around the corner, the epidemic has shocked us back to the historical mainstream; the physician can diagnose, counsel, and comfort patients and their families, but seldom cure.

The AIDS epidemic has challenged the profession to deal with previously tolerated inadequacies within our education and delivery system in the following areas:

1. Continuing medical education concerning burgeoning knowledge and new technologies.
2. The maldistribution of physicians, both with regard to geography and specialty.
3. Medical ethics.
4. Medical economics.

Since the epidemic first surfaced in 1979, we have witnessed the delineation of clinical syndromes associated with immunodeficiency, worked through the basic immunology, conceptualized risk behaviors, identified the virus,

developed screening tests and partially effective treatments. The currently existant systems for continuing education of practicing physicians (hourly didactic sessions at monthly staff meetings or tax-deductible courses at desirable locations) are inadequate distribution vehicles to deal with this information explosion. Recently developed programs at HRSA and NIMH to involve academic medicine in the continuing education of community health providers should be encouraged and expanded.

There are several reasons why primary care physicians should be encouraged to be the principal longitudinal providers of care to HIV infected individuals:

1. Patients with AIDS represent a minority of those exposed to HIV infection. Those in need of screening and counselling are usually assymptomatic and should be dealt with in an ambulatory setting.
2. If the epidemic meets current projections the resources of tertiary centers will soon be overwhelmed.
3 The epidemic is spreading from its port of entry epicenters into every region of the country. Tertiary referral resources may not be available to all infected or at-risk patients. *Home to die.
4. Tertiary care is by nature discontinuous, costly, and frequently more impersonal than

that provided by a primary care physician.

5 Modern primary care physicians receive special training in interviewing techniques, such as how to take a sexual history, interpretion of screening tests and counselling. These skills are especially germaine for the care of HIV infected patients.

6. The full-blown illness is multisystem, and patient management frequently require a broard base of general knowledges that transcends subspecialty concerns.

An optimun health care system for dealing with the AIDS epidemic would therefore foster already existant programs which were designed to redress the maldistribution of physicians in terms of both specialty choice and geographic location, and encourage primary care trainees to become knowledgeable about AIDS related matters. The relative abscence of well-trained primary care physicians, knowledgeable about AIDS, willing to serve in our inner cities, and care for people exhibiting risk behavior is the most glaring deficiency of our current system. Federal program such as Training Grants in General Internal Medicine, Pediatrics and Family Medicine, the Area Health Education Center program, and the National Health Service Corps, designed to address the maldistribution problem should be given the full support of the President and the Congress, and be encouraged to develop the training of

primary care physicians in AIDS related matters.

A related issue is the potential impact of the AIDS epidemic on career choices. Having to deal with AIDS patients is already seen as a negative factor for choosing training in Internal Medicine and its procedure-oriented specialties such as Gastroenterology and Pulmonology and Surgery, particualary at training program located in cities with large numbers of AIDS patients. Only a combination of accurate information concerning the relative risks of infection, effective risk reduction policies concernig exposure to blood and body fluids, and an appeal to our professional responsibilities to our patients can reverse this alarming trend.

The epidemic has also brought into focus the need for ethical training among physicians. Physicians are only human. We are not immune from irrational fear of contagion or prejudice against patients who have practiced high risk behavior. A consensus among the profession based on generally recognized ethical principles, concerning such issues as confidentiality, refusal to treat, intensive treatment of terminal illness, equal access to care and judgementalism vs. professional objectivity must be reached and publicly disseminated rapidly.

No lasting impact on the above-mentioned problems will be made unless the issues centering around the economics of HIV infection are also addressed. The cost of the disease is overwhelming. Many of those infected or at risk are

poor, and become the responsibility of public or charitable institutions. Those with resources find them rapidly depleted as the illness robs them of their savings, their jobs, their insurance and their dignity. Current private and public methods of financing are quite variable with regard to eligibility, coverage, definition of "prior condition," and willingness to pay for ambulatory treatment, home care, screening and prevention. Obviously, unless these problems are addressed, economics will continue to negatively effect patient care, medical education, and the willingness of physicians to treat patients with HIV infection.

FILE COPY

PAULA SPARTI, M. D.
DIPLOMATE, AMERICAN BOARD OF FAMILY PRACTICE

2630 S. W. 28TH STREET
COCONUT GROVE, FLORIDA 33133
(305) 858-8487

NOVEMBER 12, 1987

PRESIDENTIAL COMMISSION ON THE HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC

Over the past two years, I've had the privilege of working with a great number of persons with AIDS and ARC. These individuals have displayed incredible courage, and in a very significant way have affected my life. I agreed to come here today and share some of my thoughts and feelings about the AIDS crisis, because many of these special people are no longer with us; and I feel an obligation to speak for them.

I don't wish to discuss the statistics concerning the epidemic, yet I hope you are aware of the magnitude of the problem. Unchecked, this epidemic will stress and rupture every leaky seam in our society. We can take this opportunity to correct some of the inculturated injustices or continue to ignore them.

The following are areas of particular concern to my patients and myself. The first, is upcoming legislation related to mandatory testing in various settings. The word mandatory is frightening because it implies abandoning the principles of informed consent and the protection of individual rights. It is, however, becoming more obvious that this sort of legislation may very well come to pass. I ask that you strongly recommend that such testing

and reporting not be done prior to confidentiality and anti-discrimination laws being on the books and enforceable. I further encourage a recommendation that state legislators confer with state medical association AIDS task force groups, in order to evaluate whether their intended outcome of a bill is likely to be achieved. There is a strong desire on the part of many well intentioned people to do something, yet frequently their recommendations are based on fear and inadequate knowledge. This has a great potential to divert energy and money from areas of desperate need.

Education, access to health care, terminal care facilities and research must be our priorities. I encourage you to meet with the people who work in these areas everyday, to delineate the problems and potential solutions.

Individuals, because of denial, are continuing to expose themselves to this horrible disease. We need to intensify our efforts to break through this defense, and help those individuals not already infected to remain disease free. This is not an easy task and requires a concerted effort on the part of educational and psychological experts. Continued failure to give this crisis the attention it requires, is nothing short of criminal. The Helm's ammendment is further sad evidence that people are not willing to put their personal prejudices aside in order to save lives and our society.

The Surgeon General of the United States has had the courage to support all measures necessary to end this epidemic, including: situationally specific safer sex education, clean needles for IV

drug users that continue to use and abortion counseling for HIV+ women. He has come to these conclusions despite his conservative personal views and I commend him on his objectivity.

The area of access to medical care for persons suffering from this disease is of great concern to me. I see people everyday, who find themselves faced with a terminal illness and no access to care, because they are uninsured and the public health care system is overwhelmed and can't accommodate them. The only humane thing to do in this situation is to decrease the waiting time to receive Medicare benefits to no more than six months, for those individuals who have paid into the system, but will not live long enough to realize their benefits. You may ask, why are AIDS patients any different than other people with a terminal illness? In some ways they are not; my hope is that we can use this nightmare as a catalyst to right some to the wrongs that exist in our society. One of those being that access to health care is based on one's ability to purchase it, as though it were a expendable commodity.

Laws and regulations regarding the exclusion of persons with infectious diseases from terminal care facilities must be changed, to accommodate the large number of people that won't have the benefit of dying at home with loved ones in attendance. We can't continue to allow people to die alone, without any supportive care.

Last but not least, we need to look at the barriers to rapid yet academically sound research of <u>all</u> promising substances; not just substances of particular interest to notable researchers or those with substantial corporate backing. We also need to make possible the acquisition of any substance that is of potential

benefit, to persons that are unlikely to live long enough to await the outcome of ongoing research. You would want nothing less for your loved ones.

I hope that the recommendations you arrive at, are not based on fear and prejudice; but arise instead out of a dedicated effort to understand the problems ahead and formulate solutions based on knowledge and love.

FILE COPY

PRESENTATION TO PRESIDENT'S COMMISSION ON THE HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC, NOVEMBER 12, 1987

Daniel Seckinger, M.D.
Chairman, Florida Medical Association Ad Hoc Committee on AIDS

On behalf of the Florida Medical Association I would like to welcome Members of the President's Commission on The Human Immunodeficiency Virus Epidemic to South Florida and to acquaint you with some of the activities of our Ad Hoc Committee on AIDS. This multidisciplinary body of health professionals is committed to patient care and education regarding AIDS and service to the community in its understanding of AIDS related issues. We serve as a reservoir of expertise to the practicing physician, numerous public sector organizations within Florida and the Florida Legislature. Chairmen of our Standing Committees on Public Health, Corrections, Substance Abuse and School Health are members of our Committee and provide the logical matrix as AIDS considerations are inherent in each. Knowledgeable physicians in oncology, pathology, infectious diseases, internal medicine and family medicine serve as Members as well.

It became apparent that if we were to reach all health professionals and, in turn to receive input from these same professionals in the most effective manner they must be included in Committee structure. Accordingly, representatives of the Florida Dental Association, Florida Osteopathic Association, Florida Nurse's Association, Florida Practitioners of Infection Control and Florida Hospital Association have participated in our activities. Faculty from the University of Florida, University of Miami and University of South Florida are represented.

Physician education is obviously a priority. The Committee is developing a Physician's Office Manual providing specific and comprehensive data on AIDS in its many dimensions for all practicing professionals in Florida.

The safety of the health care worker is another major concern of our Committee. Occasional reports of infection of health care workers involved in care of the HIV Positive patient has alarmed all at risk. Recently published guidelines for universal precautions have been modified when indicated and are available throughout Florida. Interaction of the Medical and Nursing Professions with the Florida Hospital Association provides a convenient forum for monitoring of safety precautions on an ongoing basis.

Input provided to the President's Commission at this meeting by interested citizens, professionals and victims of this dread disease will, in all probability, be assimilated and prioritized. Great good can result from this meeting. If we are to conquer AIDS strong programatic support will be necessary. Efforts, however, cannot be sequestered within the facilities that have provided care to date. If we are to prevent another Arcadia there must be an intensive, broad based educational effort. The lay public must be made aware of medically precise facts about AIDS by professionals within their community to whom they can relate and who understand local factors. Health professionals must also accept the challenge to become more willingly involved in recognition and management of AIDS. Studies to date of physician attitudes regarding AIDS have demonstrated some concern on the part of health professionals to become involved with management of AIDS. In Florida we sense a reversal of this trend. Our Committee is developing two resource manuals to bolster our educational efforts, one oriented to the paramedical community and the other to physicians of our State.

Members of our Committee are providing perspective to Legislative Committees (ATTACHMENT A) and public sector organizations; Health and Rehabilitative Services, Department of Education and Department of Corrections. Several of our members serve in an advisory capacity to these Committees and have figured significantly in recent development of policies regarding AIDS in the public schools of Florida (ATTACHMENT B).

On behalf of the 16,000 Physician Members of the Florida Medical Association I would like to thank the Commission for this opportunity to share with you some of the activities of our Committee. The Florida Medical Association accepts the challenge to commit its resources and energies along with numerous others in the battle against the AIDS pandemic.

PRESENTATION TO FLORIDA HOUSE OF REPRESENTATIVES HEALTH CARE COMMITTEE
AIDS TASK FORCE, SEPTEMBER 4, 1987
BY DANIEL SECKINGER, M.D., CHAIRMAN, FLORIDA MEDICAL ASSOCIATION
AD HOC COMMITTEE ON AIDS

The Florida Medical Association has recently unified all AIDS related activities and formed an Ad Hoc Committee on AIDS. As Chairman of that committee, I appreciate the opportunity to impart some of our progress to you. Since its recognition AIDS has been considered as potentially impacting the citizens of Florida in the areas of Public Health, School Health, Correctional Medical Care and Substance Abuse. Now we recognize the immensity and uniqueness of the health considerations for all citizens of Florida. As one who has practiced medicine in Florida for twenty five years, and who has been involved with multiple aspects of the evolution of AIDS in high prevalence area of South Florida, I look forward to the challenge (attachment 1). Our Committee has the scope of expertise necessary for us to consider the diverse nature of this problem.

Physicians of Florida have recently participated in the deliberations of the American Medical Association in developing a major policy document "Prevention and Control of AIDS". This comprehensive report by involved and knowledgeable authorities will serve as the matrix for our Committee activities as we relate that broad base of knowledge to the needs that we identify in Florida.

You have requested specific response in four areas. I will comment on these areas requested based on our early activities and invite you to draw upon our resources in the future.

1. Physician Manpower Availability: We are fortunate that high prevalence urban areas, especially South Florida have no demonstrable primary care, specialty or subspecialty shortages. Past physican manpower surveys identifying isolated gaps in provider coverage would not appear to be significant regarding AIDS.

2. Physician Concerns Regarding Treatment of AIDS Patients: Two National surveys of physician attitudes relating to treatment of AIDS patients have shown an element of negative bias. A study of 250 physicians in the New York area by Dr. R. Nathan Link of New York University School of Medicine revealed that 25% of physicians in his study would choose not to continue to care for AIDS patients if given a choice; 24% believe it is not unethical to refuse to care for AIDS patients and over one third believe they should be given a choice of whether or not to care for AIDS patients. These attitudes have undoubtedly been reinforced by recent reports of transmission of AIDS virus to several health workers

by direct contact with blood or body fluids.

Our Commitee accepts the challenge to develop educational seminars, programs and workshops to acquaint all Florida physicians with present knowledge regarding safety precautions to prevent transmission of HIV Virus. We must reinforce our collective responsibilities to care for all patients in need. The FMA participates with the AMA in a major CDC grant to train physician speakers on AIDS.

3. Specific Provider Concerns: In addition to the many primary considerations directly related to the care of AIDS and AIDS Related Complex patients our Committee is hopeful that measures be undertaken to identify those individuals who are infected with the HIV Virus and are capable of transmitting the disease to others but who are frequently unaware that they harbor the virus. Of the estimated 1.5 million nationally who are seropositive and asymptomatic it is estimated that 100,000 know of their status. A recently announced program by Governor Cuomo and described in the New York Times of August 5th (attachment 2) will anonymously test 100,000 New York residents to determine their HIV antibody status. We have learned something of the epidemiology of AIDS through blood donor and military personnel screening but the demographics of the community at large are not known. If we relate this to Florida which is one of the higher prevalence areas we can readily grasp the need for appropriate public health measures to identify and educate those who harbor the virus. Several hospitals in South Florida are considering some aspect of screening for high risk target groups at this time.

4. The Physician With AIDS: It is axiomatic that reciprocal logic apply to precautions designed to protect the physician and other health personnel caring for the patient with AIDS. This very important aspect has not been fully examined. The patient has an equal right to know the status of his provider in this regard if direct contact with blood and/or body fluids is envisioned or would be possible. The Florida Medical Association has been in the forefront of impaired physician programs and this is yet another area for consideration.

In closing I would once again like to thank you for the opportunity to acquaint the Health Care Committee with activities recently initiated and to assure you of the Florida Medical Association's total commitment to the prevention, control and treatment of AIDS.

ATTACHMENT B

FLORIDA MEDICAL ASSOCIAITON

Presentation on AIDS

To The

FLORIDA SENATE COMMITTEE ON EDUCATION

By

Daniel L. Seckinger Jr., M.D.
Chairman, FMA Ad Hoc Committee on AIDS

Tallahassee, Florida
November 4, 1987

PRESENTATION ON AIDS TO THE
FLORIDA SENATE COMMITTEE ON EDUCATION
by
Daniel L. Seckinger Jr., M.D.
Chairman, Ad Hoc Committee on AIDS

I. INTRODUCTION

The Florida Medical Association has recently unified all AIDS related activities and formed an Ad Hoc Committee on AIDS. As Chairman of that committee, I appreciate the opportunity to impart some of our progress to you. Since its recognition AIDS has been considered as potentially impacting the citizens of Florida in the areas of Public Health, School Health, Correctional Medical Care and Substance Abuse. Now we recognize the immensity and uniqueness of the health considerations for all citizens of Florida. As one who has practiced medicine in Florida for twenty five years, and who has been involved with multiple aspects of the evolution of AIDS in the high prevalence area of South Florida, I look forward to the challenge. For your information, I have attached a summary of my curriculum vitae which provides an overview of some of my AIDS related activities (Attachment I). I have also recently been appointed by Commissioner Betty Castor, along with Dr. Linda Marraccini, Chairman of the FMA's School Health Advisory Committee, to the Department of Education Advisory Task Force on AIDS.

II. AMA REPORT ON PREVENTION AND CONTROL OF AIDS

Physicians of Florida have recently participated in the deliberations of the American Medical Association in developing a major policy document "Prevention and Control of AIDS". This comprehensive report by involved and knowledgeable authorities will serve as the matrix for our Committee activities as we relate that broad base of knowledge to the needs that we identify in Florida.

The FMA's AIDS Committee thoroughly reviewed the AMA's policy document on the prevention and control of AIDS. Upon advice of our AIDS Committee, the FMA Board of Governors at its October meeting approved the recommendation that the FMA adopt the AMA Policy Recommendations on AIDS as approved by the AMA House of Delegates to serve as general policy guidelines with regard to AIDS in Florida. For your convenience I have attached the AMA's Report on the Prevention and Control of AIDS, with a summary description as it appeared in a July, 1987 issue of the Journal of the American Medical Association (Attachment II).

The introduction to the AMA document as adopted by the FMA states: "Recommendations in this report have as their foundation an overriding concern for judicious balance between the well-being of HIV (human immunodeficiency virus) positive patients and the protection of the public health. These recommendations are based upon the best information and data available at present. The AMA [and parenthetically also the FMA] will continuously monitor and analyze developments in AIDS and update AMA policy and recommendations as dictated by advances in knowledge."

III. FMA RECOMMENDED POLICY ON AIDS AND SCHOOL CHILDREN

The following recommended policy was developed by the FMA Committees on School Health and Public Health, and endorsed by the Ad Hoc Committee on AIDS.

RECOMMENDATIONS CONCERNING IMMUNO-COMPROMISED SCHOOL CHILDREN INCLUDING THOSE WITH ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS) AND AIDS RELATED COMPLEX (ARC)

"The various school systems should address the overall needs of immuno-compromised children, including those with AIDS or ARC (AIDS-Related Complex); those with congenital anomalies of the immune system; those on immuno-suppressive drugs for the therapy of various clinical entities such as collagen-vascular diseases and malignancies, and those children on immuno-suppressive drugs after an organ transplantation.

"The complexity of the clinical status of these children, including an assessment of the emotional impact of the disease on the child, requires an individual decision for each child regarding his/her involvement in the educational system.

"Thus, with each child who falls into one or more of these categories, the child's physician and a physician representing the school system, should jointly review all the aspects of a child's health problems and develop a protocol that emphasizes the particular needs of each child.

"In the event that such physicians are not available, the school system will be represented by the county health officer or his designee; and the child will be represented by a physician appointed by the local county medical society.

"In the event of a disagreement between the involved physicians, the protocol to be followed should emphasize the totality of the health needs of all the children in that particular school, including the child under review.

"The guidelines and recommendations of the Centers for Disease Control (CDC) in regard to all types of actual or potentially infectious diseases, including AIDS or ARC, should be utilized as one component in the decision-making process regarding each individual child.

All education and public health departments, regardless of whether AIDS-infected children are involved, are strongly encouraged to inform parents, children and educators regarding AIDS and its transmission. Such education would greatly assist efforts to provide the best care and education for infected children while minimizing the risk of transmission to others."

These recommendations were submitted to the Commissioner on Education, and largely incorporated in recent policy developed by the Department of Education.

IV. MISSION OF FMA AD HOC COMMITTEE ON AIDS

For your further information, the mission of the FMA's Ad Hoc Committee on AIDS is as follows:

> THE PURPOSE OF THE AD HOC COMMITTEE ON AIDS IS TO RECOMMEND POLICY POSITIONS AND ACTIONS WHICH THE FMA SHOULD UNDERTAKE WITH REGARD TO AIDS BASED UPON THE BEST SCIENTIFIC KNOWLEDGE AND MEDICAL JUDGMENT AVAILABLE. ITS MISSION IN DEVELOPING SUCH POLICY AND ACTION RECOMMENDATIONS IS TO WORK CLOSELY WITH THE GOVERNOR'S TASK FORCE ON AIDS, THE AMA, AND OTHER APPROPRIATE FEDERAL, STATE AND LOCAL AGENCIES AND ORGANIZATIONS IN ORDER TO INCREASE THE PUBLIC'S AWARENESS AND ABILITY TO PREVENT THE INCIDENCE OF AIDS AND ITS SPREAD AMONG THE GENERAL POPULATION. THE FMA AD HOC COMMITTEE ON AIDS ACCORDINGLY WILL BE INVOLVED IN EDUCATING PHYSICIANS AND OTHER HEALTH CARE PROFESSIONALS, AS WELL AS THE GENERAL POPULATION, AND THOSE SEGMENTS OF THE POPULATION AT GREATEST RISK, IN ORDER TO PROTECT AND PROMOTE THE PUBLIC'S HEALTH. AND FURTHER, ITS MISSION IS TO DEVELOP TO THE EXTENT FEASIBLE AGREED UPON POSITIONS WITH RESPECT TO AIDS SO THAT ORGANIZED MEDICINE AND INDIVIDUAL PRACTITIONERS CAN SPEAK IN UNISON AND AUTHORITATIVELY ON THIS SUBJECT.

V. CONCLUSION

Let me conclude by stating that the Florida Medical Association through its Ad Hoc Committee on AIDS is willing and ready to serve as a technical, scientific, and medical resource for the Senate Education Committee, the Florida

Legislature, the Governor, the Commissioner of Education, and other entities of state and local government, and to the people of this great state and its many communities.

The FMA's Ad Hoc Committee on AIDS is composed of physicians who are expert in fields of pathology, infectious diseases, family practice, pediatrics, addictionology, preventive medicine and public health. Representatives of such other associations as the Florida Nurses Association, Florida Dental Association, Florida Osteopathic Medical Association, and the Florida Hospital Association are interacting with us, in fact all the associations I mentioned will be attending a meeting of our Ad Hoc Committee this evening in Tampa to address mutual areas of interest and concern pertaining to the AIDS crisis in Florida. Consequently, we feel we have the expertise and are establishing the necessary linkages to be an excellent and effective resource for addressing the AIDS crisis on behalf of health care providers and the health of the general public. Thank you.

FMA AD HOC COMMITTEE ON AIDS

Daniel L. Seckinger Jr., M.D., Chairman
Director of Laboratories
Cedars Medical Center
Miami
Pathologist

E. Joan Barice, M.D.
Palm Beach Gardens Medical Center
Palm Beach Gardens
Internal Medicine
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Linda A. Marraccini, M.D.
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Family Practice

Gerold L. Schiebler, M.D.
Associate Vice President for
Health Affairs for External Relations
University of Florida
Gainesville
Pediatrician

Joseph E. Dorsey, M.D.
Hollywood
Family Practice

A. Lewis Leo, D.D.S.
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Patrick Hanes, Advisor
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GUESTS

Joseph T. Ostroski, M.D.
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Chairman, Council on Medical Economics
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Bealer T. Rogers, M.D.
Assistant Secretary for Health
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Barbara Russell, R.N.
Mike Nilson, R.N.
Florida Nurses Association
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Richard Eicher, D.O.
Florida Osteopathic Medical Association
Seminole

Mr. Chuck Hinson
Tallahassee
Robert S. Hart, D.D.S.
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Joyner M. Sims, Ph.D.
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Ms. Mae Waters
Health Education Consultant
Department of Education
Tallahassee

Paula Sparti, M.D.
Family Practice
Miami

Michael Johnson, M.D.
Infectious Disease
Gainesville

Mr. Chairman:

I am Reverend Hugh A. Westbrook, President of Hospice Care, Incorporated. We operate comprehensive inpatient and home care hospices here in Miami, as well as Dallas, Ft. Lauderdale, Ft. Worth, and Chicago. We provide case management and direct palliative care services to more terminally ill patients than any other hospice or hospice-type organization in the United States. We regularly care for persons with AIDS in all of our hospices and have since 1984.

Although I appear here today representing our group of hospices, I am the former President of the Florida State Hospice Organization and served as the head of public policy for the National Hospice Organization. I co-chaired the National Hospice Education Project which secured the passage by Congress of Medicare reimbursement for hospice services.

A physician friend of mine is fond of recalling his first day in medical school, when a wise and thoughtful professor asked the class of new, would-be doctors how many of them had come to medical school to learn how to cure people. When all the hands had been enthusiastically raised, the professor assumed a sad face and announced, slowly and deliberately, that "100 percent of your patients are going to die."

Mr. Chairman, while all Americans look to you and this commission to do everything possible to develop public policy leading to the cure of AIDS, I am here today and hospice is here today because, absent that earnestly sought for cure, 100 percent of persons with AIDS are terminally ill. 100 percent are likely to die.

AIDS is a terminal illness and as someone involved in the care of the terminally ill for more than a decade, I believe that one of the reasons we, as a nation, seem at a loss in responding to the AIDS patient, and misunderstand the AIDS patient, and even fear the AIDS patient, isn't just because that patient may be homosexual, or just because the patient may be a drug abuser, but, also because the patient is dying.

Few of us want to confront the notion of dying in ourselves or in our patients. Like Woody Allen said, "I'm not afraid of death. I just don't want to be there when it happens."

Hospice isn't afraid of being there when it happens —— the death or the dying. It is what we do: to comprehensively manage and deliver all of the services, inpatient, outpatient, and at home, that relate to the management of a person's terminal illness —— physically, by directly employing and providing the care of physicians, nurses, therapists, aides, and homemakers specially trained, specially supervised, and specially committed to the dying patient; emotionally, through our staffs of hospice counselors, hospice chaplains, hospice social workers, hospice caseworkers, and, yes, hospice

volunteers; and financially, by taking the financial risk and responsibility to manage all the care the patient and those who share his life need within limited, prospectively-set rates.

When our patients have acute or chronic symptom management problems, we provide hospice inpatient care by rennovating existing hospital wings, creating a homelike environment, and staffing the "Hospice House" with hospice people expert in controlling and preventing pain, managing the hundred noxious symptoms that the terminally ill patient including the person with AIDS may present, and getting as many patients as possible out of institutions as soon as possible.

When our patients have homes, we provide the entire range of hospice care in their homes — medical equipment, drugs and biologicals, supplies, and all of the professional services of the entire hospice team — 24 hours a day, 7 days a week.

When our patients have no homes, we find them homes. Today, we are working with more than 100 long-term care, extended care, and residential care facilities to provide homes to dying persons who have no homes. The contracted facilities provide room and board and a minimal level of other services and hospice provides the nursing, therapy, aides, physicians, drugs, equipment, counseling, social work, chaplaincy, and volunteers that meet the needs caused by the terminal illness.

The philosophy, organization, delivery mechanism, and reimbursement methodology which governs and defines our services is diagnosis-specific case management. All we do is care for terminally ill persons and we provide all the care related to their terminal diagnoses. We are, at once, the case managers and the care providers.

The reason Congress pays, separately, for hospice care is because we are also cost accountable. For a set, pre-determined, all-inclusive price we provide all-inclusive services. In the aggregate, the government's liability for hospice is capped at a stepped-down percentage of what, absent hospice, the government pays for terminal care. The Congressional Budget Office, the Washington Business Group on Health, the Blue Cross and Blue Shield Associations, the Health Care Financing Administration, and the cost accountants and actuaries of an increasing number of the nation's commercial insurors and health maintenance organizations have found that, because we are case managers and care providers and cost accountable, every time a terminally ill person chooses hospice as a comprehensive alternative, the public or private payor saves money.

After three years experience saving money with the Medicare Hospice Benefit, Congress last year passed a Medicaid Hospice Benefit. Senator Lawton Chiles, Chairman of the Senate Budget Committee, calls hospice the politician's dream, a marriage of conscience and convenience.

It seemed to us a natural part of our mission that when AIDS patients were first diagnosed in this country, some of them Haitian refugees here in Miami,

that we should care for them. AIDS patients are dying. We are the experts in caring for the dying and in managing all of the resources compassionately and cost-effectively. So we thought caring for AIDS patients was our job, and we're trying to do that job.

In San Francisco, here in Miami, hopefully in Chicago, and elsewhere in the nation, hospices have played pivitol roles in not only caring for persons with AIDS but in organizing community networks of care.

But I believe that we are as under-utilized in the care of AIDS patients as we are uniquely-prepared to manage that care.

You have heard today and will likely hear more stunning estimates and reports of the costs of care for a person with AIDS from the time of diagnosis to the time of death, a period of time now averaging a scant eight months. Despite the varying reports of varying costs, there is one incontestable refrain: both the costs and the comprehensiveness of AIDS care are tied directly to how the care is managed, and by whom.

In general, it seems there are three ways to manage AIDS care and AIDS costs.

1. Unmanaged care and costs. Perhaps typified by Dallas, where we operate a hospice, unmanaged care is simply the lack of a system.

Patients are left to shift for themselves and so are payors. With the lack of even symbolic coordination, some providers provide some services to some patients, most providers provide few services to few patients, and wasteful duplication exists side-by-side with gross neglect. Each part of the health care system and each provider in each part plans independently, cares inadequately, and costs soar. In Dallas, for example, the diagnosis-to-death costs of AIDS care are roughly estimated to exceed $150,000, or more than $700 per calendar day.

As you know better than I, most American communities provide unmanaged AIDS care.

2. Network care. Perhaps typified by Miami, where we also operate a hospice, the network approach to AIDS care and costs is a brokerage system. One entity or group is selected as the broker of most AIDS care dollars. That broker finds multiples of other agencies, providers, and groups to each provide some slice of the needed care for some slice of the AIDS dollar. The broker is relied upon, more or less, to triage the patients appropriately. More or less, patients may find their way through the catalog of brokerage services. Care is more organized and, perhaps, more accountable than where unmanaged. Costs tend to be the same or, perhaps, less.

The South Florida AIDS Network, the broker agency, is operated by

compassionate and competent people. Yet, there is no clear reported figure on either how many patients are served or how much money is spent. Estimates run from $500 to $1,000 per day.

3. Managed care. It is the application of the hospice concept of comprehensive case management and comprehensive services to the problem of AIDS care and costs. It is the notion of substituting a risk-sharing case manager for either the total lack of coordination or the use of a broker and numerous sub-contractors.

Mr. Chairman, Hospice Care, Inc. believes that the total costs of providing total care for the person with AIDS, from the time of diagnosis to the time of death, can be reduced to less than $70,000 over an average eight month period of treatment, or $280 per day.

By using one unified plan of care and one comprehensive inpatient, outpatient, home care, and residential care provider--with few rather than many subcontracts--the costs of AIDS care can be controlled while the quality and accountability of care can be enhanced, just as hospice has done in the cases of thousands of other patients with life-threatening illnesses.

If one case management provider takes total clinical and financial responsibility for a patient and his disease, then dumping is not an issue any longer.

If one interdisciplinary team, employed and directed not by multiple agencies with multiple agendas but by one entity with one mission, includes the physician, the nurse, the counselor, the therapist, the social worker, the aide, the homemaker, the chaplain, and the volunteer, then care is continuous, coordinated, and predictable. Utilization of services depends on patients' needs, not on agencies' schedules, which may conflict, coincide, or leave gaping holes.

If one organization negotiates the prices, assures the quality, and controls the delivery of medical equipment and supplies, waste is minimized.

If one identifiable overhead price is known and paid, instead of the network approach where dozens of individual agencies create and allocate overhead costs into subcontracts with brokers, then more of the AIDS care dollar goes to the bedside, where it belongs.

If one comprehensive case manager and care provider delivers the home care, administers the budget, operates the inpatient program, calls the ambulance, provides residential care, and, yes, pays for the AZT when appropriate, then the person with AIDS and the payor for AIDS care can fix responsibility and demand accountability.

The care of AIDS patients cannot be done on the cheap, any more than the eventual cure of AIDS.

However, case managed, comprehensive care, of the kind we are proposing and of the kind we are prepared to render, can improve the stewardship of limited resources.

Here in south Florida and in similarly needful communities throughout the nation, Hospice Care, Inc. can apply its proven case management and comprehensive care system to the lifetime care of an AIDS patient for thousands of dollars less than the other two alternatives. In the final two months of an AIDS patient's life, the savings potential steeply increases as the hospice-managed approach is substituted for what otherwise is an increasingly dramatic dependence on hospitalization.

At least, we respectfully urge the Commission to consider a demonstration project to test whether case managed care, using the comprehensive hospice approach, hasn't some comparative value. The result of a similar demonstration project in testing hospice's usefulness in adding value and decreasing costs for other terminal patients was the Medicare Hospice Benefit, which the Congressional Budget Office says saves hundreds of dollars per patient and millions of dollars per year.

We have no hesitancy, confusion, or fear in caring for the person facing a life-limiting disease. We don't have to contort or invent a system to provide total care for the total person and those who share his life.

It is what we have always done and it is what we do every day.

Hospice, as the Miami News said about our organization this week, is not about dying. It's about living life fully to the end. It is about hope, for a cure or even a miracle, to be sure, but hope, as well, for a day without pain, a place to call home, and a life and death with dignity. Hospice is the realizable hope that costs can be controlled so care is not rationed. Hospice is hope until there is more to hope for.

The AIDS patient and the AIDS payor should hope for no less.

Thank you.

TESTIMONY

Patrick Haney

I'm a person with AIDS, diagnosed with ARC in June, 1984 and AIDS in September. 1987 Speaking with you is my attempt to make the most of a bad situation, and because I believe I may not have much longer to live. The public believes AIDS is a problem affecting someone else - fringe groups such as gay men, Haitians, IV drug abusers. But the public is wrong. HIV infection directly affects several million in the U.S. - indirectly it affects us all because of its impact on medical care and cost, social services, loss of productivity, loss of incredibly sensitive, creative geniuses. It affects us all. We are your sons and daughters, mothers and fathers, brothers and sisters, neighbors, co-workers, fellow students and friends. We are all one.

What is the real issue here? Between the lines of all the statistics, budgets, media hype, and talk is the real issue - human pain, suffering and death. This is not a Stephen King novel; it's not a game; for those of us HIV-infected it's 24 hours a day, 7 days a week. We can't leave our interest in AIDS at the office when we go home at night. The daily struggle of living with AIDS has to do with simply staying alive and taking each day as it comes, wondering "how many days do I have?"

There's another epidemic along with AIDS - an epidemic of AFR-AIDS. The hysteria of AFRAIDS is most clearly encapsulated in a cartoon appearing several months back. In it a man is standing in front of his employer's desk. His employer says, "Wilson, I understand your sister met a cab driver who has a cousin who knows someone with AIDS." Wilson says, "That's right." The boss says, "You're fired." This kind of hysteria continues to abound with AIDS, and the unfounded fears and panic are leading to incredibly reactionary responses which are getting worse. Violence against gays has sharply increased. Oppressive laws infringing on the most fundamental human rights are being proposed and passed, and repressive social controls such as quarantine of all PWAs and the branding of PWAs' skin are being cried for, often with no basis in medical or scientific fact. How truly sad since the panic and fear are largely groundless and can be combatted through aggressive, dedicated education efforts.

We have an epidemic of fear, hatred, intolerance, and discrimination that has gone far beyond the boundaries of medicine. Many parents, judges, legislators, educators, the general public, and even some medical professionals refuse to hear, much less believe, what the majority of the physicians and researchers are telling us. AIDS is a political, social and moral issue far more than a medical one - and those of us who are HIV-infected continue to die, often in deplorable conditions, abandoned and alone.

Like no other illness since the advent of modern medicine, AIDS carries with it stigma, shame, and a pointed finger of blame. We're seen as immoral, guilty, and at fault for being sick. We're hated, hounded, and discriminated against.

Many believe AIDS is a punishment from God. Is diabetes God's punishment for sugar eaters, or hunger and starvation His punishment of the poor? Do we blame Legionnaires for Legionnaire's Disease; children for mumps and measles; or old people for Alzheimer's Disease and death? It's nonsense in these other contexts; it's equally absurd with AIDS. As someone else once said, "if AIDS is God's punishment against gay men, lesbians must be the chosen people." Blaming PWAs is cruel, irrational, and counter-productive. Headlines such as "Even the Innocent get AIDS" underscore this pervasive perception about AIDS. It's as if it's OK to get AIDS one way, but another way, and it is somehow suddenly our fault - as if we're something less than human and undeserving of a dedicated, compassionate response to help. How isolated from society I have sometimes felt - how abandoned, alienated, and alone. The sense of urgency I feel about AIDS reminds me of the cartoon my friend John had on his kitchen wall. Two vultures are sitting on a fence and one says to the other "Patience my ass, I'm gonna kill something."

We need your help now - Americans are caring and generous people, but fear about AIDS and hatred of homosexuals has blunted this historic compassion. A massive campaign to educate the American public is vital. We need to wage a war with the goal being acceptance of all people and recognition of our common humanity. We need this country's compassion, patience, understanding, advocacy, and research grant funding authorizations. AND we need the basics of food, shelter, medical care, and other support services. For God's sake, we don't have time to wait any longer. Please convince the President, Congress, and the American public that we have no more time to waste.

All we want is the chance to live. Is that so much to ask?

LEARNING TO LIVE WITH AIDS
by Patrick Haney

I was diagnosed with ARC (AIDS-Related Complex) in June, 1984, (although I believe I was sick a lot longer), and with AIDS in September, 1987. Surviving and thriving has not always been easy. In sharing with you some of those things that have helped me, I hope to provide you with a sense of hope and possibility. Your life does not have to end just because you're diagnosed. You must believe this, because it's true. Many of us have lived with ARC and AIDS 2 years, 3 years, 4 years and longer. Giving up because you think there's no chance makes no sense. If you don't believe there's any hope, then talk with others who are surviving. We're living proof. That's one reason support groups are so important: to see other PWAs (Persons With AIDS) who are learning to cope, and often live very happily.

Getting diagnosed can be very frustrating and emotionally overwhelming. DON'T DO IT ALONE. If you know you are being tested to see if you are infected with the AIDS virus (Human Immunodeficiency Virus - HIV), or to determine if you have AIDS or ARC, tell someone you know who will be supportive. Let that person know you need help and support. It may be your lover, spouse, parent, other family member, friend or pastor. If you're not sure how this person will respond, or if you believe you have no one who will be supportive and accepting, call the PWA Coalition (582-6343), MCC Church (655-9228), A Friend Indeed (964-1362), or Comprehensive AIDS Program - CAP (582-4357). There are many people who are willing to be there for you and with you, but you may have to reach out to let us know. **A word of caution: you should be discrete about whom you tell you're AIDS-infected. There are very real problems that can be caused by telling someone who won't be accepting.

While we're on the medical part, there are a couple of things doctors may tell you that are bullshit:

1) "There's nothing we can do." This is completely false, and later I'll share with you many options you have to deal with your infection.

2) "You have only N months to live (18, 24, or whatever they may say)." NO ONE can predict how long anyone will live. It's impossible. There are plenty of exceptions to their statistics. Would you rather be a dead statistic or a live exception? The choice may be up to you, not the doctor. Don't buy into this bullshit.

Life A.D. (After Diagnosis) can have its ups as well as downs. It's important for you to remember a few things, though. First, you do belong; you don't have to deal with any of this alone. There are scads of people - professionals, non-professionals, PWAs and uninfected people who love you and want to help you. Don't try to do this by yourself. If you have a good support system of family and friends - great. If you don't, let us know, because you really do have support. You have our support anytime, any way.

Second, you have absolutely nothing to be ashamed about. IT'S NOT YOUR FAULT YOU ARE INFECTED. Do you blame Legionnaires for Legionnaires' Disease; children for measles, mumps, or chicken pox; old people for Alzheimer's disease or death? No, you don't because it's absurd and makes no sense. AIDS is caused by a virus, not behavior or identity. Don't believe any differently.

Third, don't threaten your health by not getting appropriate, reasonable, and professional medical care. I know it's sometimes scary, uncomfortable, difficult to understand, and expensive. If you can't afford private help, there are good AIDS Clinics in Palm Beach County with dedicated and compassionate staff people. If there's something you don't understand, ASK. If your doctor won't answer any and all of your questions patiently, cooperatively, and in a manner you can understand, you need a new doctor. Call CAP (582-4357 or 996-7059), the Coalition (582-6343), or the Health Department (820-3000) for help.

Fourth, focus on the positive things in your life and what you do have to be grateful for. This may be hard to do, but think about it for a minute. No matter how bad things may be, they can always be worse. That's not denying things are bad - but it is saying "OK, what can I do to make the most of a bad situation?" When Bad Things Happen to Good People by Harold Kushner was very helpful to me in this regard.

I promised earlier to share with you many of the things you can do to help yourself. This is important because it gives us a sense of power and control. We need to be able to take charge of our lives and our illness. Many of these activities can make a big difference in the quality of our lives. They include: meditation; holistic medicine; acupuncture; massage therapy; creative visualizations; affirmations; nutrition; emotional support; coping skills training; individual and group therapy; anxiety and stress reduction; relaxation exercises; experimental drug treatments; alternative therapies such as DNCB, AL721 and DTC; getting rid of negative feelings; learning to forgive; learning to love yourself; and not buying into the victim mindset. If you want to know more about any of these possible activities, contact the PWA Coalition (582-6343) or CAP (582-4357). You can also read the books I've listed at the end of the article.

Finally, I'd like to share with you some of the positive opportunities AIDS has provided me. Because of my HIV infection, I've had the opportunity to learn to accept my limitations, to learn to cope by getting in touch with my strengths, and to learn to face death with some acceptance. I've experienced more clarity of purpose, restructured my priorities, learned to live one day at a time, and learned to focus on what's good in my life here and now. It hasn't been easy, but I've had a lot of love, support and help. So can you. Don't give up. It doesn't have to be as bad as you may think.

Suggested reading list:

Feeling Good by David Burns
Getting Well Again by Simonton and Simonton
Love, Medicine, and Miracles by Bernie Siegel
Surviving and Thriving with AIDS edited by Michael Callen
(can be obtained from the PWA Coalition)
When Someone You Love Has AIDS by Betty Moffatt
You Can Heal Your Life by Louise Hay
When Bad Things Happen to Good People by Harold Kushner

Summary of recommendations presented by Jim Merriam before the Presidential Commission on AIDS meeting in Miami, Florida November 12, 1987.

I. The commission should state that there is a problem and call for a unified, compassionate response.

II. PWA (People With AIDs) involvement
- A) In future hearings
- B) As volunteers on the commission staff
- C) As paid staff members

III. Education
- A)Government subsidy of self-care manuals for PWAs
- B)Direct the Library of Congress to make self-care manuals for blind PWAs available on tape
- C)Increase quantity available of AIDS brochures
- D)Update video materials available through the Public Health Service
- E)Provide for federal underwriting of training for AIDS researchers, doctors, nurses and other care providers. Especially important for rural areas.

IV. Paying for AIDS
- A)Waive the 2-year wait for Medicare
- B)Provide more funds for research and testing of anti-AIDS drugs
- C)Provide more funds for research and testing of drugs used on opportunistic infections
- D)Federa; funding of AIDS treatment for foreigners
- E)Regulation of insurance exclusion and limits on AIDS
- F)Provide a method for PWAs who can not afford screening tests to be seen and evaluated at ATEUs - access to experimental drugs

V) Coordination
- A)Although not a federal problem, the U.S. government may be able to set an example that fosters better cooperation in existing AIDS programs

Jim Merriam is the coordinator of the Florida PWA Coalition. That coalition exchanges information with other PWA coalitions in various parts of Florida and other parts of the nation. Jim Merriam is reachable at 13967 NE 2nd Ave. N. MIami, Fl 33161
Telephone 305-895-0000

FILE COPY

THE PRESIDENTIAL COMMISSION
TESTIMONY BY MICHELE RIGAUD MD MPH
NOVEMBER 12, 1987
TOPIC: HAITIAN POPULATION AND AIDS

The Haitian people will never recover from the stigma imposed on them through their identification as a risk group for HIV infection. Strong national and local policies remain in place because of this ethnic mis-classification. Serious social issues need to be addressed by committees such as the Presidential Commission in order that Educators succeed in providing effective, positive prevention program on AIDS to the Haitian communities.

The testimony being presented today is a call for a change in policies that continue to stigmatize Haitians based on this identification with HIV infection.

It is a call for more positive, productive innovative approach in AIDS information and education for the protection of human, civil, social and ethical rights.

We will begin this testimony by identifying some serious obstacles in reaching the community:

1.- Printed documents highlighting policies which discriminate against Haitians (among other nationals) have caused not only confusion but raised some concerns among the Health care professionals representing this community. Attempts to implement a change have met resistance largely because of these policies.

TOPIC: HAITIAN COMMUNITY AND AIDS

The policies used by American institutions such as Health Organizations and hospitals have been to the detriment of the Haitian patient who is perceived as a potential HIV carrier. Haitian patients are subjected to routine testing for HIV infection solely on the basis of nationality.

2.- Another more crucial issue is indicated by the recommendations and justifications for HIV Mandatory Testing. As of december 1, 1987, regardless of nationality, all immigrants applying for permanent residency will be submitted to mandatory testing under the New INS Amnesty program. However unlike Nicaraqueans, Cubans and other political foreign nationals, the Haitians will be more likely subject to further discrimination given a HIV positive result.

These issues represent a compilation of concerns from the Haitian community nationwide. As a Haitian-American I recognized that irrational discrimination will increase social, political, psychological crisis of critical importance. As a medical professional and an AIDS educator, I am overwhelmed by the Challenge in providing education and counseling to the Haitian people, given the existing insensitive stigmatizing policies.

TOPIC: HAITIAN COMMUNITY AND AIDS

It is imperative to eliminate policies based on irrational discrimination and develop national policies based on scientifc information and medical judgement.

3.- Finally, we believe that once these social and political barriers are surmounted, and given a more suitable, compassionate climate, it will be possible to implement a comprehensive educational program.

A Resolution on behalf of the Haitian Caucus was submitted to Dr. Walter Dowdle of CDC on August 10, 1987. We recommend that these basic guidelines be followed in addressing the needs of the Haitian Population as it relates to this AIDS crisis.

Thank you for your invitation to testify for this victimized population.

TOPIC: HAITIAN COMMUNITY AND AIDS

Attachment : Resolution of the Haitian Caucus

August 10, 1987

Walter R. Dowdle, Ph.D.
Deputy Director (AIDS)
Centers for Disease Control
1600 Clifton Road
Atlanta, Georgia 30333

Dear Dr. Dowdle:

In response to the Centers for Disease Control conference on AIDS in Minority Populations in the United States held on August 8-9 1987, the Haitian Caucus has formulated this resolution:

Whereas there exist a substantial number of Haitians residing in the United States:

Whereas morbidity due to AIDS is estimated to be significantly high within the Haitian population:

Whereas seropositivity to Human Immunodeficiency Virus is estimated to be 6 to 10 percent within the Haitian population:

Whereas current AIDS surveillance indicate increasing numbers of AIDS cases among young Haitian adults:

Whereas Haitians represent a substantial proportion of documented perinatal AIDS cases:

Whereas the Haitian population has demonstrated specific social, biomedical and psychological needs in regards to AIDS:

Whereas there exist a competent pool of professional Haitians who are currently providing services to protect and improve the Health of Haitian people:

Be it resolved that:

Haitian professionals be included in AIDS program development and implementation at the Federal, State, and local levels:

TOPIC: HAITIAN COMMUNITY AND AIDS

Haitian professionals be provided intensive training by the Centers for Disease Control on all issues related to AIDS prevention and control;

Haitian community AIDS service organizations and community agencies be provided financial and technical support to organize an AIDS Information/Education Center at the State, and local levels;

Haitian professionals be actively involved in determining AIDS risk reduction strategies;

Haitian input be sought in determining funding needs and allocation;

Haitian representatives be appointed to the CDC AIDS Office to participate in Health Education / Risk Reduction activities.

The Haitian Caucus appreciates the closing statement by Dr. James Mason emphasizing the need to respond to the AIDS crisis in the minority populations. We thank you for your consideration.
Feel free to contact us for additional information.

HAITIAN CAUCUS

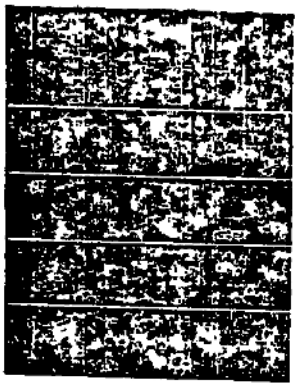
AIDS IN THE AMERICAS

Cases Reported Per Million Population

1986

Country	Cases	Cases Per Million (a)
Bermuda	21	259.3
Bahamas	50	213.7
Barbados	20	78.7
USA (b)	13,599	56.4
Trinidad & Tobago	63	52.3
Haiti	242	35.8
Canada	413	16.1
Dominican Republic	90	14.1
Jamaica	16	6.7
Panama	15	6.7
Costa Rica	11	4.1
Mexico	250	3.1
Brazil	381	2.8
Honduras	10	2.2
Venezuela	37	2.1
Chile	12	1.0
Argentina	27	0.9

(a) Ratios not computed for fewer than 10 cases.
(b) Data for Puerto Rico included in USA.



AIDS and the Safety of the Nation's Blood Supply

American Red Cross

U.S. Public Health Service

More information about AIDS and AIDS-related illnesses can be obtained from—

- Your doctor.
- Your state or local health department.
- The Public Health Service's toll-free hotline: 1-800-342-AIDS.
- Your local AIDS organization. Contact the National AIDS Network for referral 1-202-347-0390.
- Your local chapter of the American Red Cross

You Should Not Donate Blood If—

- You are a man who has had sex with another man, even one time, since 1977.
- You have ever taken illegal drugs by needle.
- You are a native of Haiti or central Africa (including Burundi, Kenya, Rwanda, Tanzania, Uganda, or Zaire) who entered the United States after 1977.
- You have AIDS or one of its signs or symptoms.
- You have ever had a positive test for the AIDS antibody, showing past exposure to the AIDS virus.
- You have hemophilia.
- You are, or have been, the sex partner of any person described above since 1977.
- You are a woman or man who is now, or has been, a prostitute since 1977.
- You have been the heterosexual sex partner of a male or female prostitute within the last six months.

[illegible] cases children have been infected through transfusion of blood or blood products. Now that all blood is screened for the AIDS virus, transfusion and hemophilia treatment pose only a very small risk.

About 5 percent of pediatric cases are still being investigated, but scientists strongly suspect that these children also became infected either before or during birth or through blood transfusion.

[illegible]

Yes. The risk of infection through blood transfusion and hemophilia treatment is now extremely small. So future cases of pediatric AIDS will likely be in infants born to infected mothers. These cases can be prevented if women at risk of infection are educated about the possible risk to their unborn or newborn babies. Women who are infected with the AIDS virus or are at increased risk of infection should avoid becoming pregnant until more is known about transmission to their babies. They should seek counseling and testing for infection with the AIDS virus from their physician or at a clinic. State and local health departments can tell women where they can go for testing. At increased risk of infection are—

- Women who inject illicit drugs.
  Women from Haiti and Central African countries.
  Prostitutes.
- Women who have had sex with—
  - IV drug users.
  - Bisexual men.
  - Men with hemophilia.
  - Men from Haiti and Central Africa.

[illegible]

Not one case of AIDS is known to have been transmitted in a school, day care, or foster care setting. AIDS is not spread through the kind of contact children have with each other, such as touching, hugging, or sharing meals and bathrooms. This is supported by long-term studies of family members of both

LATEST FACTS ABOUT AIDS

AIDS [illegible]

Children

Information for Teachers and School Officials

American Red Cross

U.S. Public Health Service

AIDS, Sex, and You

American Red Cross

U.S. Public Health Service

For More Information...

More information about AIDS and AIDS-related illnesses can be obtained from—

- Your doctor.
- Your state or local health department
- The Public Health Service's toll-free hotline 1-800-342-AIDS.
- Your local chapter of the American Red Cross

If you would like information about drug abuse treatment programs, call the toll-free hotline of the National Institute on Drug Abuse: 1-800-662-HELP

Persons at Increased Risk of Infection by the AIDS Virus

Persons in the following groups are at increased risk of infection by the AIDS virus.

- Homosexual and bisexual men (or men who have had sex with another man since 19--)
- People who inject illegal intravenous drugs or who have done so in the past
- Persons with symptoms of AIDS or AIDS-related illnesses
- Persons from Haiti and Central African countries, where heterosexual transmission is thought to be more common than in the United States
- Male or female prostitutes and their sex partners
- Sex partners of persons infected with the AIDS virus or at increased risk of infection
- Persons with hemophilia who have received clotting factor products
- Infants of high-risk or infected mothers

TOPIC: HAITIAN COMMUNITY AND AIDS

Attachment: Policy on HIV Mandatory Testing for foreign immigrants.

Questions raised on the issue of Mandatory Testing include the following:

1. Will a negative HIV result protect the foreign immigrant from ever becoming infected, particularly if he continues to reside in the United States?

2. What is the difference between a Cuban HIV positive immigrant and a Haitian HIV positive immigrant as it relates to remaining in the United States?

3. How can you keep the HIV positive immigrant from remaining illegally in the United States and probably spreading the infection within their own community group?

4. Returning the HIV infected immigrant to Haiti will increase the infection pool of that country?

5. The INS Amnesty program eligibility criteria requires that the applicant be in the United States prior to January 1982. From our clinical and scientific experience, we know that conversion from HIV infection to full blown AIDS occurs within 5 years,

This time frame demonstrates clearly that the immigrants applying for amnesty are more likely to have been infected in the United States.

TESTIMONY: AIDS AND THE HISPANIC IN SOUTH FLORIDA

PRESENTED BY: DR. MANUEL LAUREANO-VEGA , HEALTH CRISIS NETWORK

PRESTENTED TO: PRESIDENTIAL COMMISSION ON AIDS

DATE: NOVEMBER 12, 1987

PLACE: MAILMAN CENTER, UNIVERSITY OF MIAMI
MIAMI, FLORIDA

I would like to thank the commissioners for permitting me to address the issue of aids among our local Hispanic community. It is important to stress that many of us in this area have dedicated a large amount of our professional and volunteer efforts making sure that our Hispanic community is educated about AIDS prevention as well as stressing hope and its importance to our people, especially those infected with HIV. Without the control that hope gives the individual, we cannot expect to motivate our people to decisive action in facing this crisis.

I would like to tell you some facts about our spanish speaking community in south Florida. We are all very much aware of the over representation of hispanincs as a percentage of total AIDS cases on the national level. In Dade Co. we are 42.7% of the legal population and account for 24% of the total number of AIDS cases. Hispanics are mainly concentrated within the mayor metropolitan areas such is Miami, south Florida has the third largest Hispanic population in the United States following Los Angeles and New York. Unfortunately these areas also coinside with the areas where AIDS has the highest incidence. The Hispanic population of south Florida continues to increase most recently stimulated by the entrance of non-Cubans into our area. The current Dade Co. population of Hispanics is 869,100 people. If we include Broward and Monroe counties, the south Florida Hispanic population raises to 949,000. Ninety-five percent of these individuals were born in another country, and presently are undergoing the process of trans-culturation.

In order for you to get a feel for our Hispanic community there are some things you should know about us as a group. The Hispanic population in this area has and average age of 36.7 years, this is slightly above the anglo(white) average of 35.5 years. We place high values on our families as a social institution which provides stability to the countries status, and on our children. We tend to retain traditional values brought along from our countries of origin.. The Spanish language has a special meaning to us, its on of those thing that allows us to retain our independent identity. In our area, 89% speak spanish

at home, 77% speak spanish on social occasions, and 58% speak spanish regularly at work. The mayority of us would like our children to become fluent in our mother tongue.

As a group of people that God-believing we depend on the Church and the Home to transmit cultural, ethical and moral values. Our elders are respected and held in great esteem throughout our lifetimes. We depend on special media modes to recieve our daily information. These are particularly television, radio, and print. We have worked hard and have provided these modes in the Spanish language to our community. We are generally a very proud people that have come to this country looking for freedom and a way to provide a better life in this country for our future generations.We take great pride in taking care of our people within the context of the family and the community. It is perhaps in times of crisis that we show our better qualities of compassion and caring to our fellow man.

The social distribution of our Hispanic community is quite complex. We have everything from a well established middle, middle-high class , to a constant influx of refugees and migrant workers that are not yet aclimated. Yet we are a very resourceful community where 24% of the heads of household have a college education. It is from here that we expect to tap, in order to help the lower-disadvantaged groups which are also at high risk for HIV infection within our community, but may not have the means at hand, to understand the fertile grounds in which this epidemic grows.

AIDS is visualized by the Hispanic community as a white gay male disease. A disease that could never affect a household where all the males are to be"machos" and all the females are to be "virgins". Therefore my community has great dificulty identifying with AIDS as a potential risk to them of their families. There was in the beginning to discuss AIDS openly within this community because of the sexual taboos that are part of our Hispanic culture. The sexual and drug usage details must be presented in culturally acceptable terms. We have also had some dificulty attempting to make a community used to acute illness

come to understand an illness with long latency and incubation periods. They must be made to understand that risk behavior executed today may be the cause of illness many years down the line. These concepts coupled with the fact that an individual infected and asymptomatic may be infectious to others are factors that fuel the spread of the epidemic in this area.

We loose many lives quickly within our community, because many people infected are not prepared to deal with the health care system as it exist today. Therefore they wait until they cannot stand it, before going to see a physician or enter the public health care system. So we loose many lives that could be extended and productive. There are added dificulties when health care providers do not allow individuals to be open and sincere about their sexual orientation or behaviors without passing judgement. This lack of trust on part of the community does not allow many health providers to be effective in disseminating risk-reduction information.

The reluctance on part of key members of our community as well as some elected officials to be associated with AIDS and its special issues, just serves to reinforce the denial which exist within certain segments of our population. As soon as influencial members of our community stand forward and join forces with existing AIDS education/prevention groups, we will se a shifting in the general attitude.

As one of the few Hispanics involved in AIDS prevention and counseling, I stress that the greatest need of our community is access to accurate information about AIDS. Our educational messages are geared to prevention, we stress NO to sexual promiscuity and NO to drugs. These messages are stated in simple terms and are always made in the Spanish language , by culturally sensitive individuals. Our effort are such as to bring about behavioral change. We try to provide messages that let people know that they are vulnerable. We do not want people within our community to single out and alianate any one subgroup, for anyone of us can be potentially e risk for AIDS, Blacks, Hispanics, and Whites alike.

We have noticed that special forums or community conferences on AIDS do not offer an appropriate way of educating the community. There is a tendency to not be associated with these for obvious reasons. Therefore we have instituted an educational program based on mass media utilization. This provides for adequate programming to be delivered directly into the privacy of the home. The pioneer in this type of educational programming within our community has been an AM station WQBA.
There has to be an opportunity for individuals to inquire about AIDS and risk reduction practices in a confidential and appropriate manner. A permanently manned Spanish hotline must be instituted in this area. Services to this regard are being provided by Health Crisis Network. Even though it is hardly enough to meet the needs of the Hispanic Community in South Florida.

We have encountered a genuine and culturally rooted desire to take care of AIDS patients within the family structure among hispanics; but we have a lack of organized ways of assisting hispanics families to do a better job or caring for their loved ones with AIDS. We must provide the opportunity for the hispanics in this area to participate in Federal, State, and local levels in the development of appropriate strategies to educate and provide services to our own people.

In order to curtail the spread of the epidemic. You must support the establishment of community based agencies that will deal with the AIDS problem directly. Also, try elicit the support of Community Based Organizations that are already established and service minority communities.

FILE COPY

REMARKS TO PRESIDENTIAL COMMISSION ON AIDS

Joseph McQuay

President, Dade Advocates for Rights and Equality

Dan Bradley

DARE Board Member

Stop AIDS apartheid now. Stop it now.

A dentist in Broward last month stopped working on a man's tooth the minute he was told the patient merely worked in a gay bar. The dentist reportedly said he was taking an extended vacation, and would not be able to finish the job.

The Surgeon General says places of employment do not transmit AIDS.

A doctor in Hollywood two weeks ago, when talking to a Person With AIDS, said that he "wouldn't stick his neck out" by treating him.

The Surgeon General thinks some doctors are shirking their ethical responsibilities.

A while ago, a Miami landlord demanded extra money from an estate to tent the house, fumigating for AIDS. The tenant had died of AIDS, spending his last month in a hospital.

The Surgeon General says houses don't transmit AIDS.

A grocery store in Miami coerced a long-term employee into transferring to another store at a lower paying job. The man merely had been exposed to the HIV virus.

The Surgeon General says food-handlers pose no risk of AIDS transmission.

Too many voices clamor for attention. These incidents barely scratch the surface. AIDS discrimination, as Dade Advocates for Rights and Equality has documented, ravages South Florida as much as the disease. There are far too many employers

who fire or demote their HIV-exposed workers, far too many landlords who evict their tenants, and far, far too many doctors and dentists who refuse to treat AIDS patients.

This pervasive discrimination, always offensive, is no less heinous than the Knight Riders who terrorized black people in the South. The fear-mongers are treating people, our fellow citizens, as less than human. They are projecting their own fears onto people who suffer enough without the added burden of undue discrimination. Following age-old patterns of thought, they are blaming the victim.

This irrational fear serves nothing but the virus. It damages the lives of sufferers. It impedes badly needed education. It destroys the human community and rends the social fabric, pitting neighbor against neighbor. It foments more discrimination and often leads to destruction. The Ray family's house would not have burned down if the citizens of Arcadia had acted out of anything but irrational fear. This fear feeds on itself, much as the virus feeds on its host.

We have to stop this discrimination to sidetrack the cycle of fear. And the example must come from our elected leaders, guardians of the public good. But where is our national leadership. Where is the White House? Recently, Health and Human Services Secretary, Otis Bowen, testified before Congress on the subject of AIDS. He said the federal government should not attempt to protect against AIDS discrimination right now. Bowen believes the states should take the lead in this field. Taking him at his word, this only means more wasted time, more suffering, more tragedy.

How many more dentists must throw out their patients with a half-drilled tooth? How many companies must fire employees with AIDS? How many more families must be

burned out of their homes before Washington realizes that AIDS discrimination is growing, not subsiding.

We desperately need education to reach every corner of this country. The U.S. government claims we can't afford to send out the Surgeon General's report on AIDS to its citizens. Yet, the Internal Revenue Service recently mailed pamphlets regarding new tax laws to every taxpayer in the country. I ask you: What's more important? Changes in allowable interest deduction or saving people's lives.

The epidemic demands no less than massive new AIDS funding, yes a Manhattan Project. We must find a treatment, not just a vaccine for this disease. But we first must start treating 44,395 Americans like People With AIDS, not pariahs with AIDS.

You can include one thing in your report to the president that will bring immediate relief to the AIDS community. We desperately need federal legislation banning discrimination against those who are AIDS infected, or have the disease. Then, one stroke of the presidential pen could banish this irrational discrimination without costing the treasury one cent.

We have to stop AIDS apartheid now. Right now.

TESTIMONY BEFORE THE PRESIDENTIAL COMMISSION ON AIDS

MIAMI, FLORIDA, NOVEMBER 12, 1987 ORIGINAL

submitted by Bill Bahlman

Anger! Why does anger consume me? Why does anger consume so many with AIDS? And the people who love them? Do you as members of the presidential commission on AIDS understand why? You should understand that anger by now, unless you have your eyes and ears shut tight. You shduld know that your lack of ability as individuals and collectively as a commission is just a symptom of how inadequately the federal government of the United States has been, in responding to the AIDS pandemic.

I see no brilliant men or women directing our government's response to AIDS. Not in Reagan's White House. Not in the Public Health Service. Not in the Centers for Disease Control. Not in the National Institutes of Health. Not in the Food and Drug Administration. Not in the Congress. I have met with them all, and heard them speak, and they make me sick. We see their lack of direction as means of genocide.

We complained to the FDA, so they put AIDS drugs on the "fast track" to approval, but after two years of research with 2400 people enrolled in a compassionate use protocol, the drug ganciclovir (DHPG), used to prevent blindness and imminent death for PWA's with CMV infection, was turned down by the FDA for approval due to a sudden lack of useful data. Why wasn't the FDA sending their agents out to meet with the drug company, Syntex, to verify that the data being collected could indeed lead to approval? We find this passive approach by the FDA as another means of genocide.

We complained to the NIH that there were only 442 persons with AIDS enrolled in their 19 AIDS Treatment and Evaluation Units (ATEU). Now see that the ATEU program has grown but it has not expanded. With 1676 people enrolled as of September 22, 1987 a shocking 87% are in AZT

The Lavender Hill Mob
496 A Hudson St., Suite G19
New York, N. Y. 10014

studies. In New York state with only 453 PWA's enrolled 99% are enrolled in AZT protocols. Is this the best in creativeness and effort the NIH can offer? Where and when are promising treatments like ampligen, AL 721, colony stimulating factor, ribavirin, imuthiol, DHPG, foscarnet, antabuse, susidic acid, and carrisyn going to be tested? Dr. Anthony Fauci, director of the ATEU program justifies his almost exclusive testing of AZT by saying it's the only drug that has proven efficacy in fighting AIDS. AZT was "proven" efficacious by the ATEU testing program. How can our research efforts be fruitful and save lives with this kind of short-sighted, closed-minded thinking? And we find the short-sighted ATEU program as another means of genocide.

We complain to the Congress, where at least they have continually doubled President Reagan's budget proposals for AIDS funding, and we find Jesse Helms proposing an amendment to disallow federal funding for safer sex educational materials that promote or encourage homosexuality, either directly or indirectly. In its homophobia the amendment disallows the teaching of safe measures of same sex intimate companionship. The Helms amendment passed in the Senate 94 to 2. The Congress says "Let the queers die", and this we see as another means of genocide.

Gary Bauer, President Reagan's domestic policy advisor, and a key figure in the development of the administration's policies regarding AIDS, and I'm sure no stranger to the members of this commission who may very well owe their positions on the presidential commission to Mr. Bauer, has recently said in the October 19th issue of the AIDS Record: "I haven't seen a good (AIDS) discrimination case made. Often quoted is the burning out of the family in FLorida. What is missing is that, overwhelming, AIDS children are attending schools with the knowledge of the school districts. In lorida, the decision was made that those kids should attend school."

Gary Bauer hasn't heard of "a good case of discrimination", being burned out of your house has got to be one of the worst examples of (AIDS) discrimination, short of murder. There is no compassion in this kind of thinking. No letter from the President to console the family, and we see this as yet another means of genocide.

And AIDS rages on!

Address to the
Presidential Commission on the Human Immunodeficiency Virus Epidemic

Harry I. Shuman, M.D.
Regional Health Services Director
Florida Department of Corrections

November 12, 1987

Gentlepersons:

I appreciate the opportunity to speak to the concerns of AIDS and HIV infections in the correctional setting. At the same time, I hope it is realized that the issues are too numerous and too complicated to be covered in the short amount of time allotted.

As health care professionals within the Department of Corrections, we want what is best for our patients. At the same time, we feel a fiscal responsibility to the taxpayers in utilizing the available health services funding in ways that will be most beneficial to the health and safety of the inmates, as well as protecting the public health upon our patients' return to society. We have begun to feel pressure from the outside to institute mandatory HIV testing on all inmates. We would like to be able to convince you that such a policy is irrational, fiscally irresponsible, and medically unsound.

In his article entitled, **"The Cultural Impact of the 'AIDS' Test: the American Experience,"** S.C. McCombie states, **"In those public health jurisdictions that have undertaken this approach, use of the test appears to function as a magical control measure. In this context the test becomes a ritual, as have many other screening tests. Its administration reduces the anxiety generated by a perception of a disease out of control and masquerades as intervention. Supporters of Malinowski's theories on religion would enjoy hearing the response to criticisms about these testing programs, which consist of statements such as 'this is a serious**

disease, people are frightened, and we have to do something.'"[1]

The ELISA screening test currently employed was designed with high sensitivity and moderate specificity with the intended use of protecting our nation's blood supply. With any suspicion of positivity, the identified unit of blood can be disposed of efficiently. Human beings showing the identical positivity cannot be so easily dispatched. The test further suffers from lack of predictions: while it may identify those who are infected it cannot prophesize which of those infected will go on to the disease state.

We do not deny that our incarcerated population contains an over-representation of individuals from the high-risk group of intravenous drug abusers; nor do we deny that homosexual activity occurs with greater frequency in our population than in the population at large. However simple identification of infected individuals can serve no utilitarian purpose. In fact, such information can increase the risk of harm to those so identified as HIV positive, because of ignorance and fear on the part of both inmates and security staff. Segregation of individuals who are HIV positive yet are not engaging in high risk behaviors is medically unwarranted and sends a dangerous message to the public: that is, the concept of an "AIDS Colony", and may affect both the public's perception of the disease and the way to control it. And while all health care workers within a correctional setting believe in the importance of confidentiality regarding medical issues, in reality it often cannot be completely achieved because of security concerns.

As health care workers, we firmly believe that education is the only viable way to contain this epidemic. At the same time we recognize that

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[1]McCombie, S.C.
"The Cultural Impact of the 'AIDS' Test: the American Experience"
Soc Sci Med 23(5):455-9 (1986)

the psychological make-up of many of our inmates makes some of the usual educational materials which are based on prevention through fear ineffective. Instead we support, and ask for your support, in the continuation of specific educational programs targeted at our special population.

We also request that any medical developments which prove beneficial in either prevention or treatment not be withheld from our patients on the basis of their incarcerated status.

In summary, the goals of health professionals in correctional medicine are identical to the public health goals of the population at large: primary, secondary and tertiary prevention. We request that no "We/They" dichotomy be established when considering measures to control and/or treat HIV infections in our patients as opposed to those in the free world. Mandatory testing, with or without segregation, will lead to medical, legal, administrative and financial nightmares without advancing the ends of public health.

I am also submitting to you a written report entitled "AIDS, Inmates and HIV Screening: A Rational Approach to Acquired Immunodeficiency Syndrome in Correctional Facilities" which covers our concerns in greater depth, and which based on research from medical, legal, and public health publications.

Thank you for your time and consideration.

Harry Sherman, M.D.

Regional Health Services Director
Florida Department of Corrections

AIDS, Inmates and HIV Screening:
A Rational Approach to Acquired Immunodeficiency Syndrome in Correctional Facilities

Harry I. Shuman, M.D.
Regional Health Services Director
Florida Department of Corrections

Submitted to:
PRESIDENTIAL COMMISSION ON HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC
November 12, 1987

Introduction

Although originally developed to screen blood donations, the enzyme linked immunosorbent assay (ELISA) test to detect antibodies to the Human Immunodeficiency Virus (HIV) has come into vogue as a clinical tool for the evaluation of patients. There are many problems with this turn of events. The ELISA test, along with the comfirmatory Western Blot (WB) are, after all, not predictive of disease, but of prior exposure and infectivity.[1] Donated blood which shows even a questionable reaction to the test can be destroyed; human beings displaying the same positivity cannot. Who should be screened? And since there are currently no known implements for secondary or tertiary prevention, what impact does this test have on primary prevention which would make its use rational?

The initial victims of Acquired Immunodeficiency Syndrome (AIDS) in the United States were entirely comprised of those considered "undesirables" by the majority of the population[2] and there was no outcry for either prevention nor intervention. As the disease has entered more members of the mainstream population, the government, the medical community and the political organizations representing the high-risk groups have finally been called into action, albeit several years too late. In the catch-up process which has ensued, lack of both

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[1]Ory H.W. Koplan J.P. and Allen J.R.
"Assessment of Screening as a Preventive Technology: the Example of HTLV-III/LAV Antibody Testing"
Isr J Med Sci 22(7-8):524-8 (1986 Jul-Aug)

[2]Shilts, Randy
And the Band Played On: Politics, People and the AIDS Epidemic
St. Martins Press 1987

organization and logic has been the rule rather than the exception.[1] The result has been a "We/They" situation, in which mainstream America has called for wholesale screening of the at-risk populations and, in some cases, isolation of those infected.

S.C. McCombie, in "The Cultural Impact of the 'AIDS' Test: the American Experience" writes:

> In those public health jurisdictions that have undertaken this approach, use of the test appears to function as a magical control measure. In this context the test becomes a ritual, as have many other screening tests. Its administration reduces the anxiety generated by a perception of a disease out of control and masquerades as intervention. Supporters of Malinowski's theories on religion would enjoy hearing the response to criticisms about these testing programs, which consist of statements such as 'this is a serious disease, people are frightened, and we have to do something.'[2]

Voices of reason have managed to at least temporarily halt the demands for widespread testing, based more on the tangible statements of cost for such a venture than on medical or sociological factors. However, selected subgroups of the population are still being targeted for testing. These include hospital admissions, those about to be married[3], armed forces recruits, and inmates in correctional institutions.[4] Prisoners in particular have been an easy target for several reasons: they are already isolated from the general population

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[1]Shilts, Randy
And the Band Played On: Politics, People and the AIDS Epidemic
St. Martins Press 1987

[2]McCombie, S.C.
"The Cultural Impact of the 'AIDS' Test: the American Experience"
Soc Sci Med 23(5):455-9 (1986)

[3]Cleary P.D. Barry M.J. et al.
"Compulsory Premarital Screening for the Human Immunodeficiency Virus"
JAMA 258(13):1757-1762 (Oct 2, 1987)

[4]Hammett, T.M.
AIDS in Correctional Facilities: Issues and Options
National Institute of Justice
May 1987

and are an easily defined group for study; they contain a large proportion of those at risk, including intravenous drug abusers; and there is a public perception that homosexuality, another high-risk behavior, is rampant among that population.

I contend that mass screening of inmates in correctional institutions is an unnecessary, dangerous, and irrational response to the AIDS epidemic. Furthermore, the same tool employed in the general population as a form of primary prevention (i.e. education) is the approach that is needed in correctional institutions, taking into consideration both the personalities of inmates as individuals and ecosystem within which they function as a community.

Literature Review

In "AIDS Screening, Confidentiality, and the Duty to Warn"[1], authors Larry Gostin, JD and William J. Curran, JD, LLM propose five criteria necessary on which to base screening of a population in which the achievement of the protection of public health clearly outweighs the invasion of individual privacy as well as other possible negative outcomes (e.g. loss of employment, immediate danger to the individual's life by threats from others). These criteria include: (1) the selected population should have a high enough reservoir of infection so that there are not disproportionate numbers of uninfected persons having to submit to testing procedures; (2) the environment in which the population lives poses a risk of communication of infection; (3) the knowledge obtained as a result of testing should enable the authorities

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[1]Gostin L. Curran W.J.
"AIDS screening, Confidentiality, and the Duty to Warn"
Public Health and the Law
Am J Public Health 77(3):361-5 (1987 Mar)

o take precautions to reduce the spread of infection which they would
e unable to do without such results; (4) the risks of the testing
should not outweigh the benefits; and (5) there are no less-restrictive
alternatives which would be equally or more effective in meeting public
health objectives.

Using these criteria, a proposed system for the mass screening of a prison population can be evaluated. On the positive side, prisons are a potentially large reservoir for HIV infection, with greater than 30% of the inmates offering a history of intravenous drug use[1] and an admitted participation in homosexual behavior while institutionalized of approximately 30%[2] which is about three times that estimated for the population at large. The virus can be spread through both forced and consensual sexual activity as well as through the sharing of needles, all of which can and do occur within the prison environment.

A few States test and segregate inmates based on HIV status. This segregation has been upheld by lower courts provided that the involved inmates are given separate but equal social, rehabilitational, and recreational facilities. Failure to provide such facilities could and has resulted in litigation under the claim of "cruel and unusual punishment" under the Eighth Amendment to the Constitution.[3,7]

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[1]Kelley P.W. Redfield R.R. et al.
"Prevalence and Incidence of HTLV-III Infection in a Prison"
[letter]
JAMA 256(16):2198-9 (1986 Oct 24-31)

[2]Kelley P.W. Redfield R.R. et al.
"Prevalence and Incidence of HTLV-III Infection in a Prison"
[letter]
JAMA 256(16):2198-9 (1986 Oct 24-31)

[3]Hammett, T.M.
AIDS in Correctional Facilities: Issues and Options
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However, HIV testing and segregation can be challenged as an over-inclusive policy as only a small percentage of those infected will engage in behaviors necessary to spread the virus. A study of 1350 inmates with an initial prevalence rate of HIV infection of 1.0%, showed incidence rate of HIV conversion of initially seronegative inmates of 0.0% over 685 person-years.[1] Therefore, restricting the activities of HIV-infected inmates, provided that they do not engage in high-risk behaviors, appears unwarranted.

Segregation and screening also have other hidden costs. Widespread ELISA screening with confirmatory repeated ELISA and WB tests, would incur significant costs in both administration and interpretation. Periodic rescreening of the uninfected population would be necessary for several reasons: prisons are not truly closed populations, and illicit sexual behavior during visits with outside friends and family does occur; drug paraphernalia is often brought into institutions, both by visitors and staff; and there is a "window period" during which an infected person may not have sufficient antibody levels to be picked up by the test.[2] Screening invades privacy rights by the collection of sensitive health-related information. Particularly in a prison setting, confidentiality cannot be assured. If information about positivity is disclosed, the inmate may be stigmatized and his life placed in immediate jeopardy, and may harm his future prospects for jobs, housing, and insurance upon his release.

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[1]Kelley P.W. Redfield R.R. et al.
"Prevalence and Incidence of HTLV-III Infection in a Prison"
[letter]
JAMA 256(16):2198-9 (1986 Oct 24-31)

[2]Matuszak D.L. Israel E. Horman J.T. Joseph J.M.
"Update on HIV Infection: HIV Antibody Testing"
MD Med J 36(1):40-3 (1987 Jan)

Furthermore, the segregation of seropositive prisoners within an environment with a very high potential for repeated HIV exposure might significantly increase the health hazard to the inmate, as the continued contact with the infectious agent may contribute to the onset of frank illness.

The decision to impose mandatory screening and segregation in prisons sends a dangerous message to the public, that of the concept of an "AIDS Colony", and may affect both the public's perception of the disease and the way to control it.

The question of "duty to warn" must also be taken into consideration. **Tarasoff v. The Regents of California** found a psychologist liable for failure to warn a third party of his patient's intention to murder her.[1] However, in **Gammill v. United States**, it was held that there was no legal obligation to warn the general public of hepatitis B in the community.[2] A reasonably specific and high degree of potential harm is required before the court will find an affirmative duty to disclose confidential information: the specific risks to specific individuals must be known. In Arizona, a case seeking the removal of an inmate with AIDS from the institution was dismissed, as was another suit seeking damages for "severe emotional distress" as a result of being housed in the same unit with an ARC patient.[3] Correctional systems have not been held responsible for insuring absolute safety of persons in their custody. Courts have upheld that

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[1]**Tarasoff v. The Regents of California**
551 P.2d 340 (1976)

[2]**Gammill v. United States**
727 F.2d 950 (1984)

[3]Hammett, T.M.
AIDS in Correctional Facilities: Issues and Options
National Institute of Justice
May 1987

damages resulting from inmate-on-inmate assaults are reasonable only if prison officials knew - or should have known - in advance the risk to that particular inmate.

Sexual activity between prisoners as well as the possession or use of any drug paraphernalia is strongly proscribed within correctional institutions, and failure to comply with regulations is often met with disciplinary confinement, loss of privileges, and/or additional sentence time. Since these are the activities that spread the HIV virus, it would not seem reasonable to perform activities such as widespread testing and segregation, in order to lower the health risks of individuals engaging in such behaviors.

There are multiple problems with the test itself, and what the results mean to the individual being tested, the health care worker, and the public at large. The ELISA has quickly acquired the misnomer - "The AIDS test" - and its rapid diffusion and implementation in a variety of non-medical circumstances has proceeded at a frightening pace.[1] By simple association, all of the negative attributes of AIDS have been projected onto those who test positive. Even in the context of Western Medicine, the labelling process employed suggests that contagion has a social definition. In short, the testing procedure illustrates the extent to which cultural beliefs affect public health and medical practice. McCombie summarizes:

> The social response to this epidemic has been determined by pre-existing economic, political and religious systems and has been characterized by confusion, panic, and prejudice. Even educated professionals interpret the disease as a punishment for social and sexual deviance, and call for quarantine and

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[1]McCombie, S.C.
"The Cultural Impact of the 'AIDS' Test: the American Experience"
Soc Sci Med 23(5):455-9 (1986)

isolation of those they perceive to be infected.[1]

The ELISA test also suffers from some problems of specificity and sensitivity.[2] Both false negatives and false positives do exist. False positives are less of a problem as it is considered unconscionable to label someone as "HIV positive" without the use of confirmatory tests, including a repeated ELISA and WB. False negatives pose the problem of labelling an individual infection-free which, without proper education, might make him the source for infection to others should no behavior modification occur. Zafar[3] found a cross reaction with the ELISA resulting in false positive results in individuals with alcoholic hepatitis and those with antibodies to both P. Vivax and P. Falciparum malaria. Alcoholic hepatitis is a common occurrence in those entering the prison systems. Malaria, while not wide-spread, is prevalent among those incarcerated for federal crimes such as drug smuggling, because of the endemic nature of the disease in the countries from which these inmates hail.

Once labelled as AIDS, ARC or HIV positive, the inmate is apt to suffer severe consequences when the information is released. Multiple authors[4,3,4,7] have pointed this out. On a personal level, while

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[1]McCombie, S.C.
"The Cultural Impact of the 'AIDS' Test: the American Experience"
Soc Sci Med 23(5):455-9 (1986)

[2]Lantin J.P. Peitrequin R. Frei P.C.
"Screening for Anti-HTLV-III/LAV Antibody in High-Risk Subjects: Sensitivity and Specificity of Commercial Tests"
Int Arch Allergy Appl Immunol 82(3-4):487-9 (1987)

[3]Zafar N.Z.
"Screening for Antibodies to HTLV-III/LAV in Our Population. A Word of Caution"
JPMA 37(4):84-5 (1987 Apr)

[4]Shilts, Randy
And the Band Played On: Politics, People and the AIDS Epidemic
St. Martins Press 1987

working in various correctional institutions, I have been informed by certain inmates that any individual discovered to fit one of these categories would be executed by other inmates. While confidentiality concerning both illness and test results should be assured, the reality is that this is not the case within many institutions. Upon publication of HIV positivity in these situations, the inmate is also apt to receive poorer treatment from correctional officers.[1]

One final and critical question needs to be answered: Since the results of HIV testing are not predictive of eventual disease, does an individual's knowledge of his own HIV status impact on his behavioral patterns? This is especially important in view of the fact that many of the institution's where mass screening is being proposed have neither the space nor the financial means to physically separate those who are seropositive from the rest of the population. Under these circumstances, in order for mass screening to be worthwhile, the knowledge of potential infectiveness, coupled with appropriate education, should cause the individual to modify his behavior to minimize risk to others; and a negative test result should motivate an individual to modify his behavior to avoid infection.[2] While these would be ideal outcomes of such knowledge, reality has not substantiated their accuracy. The fact that someone has tested negative may increase the likelihood of his "personal fable" presenting the belief that his previous practices are indeed <u>not dangerous</u> and there is no reason to

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[1]Hammett, T.M.
<u>AIDS in Correctional Facilities</u>: Issues and Options
National Institute of Justice
May 1987

[2]Ory H.W. Koplan J.P. and Allen J.R.
"Assessment of Screening as a Preventive Technology: the Example of HTLV-III/LAV Antibody Testing"
Isr J Med Sci 22(7-8):524-8 (1986 Jul-Aug)

stop such behaviors because he is "immune" to any negative outcomes. On the other hand, the knowledge of positivity may result in anger on the part of the individual, in which case he may try to seek retribution by imparting the illness to more people. This was best exemplified by author Randy Shilts in And the Band Played On in his accounts of Gaetan Dugas, a homosexual airline steward who is thought to be the index case of AIDS in the United States and who directly or indirectly was responsible for at least forty-one of the original cases in New York and California.

> Back in the bathhouse, when the moaning stopped, the young man rolled over on his back for a cigarette. Gaetan Dugas reached up for the lights, turning up the rheostat slowly so his partner's eyes would have time to adjust. He then made a point of eyeing the purple lesions on his chest. "Gay cancer," he said, almost as if he were talking to himself. "Maybe you'll get it too."[1]

Questions for Correctional Authorities

Before deciding on a course of action regarding the use of mass HIV screening in a correctional setting, the following questions must be answered:

1> Why should correctional systems take steps not being taken in the community at large?

2> What are the policy implications of identifying seropositive individuals?

3> How would mass screening affect education and prevention programs?

4> Is it possible to develop a reliable and confidential screening program?

5> What are the legal implications of screening?

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[1]Shilts, Randy
And the Band Played On: Politics, People and the AIDS Epidemic
St. Martins Press 1987

6> What are the costs of mass screening?

7> Will mass screening allay or inflame fears?

8> Are there feasible alternatives to screening?[1]

Mass screening refers to the testing of individuals for HIV antibodies in the absence of any clinical evidence of illness. Two years ago, four States developed policies which called for HIV screening of all inmates. It is interesting to note that none of these States are places where there has been a high prevalence of actual AIDS cases either among the general population or the prison population. Since that time, two of the States have dropped that policy: Missouri has decided that mass screening is unnecessary and Iowa dropped the idea after an initial screening of 800 inmates turned up none who were seropositive. At the same time, South Dakota, another State in which the incidence of the disease is low, adopted mass screening procedures. These States are convinced that identification of seropositives is necessary to prevent transmission and to provide effective treatment for their populations. Those states not performing routine tested cited reasons including equivocal results of the ELISA test, logistical and cost problems caused by the need to repeat testing, inability to guarantee confidentiality, and in at least two States, laws prohibiting such tests without informed consent.[2]

Outside of certain institutions, only the Federal government has resorted to mass screening in the case of armed forces recruits. They

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[1]Hammett, T.M.
AIDS in Correctional Facilities: Issues and Options
National Institute of Justice
May 1987

[2]Hammett, T.M.
AIDS in Correctional Facilities: Issues and Options
National Institute of Justice
May 1987

provide two arguments to support this position: (1) they consider all personnel as part of a walking blood bank, and cannot afford contamination, and (2) since military personnel must receive multiple vaccines for their foreign travel, immunosuppressed individuals should not be considered for duty. The first argument is illogical in light of the fact that being seronegative upon entrance into the armed forces does not insure continued negativity. The second argument is also moot: HIV antibody positivity is not in any way equal to immunosuppression. Instead, it is widely believed that the HIV screening was instituted to keep homosexuals and other "undesirables" out of the military.

In June 1987, the American Medical Association, while condemning the idea of mass screening for the general population, recommended HIV screening for all of those who are incarcerated. This was particularly disturbing when the AMA's own subcommittee on corrections, the American Correctional Health Services Association, as well as the National Commission on Correctional Health Care, denounced such an idea. This can only be viewed as political expediency and as a continuation of the "we/they" approach to this epidemic.[1] Proponents of mass screening in prisons cite the fact that the rate of transmission of AIDS within prisons is high, and screening is necessary to protect the prison population. At least two studies have not shown this to be true. While the prevalence of AIDS and HIV positivity in prisons is expected to be higher than in the general population mostly because of the concentration of IV drug abusers and prostitutes, when the prevalence of HIV positivity of those incarcerated for greater than seven years (i.e.

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[1]"ACHSA Opposes Mandatory Testing of Inmates for AIDS"
Corhealth: The Newsletter of the American Correctional Health Services Association
August 1987

prior to the epidemic) is examined, it is low.[1]

Proponents of mass screening again believe that only through this process can seropositives be segregated and the rest of the prison population can remain safe. Again there is the potential problem with repeat screenings for those who are initially seronegative, as well as the chance for infection from outside sources by way of staff and visitors. States such as New York, California, New Jersey and Florida, where the incidence of AIDS in the general population is high, are likely to have a high percentage of HIV positive inmates in the prison populations and would be unable to meet the demands for segregated housing. The question of staffing these all-HIV-positive centers would also become a nightmare.

It is counterproductive to target educational programs and preventative measures to seropositive individuals. Such programs will only stigmatize those individuals, subjecting them to potential threats and violence. Furthermore, seronegative individuals may be viewed as "safe" for sexual victimization by other inmates, or they might unjustifiably consider themselves "safe" and therefore pay little attention to the recommendations and admonitions of AIDS education programs.

Blood bank studies have shown that actual HIV virus could not be cultured in 10-30% of those units testing positive for the antibody. Because the test was developed to protect the nation's blood supply and not for use on people, it was designed to have a high sensitivity, erring on the side of safety, thus producing more false positives. False negatives also exist, which would allow the potential presence of

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[1]Maryland Division of Corrections
"Results of Surveillance for Serologic Evidence of Infection with HTLV-III/LAV in Inmates"
Press Conference, Baltimore, December 19, 1985

HIV infected inmates into a population which has been screened. But it is most important to remember that neither the ELISA test, nor the Western Blot, can predict who will actually develop symptoms of the illness.

As far as legal implications are concerned, California and Wisconsin recently passed legislation prohibiting HIV antibody testing without informed consent. Some correctional officials which support the idea of testing and segregation, do so out of fear of potential lawsuits naming them as liable for failure to protect. Lawyers, however, argue that the primary methods of contracting the infection, sexual contact and intravenous drug use, are already prohibited in prison, and thus only victims of forced sexual assault could bring such claims. They stress policies and procedures which would prevent sexual victimization, if appropriately enforced, would defend against such charges of negligence.

The cost of performing a single ELISA test ranges from $3 to $7. As an example of the cost of mass screening, the prison population in the State of Florida during 1986 at any one time approached 30,000. However, because of new commitments and releases, over 56,000 inmates were incarcerated during the year. The simple mathematics are as follows: Assuming a $5 average per test, the initial cost for those inmates would be $280,000. Assuming a positivity rate as high as 5%, the cost for repeat ELISA testing would be an additional $14,000. The obligatory Western Blot which would be done in the presence of 2 positive ELISA tests for confirmation costs approximately $75 to administer, adding $210,000, bringing the total for an initial study to over half a million dollars. Since all seronegative individuals would require--retesting at various intervals, it is estimated that the cost would rise to well over one million dollars annually. The Department

currently spends approximately $50,000,000 annually on health care, which covers salaries, equipment, and community hospitalizations. Were the outcome of the test either predictive of disease or were there treatments available to prevent the disease in new convertors, the expenditure would be well worthwhile. However, neither of these currently exist.

Added to the cost of testing must be the costs of implementing any policy decisions regarding seropositives. These might include construction and renovations required for separate housing units, as well as extra staff to cover these units. The Department has instead chosen to consider all inmates potentially infected and infective, and proceeds accordingly. With the small amount of useful information that an ELISA test provides, and with the lack of space to house its ever-growing number of inmates much less build separate units for inmates who are seropositive, this appears to be the only logical way to proceed.

Many clinicians, including myself, argue strongly that the HIV antibody tests should not be even be used to support diagnoses of AIDS or ARC, let alone screen inmates for seropositivity. AIDS is a syndrome rather than a disease in and of itself, and the presence of antibodies to HIV are not even a consideration when using Centers for Disease Control criteria for making the diagnosis.[1] Better and truer methods to assess patient illness exist including complete histories and physical examinations, complete blood count determinations, skin tests for anergy, and T-Cell studies. Prison health care workers should be attuned to subtle changes in their patients, and follow those at high

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[1]Revision of the CDC Surveillance Case Definition for Acquired Immunodeficiency Syndrome
MMWR Supplement
Vol 36(1S):August 14, 1987

risk closely. In Illinois, a high-risk protocol is in place so that all of these inmates are evaluated at least every three months. A similar situation exists in New York, and currently plans are underway to implement such a program in Florida. Physicians in general, and prison physicians in specific, need to get away from the concepts of "Modern Medicine" when evaluating this syndrome: it is an illness rather than a disease, and there is no simple test which can be used to make the diagnosis.

Health Care and Corrections

Inmates in correctional facilities are the only United States citizens who are Constitutionally guaranteed the right to health care. Until the last decade, however, this guarantee was carried out with little more than lip service.

The 1960s brought social and rehabilitational programs to the prisons, but for the most part, medical services remained woefully inadequate. These social programs were a mixture of the liberalism and idealism that was then in vogue. However, as the pendulum began to swing toward more conservative interests, the programs were abandoned. As an excuse for these failing programs, the popular phrase became, "You can't rehabilitate people who have never be 'habilitated'".

The first of many class actions suits brought by inmates about the deplorable medical conditions in the prisons arrived in the early 1970s. Court-appointed medical teams were appalled by their discoveries inside the institutions: care was being delivered by untrained and unlicensed personnel; controlled substances and prescription drugs were distributed by security officers, either at the request of the inmates or upon their own "diagnosis" of what the inmate required; minor and major surgery was

being performed by inmates upon other inmates, with the outcome sometimes contingent upon gang loyalties. Prisons had become the dumping ground on both sides of the bars. Inmates who had broken written laws were confined on one side. Health care workers who could not function in the outside community were on the other.

As these findings reached the media, several people in search of challenges decided to go to work at these institutions, much to the consternation of their colleagues. When asked how they could dedicate their professions to such an undeserving group, Dostoevsky's statement that societies could be judged by the way they treated their prisoners was often echoed. As more and more lawsuits developed, the catch-phrase "community standards" made its way into each of the consent decrees, and defined the level of care which would be considered acceptable by the courts. More and more qualified health care professionals found correctional medicine to be an acceptable and desirable alternative to free-world practice.

As patients, inmates are a diverse and always interesting group of people. Their seductiveness and their ability to control other individuals[1] adds an unusual dimension to the daily health care routine. Clinically, they are considerably lower on the wellness continuum than their counterparts on the streets: they have often left medical problems untended for all the reasons that those from the lower socioeconomic strata from which they are drawn often do; they also suggest that seeking medical care interferes with their criminal lifestyles on the street. They are prone to trauma-related illnesses including a four fold increase in the prevalence of head-injury-related

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[1]Bud Allen, Diana Bosta
#Games Criminals Play: How You Can Profit by Knowing Them
Rae John Publishers 1981

seizure disorders compared to the general population,[1] as well as bone and abdominal maladies secondary to gun shot wounds. Progression of chronic illnesses is often seen at much more advanced stages than would be expected for their ages, singularly because of their lack of treatment while in the general population. A recent statistical finding is that incarcerated males have a high risk of heart disease and sudden death, a risk that remains with them even after their release from prison.

Some portion of the inmate population falls into the category of psychopath, also known as sociopath or sociopathic personality disturbance. According to the Diagnostic and Statistical Manual of Mental Disorders, the disorder is defined as follows:

> This term refers to chronically antisocial individuals who are always in trouble, profiting neither from experience nor punishment, and maintaining no real loyalties to any person, group, or code. They are frequently callous and hedonistic, showing marked emotional immaturity, with lack of responsibility, lack of judgment, and an ability to rationalize their behavior so that it appears warranted, reasonable, and justified.

Along with these attributes are others which may hinder them from benefiting from the usual form of health education programs offered. Psychopaths do not develop fear responses readily and therefore find it difficult to learn responses that are motivated by fear and reinforced by fear reduction.[2] Their behaviors are neither motivated nor guided by the possibility of unpleasant consequences, particularly when the cause and effect are separated by a long period of time. Furthermore, they are unlikely to be influenced by the relationship between their past events and its relationship to their current circumstances. Other well-defined

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[1]King L.N. Young Q.D.
"Increased Prevalence of Seizure Disorders Among Prisoners"
JAMA 239(25):2674-5 (Jun 23, 1978)

[2]Hare R.D.
Psychopathy: Theory and Research
John Wiley and Sons, Inc. 1970

characteristics include a low resistance to temptation and an inability to delay gratification. Psychopaths do, however, perform well on verbal conditioning and rote-learning, as well as on tasks that are not dependent on acquired fear.

Sagarin[1] studied the effects of forced sexual activity in prisoners and its effects on their sexual orientation upon release. Although his sample was small, he discovered that none of the "aggressors" continued homosexuality upon returning to the streets, yet all of those "subdued" continued to practice homosexuality, in spite of the fact that each of them had been involved in heterosexual relationships prior to their incarceration. Both Sagarin as well as Moss and Hosford[2] noted that none of the aggressors considered themselves to be "homosexual" nor their activity as a form of homosexuality. This is an important point to remember when developing an educational program on AIDS: the virus does not care who you are or how you define yourself, but it thrives upon what you do.

Designing an AIDS Education Program

Considering the above information, it should be clear that the only viable way of stopping the transmission of AIDS within our correctional institutions is through education, but with the important caveat, that the program needs to be designed for the audience to which it is being directed. While this point may seem obvious, many institutions have

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[1]Sagarin E.
"Prison Homosexuality and Its Effect on Post-Prison Behavior"
Psychiatry (39):245-57 (Aug 1976)

[2]Moss C.S. Hosford R.E.
"Sexual Assault in Prison"
Psychological Reports (44):823-8 1979

simply taken the AIDS pamphlets, videotapes, posters, etc. which were designed for the community at large and presented them to inmates while congratulating themselves on providing effective AIDS education. While educational programs designed to decrease high-risk behaviors among homosexual men have been successful to some degree, similar programs aimed at intravenous drug abusers have been less so.[1] Reasons for this apparently include both the lower socioeconomic status and intelligence of the drug abuse population, their failure to seek health care in places where education is presented, and the physical addiction that accompanies their high risk behavior. However, the information about the dangers has slowly diffused itself into the drug-addicted community, as evidenced by an increased demand for sterile needles from drug dealers, which they have begun to offer.[2]

A very effective videotape presentation entitled "AIDS - A Bad Way to Die"[3] was produced by inmates for inmates in New York State correctional facilities. It follows the course of three inmates through their hospitalizations to their deaths. One man is homosexual, another is an IV drug abuser, and the third used unsterile needles shared by other inmates for tattooing, a popular practice particularly among gang members. Messages about the illness are presented by the inmates themselves, the New York State Commissioner of Health, and health care workers within the prison system. These "senders" are probably more

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[1]Shilts, Randy
And the Band Played On: Politics, People and the AIDS Epidemic
St. Martins Press 1987

[2]Des Jarlais et al.
"Correspondence: Free Needles for Intravenous Drug Users at Risk for AIDS: Current Developments in New York City"
NEJM December 5, 1985 p.1476

[3]AIDS - A Bad Way to Die
New York State Department of Corrections
Taconic Correctional Facility 1986

credible to the inmates than would be prison administrators.[1] The inmates, in particular, espouse the same values that are likely to be held by the majority of the "receivers." One man describes himself as "one hundred percent gangster". The "message" of course is to avoid needles and homosexual contact, and at the same time quell fears that the illness is spread by casual contact. Considering what has been stated about psychopaths, it is interesting to note that all three inmates on the tape believe that they contacted the virus while in prison, from high-risk activities performed while in prison, and only months prior to the onset of their illnesses. Although the ravages of the illness are graphically portrayed, it is the sincerity of the message and the senders that is most remembered, rather than the fear of the consequences of the illness. In informal surveys of inmates, the viewing of this videotape is the most often cited cause for any change in high-risk behavior.

Correctional systems should institute training programs as early as possible, and should maximize opportunities to provide educational information on AIDS. Because much of the information is easily forgotten, and because of the changing nature of the illness itself, educational programs should be repeated frequently, and used as an opportunity to offer timely information to counteract unfounded rumors. Reeducation immediately prior to release may be extremely useful, making the inmate fully aware of the risks he will face upon return to the community at large.

Educational programs should be targeted to the identified concerns and the informational needs of the audience. Polling inmates and staff

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[1]Hammett, T.M.
AIDS in Correctional Facilities: Issues and Options
National Institute of Justice
May 1987

about their concerns prior to the development of an educational program would only seem logical. During these presentations, the labelling process should be stressed, i.e. even though an inmate does not consider himself either homosexual nor drug addicted, if he even occasionally indulges in these behaviors he carries the same risk as those who are so labelled.

Passive educational programs such as printed material and slide shows, are probably insufficient. While only 37% of State and Federal institutions responding to a joint study by the National Institute of Justice and the American Correctional Association used "live" presentations for their AIDS training, these were viewed by both inmates and staff as much more effective in changing attitudes about the illness than were the distribution of pamphlets or taped presentations without a live moderator.[1] Anonymous polling of the audience should continue in order to tailor the program to inmate concerns and monitor its effectiveness as a modifier of behavior.

One point that cannot be stressed strongly enough is that the education must be presented to all inmates and not just the high risk groups. In 1984, Stateville Correctional Center in Illinois almost brought about disaster, where, because of lack of funding, a pamphlet entitled "What Gay and Bisexual Men Should Know About AIDS" was planned to be distributed to only those individuals who had been treated for a venereal disease while incarcerated or who, in other ways had been identified by the staff as engaging in homosexual activity. Had the event occurred, the little green booklets would have marked those inmates for easy victimization by others. Instead, a copy of the

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[1]Hammett, T.M.
AIDS in Correctional Facilities: Issues and Options
National Institute of Justice
May 1987

pamphlet was delivered to each cell, regardless of known or suspected sexual orientation. While prison officials tend to deny the presence of intravenous drugs in their institutions, the fact remains that contraband containing needles and syringes is uncovered at many of these facilities on a daily basis.

Inmate training can be effective in reducing fears and changing behaviors. Correctional administrators believe that sexual practices in prisons are changing as a result of educational efforts.[1] A way to definitively test this assumption would be to track changes in the incidence of venereal diseases in the institutions and compare the results to those obtained prior to beginning education programs.

Conclusions

There is no doubt that AIDS and the prevention of AIDS are major problems facing the correctional systems. Because of the concentration of certain factions of high-risk groups within the institutions and because of the propensity of certain of these individuals to continue these behaviors or indeed begin new ones while incarcerated, it is likely that the number of individuals affected by the syndrome will rise within these settings.

HIV screening with tests that cannot predict outcomes and where there are no assurances that the results of the tests will positively modify the individuals' behavior, may be more ritualistic than of technological significance. The testing procedure is also very costly, and without assurances of confidentiality, may provide more dangers than

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[1]Hammett, T.M.
AIDS in Correctional Facilities: Issues and Options
National Institute of Justice
May 1987

they alleviate. If prison screening and segregation were adopted as policy, substantial parts of the prison population would need to be housed in separate facilities.

A more enlightened policy would be to control the spread of AIDS through a reduction in unsafe sexual behavior and IV drug use, activities already proscribed. Comprehensive and continuing education on HIV transmission and on risk-reducing behavior should be implemented. Security measures including better lighting, increased staffing, improved training and supervision, monitoring and enforcement which would serve to discourage dangerous sexual and needle-sharing behaviors should be established.

Efforts should be focused on means of primary prevention, namely the development of educational programs targeted for the special population of inmates, paying close attention to their underlying personality structures and to the environment in which they interact.

In summary, prison screening and segregation would not achieve a valid public health benefit, would adversely affect the health and privacy of seropositive prisoners, and would divert attention from less restrictive, more effective, policy alternatives.

FILE COPY

DADE COUNTY CHAPTER OF THE
NATIONAL ORGANIZATION FOR WOMEN

Remarks to Presidential Commission on AIDS

Fran Bohnsack-Lee

President, Dade County Chapter of the National Organization For Women

Michael E. Melody

Chair, DADE NOW Task Force on AIDS Discrimination

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As a statue in front of the Archives building in Washington proclaims: "The Past is Prologue." By studying the past we can gain fundamental insights into consistent and enduring patterns of thought and action. In discussing AIDS, for example, it is helpful to reflect upon the social hygene movement which existed earlier in this century.

As we would learn, diseases have a social construction, especially venereal ones. And this construction conditions public response. Like Syphilis, many view AIDS as a consequence of corrupt sexuality. They see it as a sign of pollution and contamination. It heralds a decaying social

order. Some even think that AIDS is God's punishment for a peverse lifestyle. Many think AIDS, like syphilis, is a disease of choice, resulting from a risk freely taken.

Reflecting enduring patterns of thought, government policy is confused. The Surgeon General says one thing, the Secretary of Education, a righteous man, another. Our AIDS policy parallels the social hygene policy of the U.S. Army during World War II. To try to keep soldiers uninfected by syphilis the army could never really decide whether to use horror stories, graphic films for example, or distribute condoms. The army did both in a

confused, inconsistent pattern.

AIDS, regardless of erroneous structures of thought, is caused by a virus which destroys a critical component of the immune system. It is, per se, a medical issue and should not become fodder for ideologues. We cannot really deal with this tragedy until we begin to distinguish between the medical issue of AIDS and the ideological nonsense uttered by self-proclaimed guardians of the public morality. The Past tells us to learn; it calls us to act effectively. Let's learn from the army's efforts, not duplicate them.

AIDS, contary to what many think, is not the result of peverse choices. Individuals struggling today with the monstrous burdens of HIV (Human Immunodeficiency Virus) infection probably acquired it long before much was known about AIDS. With great stealth, HIV came quietly into their lives, long before anyone could raise the hue and cry. The alarm was sounded, but it was already too late for about two million Americans. Now, reflecting the hue and cry, gay men have radically altered their lifestyle. Current data indicate that the transmission rate of sexually transmitted diseases is dropping rapidly among gay men.

Gay men are now an embattled community called to heroism on a daily basis. They are meeting this monstrous challenge. The have organized massive corporations to care for all the sick. Unlike some of us, they do not ask how anyone acquired the infection. More important, they have come to nurture each other in confronting this scourge. It is now common for one gay man to cradle another as he lay dying. They have cried their tears, a Mississippi of them, burried their dead and wait in terror for It to strike again. For as they have realized, it will visit them again, and again, and yet again.

As gay men have discovered their own herorism and compassion, virtues of great beauty, we have largely failed them. We debate whether the term condom can be used in polite conversation, while they stand watch at the gates of terror. In Miami, we debate using six billboards for AIDS education, while a Person With AIDS, abandoned by all, is engulfed in flames in a hospital bed. We debate about the schools, while a house is torched in Arcadia, Florida.

Certainly the nation that went to the moon can do more when 25 thousand of its citizens have died. Certainly the nation that reaches to the stars can do

more when another 20 thousand of its children are sick. Certainly the nation that routinely wins Nobel Prizes in medicine and has vast wealth can mobilize more resources to attack this scourge. Just as we triumphed in the Manhattan Project during World War II, so we must, and so we shall. Our sons AND DAUGHTERS are dying. No nation which allows this can long endure.

If this is the prologue, then the archive created by this commission is a test of our nation's fiber; our common commitment to our shared humanity. The virus does not discriminate, neither should we.

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ORIGINAL

I am Ruth Shack, executive director of the Dade Foundation this communitys foundation and I thank you for the opportunity of giving testimony this morning.

After seven years of researching the human immunodeficiency virus, discovering its impact on the immune system, implementation of treatment protocols and initiating vaccine development, it is surely time to re-examine and evaluate our educational programs and the way to effectively reach the diverse components of our community on the topic of AIDS and AIDS related issues with emphasis on prevention.

South Florida is unique in its mixture of rich cultural and ethnic backgrounds. While that diversity creates the multi-textured appeal of this community it also presents specific problems when dealing with AIDS education.

Education must be targeted for the various groups within the individual community. What works for the upper-middle class parent of the Kendall area will not meet the needs of the welfare recipient mother of Liberty City, nor the migrant workers in the south of our county. Each distinctive group within the greater community must have access to information and education and training that is relevant to their way of life and within their standards of acceptability.

The need for well-trained staff, hired from the communities themselves is evident. Miami Haitians can educate other Miami Haitians, can gain access and understanding where the white anglo individual might often fail due to limited language skills, simple misunderstandings of appropriate protocol and hard-to-erase long standing differences in cultural backgrounds.

These problems in educating the community can best be surmounted by developing programs specially targeted and delivered by members of these groups.

To avoid expensive duplication of administration, support, and service systems, a central organization, such as Miami's Health Crisis Network, could function as the home base for small "neighborhood" outreach programs designed to educate, do initial counseling, and to channel those in need to the central service providers.

The staff of each of these "neighborhood" programs should consist of persons hired directly from the community they serve who can be provided training from the existing organizations with careful consideration to the special "tailoring" of presentation and initial counseling sensitive to the community's cultural needs.

In the development of these educational programs special attention needs to be focused on the following:

- *Materials developed by each community with relevant language and graphics. Materials should not be simply translated from English, but rather represent meaningful issues to each community.*

- *Inclusion of clear, graphic materials tastefully presented by facilitators comfortable with discussion of all aspects of human sexual behavior and drug usage.*

- *Educational materials need to be updated and evaluated for accuracy and effectiveness.*

- *Inclusion of AIDS education materials for person already infected with the virus. AIDS is not a "them-us" educational experience. Many persons learning about AIDS may or may not know they are infected with this virus. For persons who do not know they are infected, materials need to include basic immunology, resources for support, and the most current information about intervention protocols.*

- *Education, programs with the purpose of "Training the Trainers" that not only include facts and examination of the attitudes, but also incorporates skill development.*

Miami, Dade County and South Florida are composed of unique communities within the greater community at large. Each of these special communities add to but can gain from the greater community knowledge and progress in dealing with this health crisis. Working Together, Hispanic, American Black, Caribbean Black, Migrant workers, and Anglo Americans can provide proper and effective education and prevention for AIDS in their individual communities with lasting effect for the community as a whole.

Testimony to

Presidential Commission on the HIV Epidemic

AIDS Education in Florida

Spencer Lieb, M.P.H.
AIDS Program Supervisor
Department of Health and
Rehabilitative Services

November, 12, 1987
Miami, Florida

It is often stated--and bears repeating--that, without a vaccine or medical cure for HIV infection and AIDS, education is our only preventive tool. Some have even said that education is the vaccine for AIDS, but we may do well to resist this metaphor.

Oral polio vaccine will reliably elicit the same protective response in just about everyone, no matter who prescribes it, no matter who administers it. With regard to AIDS prevention, of course, the risk reduction message must often be tailored to a given culture and lifestyle and the messenger must be credible to the audience. Otherwise, the information is much less likely to elicit the protective response, and the messenger may be viewed with distrust as an "outsider."

In Florida, AIDS has involved a somewhat broader cross-section of society than in many other states at this time. As you've probably learned in the past two days of your visit, heterosexual transmission is relatively common here, as is AIDS in women and children. Minorities are overrepresented among the 3,300 AIDS cases in Florida reported to date. No doubt, the great majority of white, black, Hispanic, and other Florida residents practice personal behaviors that do not place them at risk for AIDS. However, the small but significant proportion who are at risk is increasingly becoming infected, mostly due to unsafe sexual or drug abusing behaviors. It is critical to convey a sense of vulnerability to those at risk. This is a first step in promoting change in behavior and ways to sustain that change. To those not at risk we must convey information that will reduce fear so that rational problem solving can take place without stretching the fabric of society.

Persons who voluntarily seek HIV antibody counseling and testing anonymously through the state's network of county public health units would not be there if they did not already sense this vulnerability. Non-judgmental, one-on-one counseling has been provided in pre- and post-test settings to more than 20,000 individuals attempting to adopt or sustain positive health behaviors. Counselors trained by AIDS Program staff carefully avoid stereotyping by emphasizing the factors and behaviors that incur risk rather than the personal characteristics of infected individuals.

Confidential counseling and testing sites are now being established in all county health departments. Attendance is not dependent on word-of-mouth or other publicity, nor on prior awareness of AIDS and its risk factors. AIDS information and education and counseling and testing services are routinely made available to interested clients in STD and other clinics. Clients choose to participate voluntarily by giving their informed consent.

Partner notification and referral programs are a logical extension of confidential counseling and testing. Here, health department staff can offer the same service to very high risk people who have had "unsafe" sex or have shared needles and syringes with an infected person and may not otherwise learn of their risk status.

In the past two years, the AIDS program has contracted for services with several AIDS Service Organizations. This year contracts will be developed with as many as ten minority community groups as well. Thus far, these contracts have enabled well-trained professionals to reach important segments of the at-risk community on a peer-oriented basis. The successful development and distribution of a survey instrument on AIDS would not have been possible without the contractual involvement of four major community-based groups. This strategy is now being expanded--up to 15 such contracts will be developed in the next six months. Providers will 1) conduct extended counseling for seropositive persons upon referral from health departments, 2) establish counseling and testing program of their own, and 3) conduct outreach into targeted segments of the community.

A Minorities AIDS Information Initiative grant from CDC will enable us to promote the credible delivery of risk reduction services by many black and Hispanic operated organizations through contract agreements. Where needed, training and technical assistance will be provided by AIDS

program staff and/or experienced AIDS Service Organizations. (Many of the ASOs report having extensive, practical experience in developing decision making skills and sexual negotiation skills in the gay community. These may be translatable to other groups as well.)

Printed educational materials on AIDS are ineffective with groups having high illiteracy rates. One approach that our Dade County staff are pursuing is the development of audio cassettes with a 15-minute AIDS educational program in Haitian Creole on one side and English on the other.

A staff member in Palm Beach County helped introduce a novel approach that made risk reduction counseling both palatable and digestible. Women with AIDS and female sex partners of men with AIDS were presented with vital preventive information in the context of a regularly scheduled sewing circle.

"Train-the trainer" programs are underway to reduce the labor intensive aspects of AIDS education conducted on a larger scale. This has worked well in some areas with AIDS program workers training drug abuse treatment center staff, American Red Cross home health aides, and Salvation Army staff who work with prostitutes on probation. In one county 43 drug abuse treatment centers initially had a regressive or no policy on HIV infection and AIDS; 28 of these have now adopted policies specifying that seropositive clients will no longer be excluded; 18 of these programs now provide counseling and testing on the premises.

School-age and college students may need skills in decision making and resisting peer pressure, especially concerning sex or IV drug use. Curricula on STDs and AIDS for public schools are being developed with the State Department of Education. A model AIDS peer education program based in dormitories and classrooms was designed and implemented recently at a college. AIDS program staff trained 20 student leaders to conduct activities there in concert with the Student Health Service.

Last month a set of formal recommendations on AIDS and public schools was announced by the State Department of Education. Consistent with AIDS program recommendations, it ensures equal educational opportunity for HIV-infected students in the least restrictive setting. We regard this as a true milestone for containing unwarranted AIDS-related fears in the general public.

Statewide, an effective network is in place for disseminating AIDS information to the general public via

public health workers at the district and county levels. This past summer, in South Florida, we conducted a billboard and bus placard campaign, aimed at the general public. For two months, basic AIDS awareness messages were conspicuously posted in Spanish, Creole, and English. An original music and "rap" advertisement was also developed and air-time purchased on three popular, black-oriented radio stations. The combined campaigns, which promoted Florida's toll-free AIDS Hotline telephone number, have resulted in a sustained three-fold increase in calls to the Hotline.

Health care professionals, emergency medical technicians, police and others need to understand modes of HIV transmission and how to comply with infection control procedures. While plans for reaching these important workers are underway, it is worth noting that a progessive statewide policy on AIDS is institutions and a program for training institutional staff have already been developed.

This past Spring we conducted a non-random survey of AIDS knowledge, attitudes and behaviors among 2,300 predominantly at-risk Floridians. Knowledge about transmission modes failed to show a significant association with condom use. Almost half of the currently sexually active respondents who reported that condom use was an important means of protection never used them in the last 12 months. The fairly widespread favorable attitude towards the use of condoms only marginally translates into behavior. Other factors besides the general attitude obviously take precedence.

Our data strongly suggest where to look for these competing factors. On one question, we asked respondents, "Suppose you learn that someone <u>you</u> have sex with has the AIDS virus--would you be sure to use condoms when having sex with this person?" Overall, more than 85% said yes, they would use condoms. Even among the large number who presently <u>never</u> use condoms, more than 80% would use them in this hypothetical situation. Clearly, in our sample, the decision to use or not use condoms seems largely based on an assessment of the partner's chances of being infected. Not lack of knowledge, but subjective assessments (and the perceived inconvenience) prevent a wider use of condoms. These risk assessments seem hard to change unless there is a dramatic increase in awareness of the level of HIV infection in at-risk populations.

We plan to re-survey comparable samples of persons on a yearly basis. While generalizations from non-randomly selected groups such as these must be made with caution, trends can nonetheless be monitored.

In summary, the only way to prevent new infections and curb the epidemic is through effective, sensitive education and intervention. An uninformed community contributes to the problems of AIDS at every level of society. Inappropriate responses by those who <u>are not</u> at risk (such as hysteria in the general public) create barriers to rational problem solving. Inappropriate responses by those who <u>are</u> at risk or already infected (such as continued unprotected sex and needle-sharing) increase the spread of the virus. In Florida, the unique combination of cultures and life styles demands innovative approaches, some of which I have highlighted. Systematic and ongoing evaluation is essential to ensure that several years from now we have not missed the boat, and that we make the necessary mid-course corrections in our strategies.

Thank you.

Rev. Wisler Marcelus

ORIGINAL

State of Florida

Department of State

I certify that the attached is a true and correct copy of the Articles of Incorporation of HAITIAN LUTHERAN SERVICES PROTESTANT VOICE, INC., a corporation organized under the Laws of the State of Florida, filed on August 29, 1985, as shown by the records of this office.

The document number of this corporation is N10921.

Given under my hand and the Great Seal of the State of Florida, at Tallahassee, the Capital, this the 30th day of August, 1985.

George Firestone
Secretary of State

CER-101

Good morning Ladies/Gentlemens,
my name is Rev. Wisler Marcelus
I was born Haiti
I would like to tell you a little about myself.

I Stand here on the behalf of my People And other unfortunate people who have been affected With the disease Aids not excluding those Who have love ones that have lost their life to this deadly disease.

From Studies and Statistics it is well known that Aids Kills no one because of their Creed Color or Character People from all walks of life are affected. No one Should be denied the needed help A human being is a human being regardless of origin background.

The only way to Conquer this disease is by We the people coming together as One forming Organizations and Setting up Funds for people and again I Stress people

Who are standing with a need. I have noticed when a person from a Poor or bad enviroment is affected no one seems to care these people

are not equally treated, When a Celebrity is affected then Funds are raised the Whole high officials In high places come out to help. I want Justice for all people

Remember We are All Gods people Lets care and roll up Our Sleeves and get to work.

HAITIAN LUTHERAN SERVICE
PROTESTANT VOICE INC.
1012 S. 26 th AVE.
Hollywood F/A 33020

RE: Rev. WISLER MARCELUS
(305) 921 2745
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ORIGINAL

Fact Sheet on AIDS in Women and Children

Gwendolyn B. Scott, M.D.
Associate Professor of Pediatrics
Division of Infectious Disease and Immunology
University of Miami School of Medicine

Since the first case reports of AIDS in children in 1983, the numbers have increased steadily. As of September 7, 1987, The Centers for Disease Control had received reports of 574 cases of AIDS in children under 13 years of age. The majority of these cases (78%) were due to perinatal transmission, i.e. from an infected mother to her infant. However, this number grossly underestimates the actual number of infected children since there is a broad spectrum of clinical illness associated with HIV infection in children and only the children with more severe illness meet the definition for AIDS and are reportable cases. Using the surveillance definition in force prior to September 1, 1987 for every one child reported with AIDS there were at least two or more children who were clinically symptomatic but did not meet the criteria for the diagnosis of AIDS. Under the new broader definition, approximately 50-60% of cases will be reported. An additional 166 cases are reported nationally in the 13 to 18 year age group. In Miami, we have diagnosed 190 HIV infected children at our medical center between January, 1981 and October 31, 1987. At the present time we are actively following about 100 infected children. Almost all of these children are identified as infected because of the presence of clinical disease. It is not known how many children have infection but are asymptomatic.

In children under 13 years of age, the majority of infection occurs as a result of perinatal transmission. An infected mother may transmit the virus to her infant across the placenta during pregnancy, at the time of delivery, or postnatally by ingestion of infected breast milk. Other causes of infection in this age group are blood or blood product transfusions from an infected donor. In the 13 to 18 year age group, the causes of infection are more similar to those in adults. Approximately 48% are homosexual or bisexual males, 22% have hemophilia or a coagulation disorder, 6% are from blood transfusion, 6% from drug abuse, and 3% from heterosexual contact.

Cases of AIDS in children are reported from 34 states, the District of Columbia and Puerto Rico, but the majority reside in one of four states, New York, Florida, New Jersey and California. AIDS is generally a disease of metropolitan areas and the majority of cases are reported from New York, Miami and Newark. In children, this illness is common in those living in the inner city who come from low socioeconomic backgrounds. Recent national statistics, show that 54% of children are Black, 25 % are Hispanic, and 21 % Caucasian. It is estimated that about 70 % of these cases can be related to drug abuse in one of the parents.

HIV infection in children is largely a disease of infants and toddlers. Over 80% are diagnosed in children under 3 years of age and the majority of children present with clinical illness in the first two years of life. There are a few children who do not develop clinical illness until after age 3, but these are in the minority. Overall, the sex distribution in children is equal. Unfortunately, the prognosis is grim. The proportion of children with AIDS who die is high and national statistics suggest that once a child is diagnosed with AIDS, the median survival is less than one year. The majority of deaths in this illness occur in the first two years of life. There are a few children with long term survival, but many of these eventually develop disease and have significant morbidity and mortality despite longer survival.

The disease in children differs from that in adults. For instance, Kaposi's sarcoma in children is rare, whereas it is common in HIV infected adult males. Also, between 30 and 50% of children develop a lung condition called lymphoid interstitial pneumonitis which is uncommon in adults. Such differences stress the importance of studying the natural history of this disease in children. Also, the diagnosis of disease in infants is more difficult because mother passes gamma globulin containing antibodies across the placenta before birth. If the mother is seropositive to HIV then the baby's serum will also contain antibody to HIV. This is called passive transfer of maternal antibody. However, early in life we cannot tell whether this represents actual infection in the infant, or only passive transfer of antibody from mother to infant. Therefore, antibody testing alone cannot determine whether or not an infant is infected. In some cases this maternal antibody may persist for several months and the child's HIV status may not be able to be determined until 15 or 18 months of age. A definitive diagnosis of HIV infection under 15 months of age can only be determined by the presence of clinical illness, a positive virus culture, or a positive antigen test. Research efforts need to be directed toward the development of simple laboratory tests for diagnosis in the child less than 15 months of age.

From this information, it is clear that if children are to be saved from the devastation of this disease, infected children must be identified early, preferably before the onset of significant clinical symptoms and treated. At present, Phase 1 treatment protocols with both Ribovirin and Azidothymidine (AZT) are underway in children with clinical illness. Results of these trials are preliminary. Drug studies in children have lagged behind those in adults but the urgency to gather information on drugs and move into Phase II treatment trials is no less urgent. It is also important to gain more information about when and how the infection occurs in perinatal transmission. If infants are infected while still in the uterus, then perhaps even treatment at birth will not be effective and antiviral drug treatment should be evaluated in infected women who choose to carry their pregnancy to term in an attempt to prevent disease in their newborn. If the infection occurs at the time of delivery from exposure of the infant to bloody secretions, then an approach similar to that used in prevention of Hepatitis B in infants might be helpful--i.e. to give hyperimmune globulin (high titered antibody against the infecting

agent) in this case antibody to HIV, in an effort to prevent infection.
This could then be combined with a vaccine when available or antiviral
therapy to hopefully protect against disease transmitted through infected blood at the time of delivery. This approach has been very successful in preventing hepatitis B infection in newborns born to women who carry the hepatitis B infectious antigen particle in their blood. Thus, efforts toward the development of high titered antibody to HIV for use in post exposure prophylaxis should be supported. The newborn population is also an ideal population to target for early vaccine trials.

In addition, new drugs must be made available to children as soon as safety is established so that efficacious drugs will be available for treatment of infected children as well as adults. Since many of these children will come from families who are poor and cannot afford the cost of drugs, it is important that these drugs be made generally available so all children have an equal chance for treatment. This will likely require a large allocation of funds to pay for these treatments. Priority should also be given to the development and clinical trials of new antiviral drugs.

One of the keys to control of this disease in infants and young children is to prevent disease in women. Presently the ratio of male to females in the United states infected with AIDS is about 15:1 However over the past year the greatest percent increase in number of cases has occurred in females. As of September 1, 1987, 2840 women had been reported with AIDS. If the number of asymptomatic cases of HIV infection in females is similar to that in males, there may be up to 100 more times this number infected, but not clinically ill. These women are in the child bearing age group and the majority are Black or Hispanic. In our experience with perinatal AIDS, the majority of women are asymptomatic at the time of delivery of their first infant with AIDS. The infant is frequently the first member of the family identified as having HIV infection. In order to deal with this epidemic it is important that women know their HIV status,--to provide the best medical care for themselves as well as to make educated choices about becoming pregnant and having an infant. It is estimated that about 30 to 50% of infants born to HIV positive mothers will be infected. This is a significant risk. Thus, I think it is important to provide testing and counselling in settings such as family planning clinics, prepartum clinics and at the time of delivery. This would provide the pediatrician an opportunity to identify a child at risk early and provide better medical care for this child. Also, as treatments become available then testing and identification of infected infants will become crucial so they can be placed on treatment protocols early.

As stated earlier, the mode of transmission in perinatal disease is not well established. More research is needed in this area. If most of the disease occurs early in gestation then it is logical that women who are HIV positive should be treated with antiviral drugs that are safe to use during pregnancy to prevent infection in the fetus. If

the disease occurs at the time of delivery then a model similar to hepatitis B preventation in the infant might be utilized ie, high titered antibody plus vaccine. In the case of HIV infection, the use of high titered HIV antibody plus antiviral drugs or when available, HIV vaccine. Transmission of the virus via breastfeeding has not been studied extensively, but the virus has been cultured from a small number of specimens of breast milk and there are three reported cases in the literature that are convincing for transmission of the virus by breastmilk to an infant. In one case, mother was infected just after
delivery by a transfusion. She breastfed her infant and seventeen months later both mother and infant were found to be infected with HIV. We do not know whether breast milk from all infected mothers in all stages of disease can transmit the virus. More research is needed in this area, since breast milk is essential in many parts of the world for survival. It is unknown what the incremental risk of infection is if a mother who is HIV positive breastfeeds her infant.

Lastly, I would mention the adolescent age group--generally an ignored group but in the context of AIDS--an important one. The mode of transmission in this group is more similar to adults, ie IV drug abuse, sexual transmission, both homosexual and heterosexual, and transfusion of infected blood or blood products. We have no idea how many adolescents might be infected--even in areas of high prevalence. This is a group where education is essential and they must be aware of how this disease is transmitted. To my knowlege there are few programs and little research effort targeted toward this group. It would be important to obtain baseline data regarding incidence of HIV positivity in adolescents and college students. It is important to learn how to educate this group, and adolescents in high school and college students should be targeted for major educational efforts. They must be aware of how they can protect themselves.

In closing my recommmendations will generally be directed toward women and pediatric populations including adolescents.

1) There should be continued support for study of the natural history of this disease in infants and children as well as the prospective followup of infants born to HIV positive women to determine what proportion of infants will be infected.

2) To better understand the pathophysiology of disease in children, additional funds need to be allocated for the study of organ specific diseases such as: encephalopathy and developmental disabilities in children, cardiac involvement, renal disease and pulmonary disease especially lymphoid interstitial pneumonitis.

3) Support for studies of perinatal transmission including maternal factors which may promote transmission from mother to infant, as well as mechanisms of in utero transmission. In addition, studies of the

role of breast milk in transmission are important. Basic information as to whether the virus is present in breast milk from women in various stages of disease is not available. We also do not know what role specific antibodies in the breast milk play in protection from HIV if the infant is breastfed. The incremental risk to the infant for developing infection if mother is HIV positive and breastfeeds her infant has not been determined.

4) Additional support should be provided for the development of new diagnostic techniques for detection of infection in newborn infants.

5) Support for development of new antiviral drugs is crucial. Drug studies need to be instituted early in children. Treatment programs should be targeted to prevention or modification of disease in newborn infants by treatment of the HIV positive pregnant female or the newborn infant.

6) Funds need to be allocated to provide treatment for all HIV infected individuals.

7) Development of other potential therapies, such as high titered HIV antibody preparations, should be supported.

8) Vaccine development should be a priority.

9) Special funds allocated for development of research space for AIDS activities.

10) Support for development of model programs for education and counselling for families with HIV infection.

11) Support for education and counselling programs stressing modes of transmission and how to avoid infection targeted to school children, adolescents, college students and women.

UNIVERSITY OF Miami

November 12, 1987

Admiral James D. Watkins (Ret.)
Chairman
The Presidential Commission on the Human
Immunodeficiency Virus Epidemic
655 15th Street, N.W., Suite 901
Washington, D.C. 20005

Dear Admiral Watkins,

I have some important testimony that I would very much like you to read, that I did not present to you in person today. The attached testimony includes the presentation I made today, but the additional section, printed in bold face print, begins on page 3 and ends on page 4.

Would you please take a moment to read these two short pages? I cannot express how important I feel your judgments and decisions are. I hope this information is helpful to you, as you make your recommendations for action against AIDS.

I will be glad to assist you in any way I can. Thank you for your time.

Most sincerely,

Lisa Marchette

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Testimony to the
President's Commission on the Human Immunodeficiency Virus Epidemic
by Lisa Marchette,RN, PhD
Associate Professor, University of Miami School of Nursing, and
Nursing Research Coordinator, Mount Sinai Medical Center
Mailman Center for Child Development, Miami, Florida
November 12, 1987

I appreciate the opportunity to address this important commission. I would like to share with you my assessment to some critical problems in nursing, related to AIDS.

First, the shortage of nurses and nursing students is a major nursing threat that has been heightened by nurses' feelings about caring for people with HIV infection (which includes PWAs and PWARCs). Nurses experience fear, anxiety, anger and depression when they care for people with HIV infection. These feelings decrease nurses' morale and in some cases, their willingness to care for people with HIV infection. This unwillingness to care for people with HIV infection is closely linked to nurses' migration to other professions. Most importantly, the quality of care to people with HIV infection.

In addition to education and support groups, strong leadership from the Center for Disease Control (ie, universal precautions), Occupational Safety and Health Administration and the Joint Commission for the Accreditation of Health Care Facilities, can help to prevent havoc in health care facilities. Their rules, guidelines and scientific rationales must continue to guard the health of care providers, while protecting the rights of patients. Specifically, I refer to mandatory testing of all patients in facilities, so that some nurses and other care providers can take special precautions with patients who are infectious. The CDC universal precautions guidelines are much more reasonable than mandatory testing of all patients. Mandatory testing of all patients would (1) violate patients' rights to privacy (especially when confidentiality is often violated), (2) present positive test results to patients who cannot emotionally copy with the results, (3) cause people who suspect they have HIV infection to avoid health care facilities, because HIV is the root of much discrimination, and (4) cause health care providers to falsely assume that patients with negative HIV test results are non-infectious, leading to poor handling of body fluids and subsequent infection of care providers.

Second, nursing research is needed to determine the effect of non-medical "alternative" and "holistic" therapies for HIV. The literature cites treatments for AIDS that include: meditation, yoga, macrobiotics, vitamins, relaxation, visualization, therapeutic touch, acupuncture, homemade medicines, medicinal herbs, aerobic exercise, subliminal messages. Research is needed to determine the effects of these therapies, the types of people who choose them and the types of people who are satisfied with them.

Third, funding incentives and support are needed for AIDS-specific education in nursing baccalaureate, masters, doctoral and continuing education. Nurses must continually learn about AIDS discoveries and decisions.

Fourth, I commend the highest priority of nursing research funding given for AIDS nursing research, by the National Institutes

of Health's National Center for Nursing Research and other nursing specialty organizations. Nurse researchers have a unique contribution to make to the AIDS knowledge base. The needs of people with AIDS and ARC are nursing intensive. Traditional and innovative nursing methods must be tested for their effectiveness in people with AIDS, ARC and HIV infection alone. Funding must be increased for NIH National Center for Nursing Research and earmarked for AIDS-related nursing research.

Added the night of the hearing:

When Dr. Primm asked me, at the hearing today, if I thought that higher wages for nursing care provided to people with AIDS would alleviate the nursing shortage and low nursing morale, I replied that money is a good incentive, but nurses must feel comfortable with their job stress levels if they are to cope with their fears, anxiety and depression.

The antidote for the heavy emotional toll that nurses feel related to AIDS, I believe, is APPRECIATION. Many have called the fight against AIDS a war, and it follows that the nurses who consistently drain themselves physically, emotionally, and financially to stay in nursing and care for those fallen in this war, deserve a hero's recognition. Going home with that each day will mean so much to nurses; it will help to balance the emotional baggage nurses bring home.

To use the analogy of war again, I'd like to point out that the nurses who comprise most of the 10,000 women who served in the Vietnam War have raised money for a women's monument to sit near the Washington,D.C. granite monument to the men who died in the Vietnam War. But they cannot get permission to erect their monument. Women, including nurses, deserve and need appreciation for their services as much as men do.

You may think that health care providers feel appreciated and needed and effective. I say that that is why they entered nursing, but I know of few who feel these vital feelings enough to outweigh the costs of nursing.

The form of recognition can be creatively determined by facility administrators and staff. A dramatic but probably effective way that could recognize nurses and others is an issue of a popular magazine with snapshots and one line statements about randomly selected health care providers who have provided a valuable service to PWAs, PWARCs, HIV infected individuals and prevented people from becoming infected. This could be as dramatic as the Newsweek issue that published photos and one line statements about people who had died during one year. Think of the impact this would have on health care providers and on those who may be open to the idea of preparing for a health care career.

A warm thank you and recognition as someone special who is caring for God's children, although that care is many times difficult to give, is what I believe nurses need. Nurses' Day and Nurses' Week come and go each spring, but nurses need their recognition and appreciation every week.

Many nurses love to care for people with AIDS. They not only help them at work, but also volunteer in agencies that provide AIDS-related services. Contrarily, I have been told of nurses who are

relatives of patients with AIDS, of newly graduated nurses who work in AIDS clinics and perform "as though they are robots,...burned out and wearing emotional armour." Still other nurses tell me they left nursing because their spouses were afraid that the nurse would contract HIV from patients and transmit it to the spouse and children. Many nurses still want to care for people with AIDS but need some emotional relief, so they stay in nursing and be caring.

Thank you again for allowing my testimony. I greatly admire your dedication on AIDS and your great responsibility to the President and all Americans.

TESTIMONY

OF

LEON B. KELLNER
UNITED STATES ATTORNEY
SOUTHERN DISTRICT OF FLORIDA

BEFORE THE

PRESIDENTIAL COMMISSION
ON THE
HUMAN IMMUNODEFICIENCY
VIRUS EPIDEMIC

NOVEMBER 12, 1987

PRESIDENTIAL COMMISSION ON THE
HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC
NOVEMBER 12, 1987

Mr. Chairman and members of the Commission,

I want to thank you for inviting me to appear before you today. I must admit that I am a little puzzled about how I can assist you in your work. As United States Attorney for the Southern District of Florida, I am responsible for the prosecution of federal crimes in South Florida. Because of a variety of factors, my office handles the largest serious criminal caseload in the United States. Approximately 50% of that caseload involves narcotics trafficking. As there is a high correlation between I.V. drug abuse and the spread of the AIDS epidemic, we share the same frustrations; dealing with an intractable illicit drug problem. My office deals with the problem from the supply side. My prosecutors and the federal law enforcement agencies assigned to South Florida deal with the importers, distributors and those people who facilitate the flow of narcotics through South Florida.

I want to emphasize that South Florida holds a unique position in drug trafficking. Approximately 70% to 80% of the cocaine and marijuana imported into the United States comes through this area. The vast majority of this illicit trade does not stop here, but rather, the drugs are shipped to the rest of the United States. As a result, those of us in law enforcement in South Florida, be it at the Federal, state or local level are working at the critical juncture in the drug trade. We are trying to stop these drugs from reaching the distributors who sell it on the streets of our cities.

Federal law enforcement in South Florida has focused on the cartels who are responsible for the importation of much of the cocaine imported into the United States. We have also focused on people who assist in the movement of the drugs into the country, be they corrupt foreign officials who provide safe refueling stations, professionals who launder drug proceeds or state, local or federal officials who are corrupted by the extraordinary sums to be earned in the drug trade. Additionally, because South

Florida is the first landfall for so much of the drug trafficking, the United States Coast Guard and the United States Customs Service focus their interdiction efforts here.

I could go on and describe the large number of significant cases that have been made in South Florida. I could also describe to you the substantial changes that have been made in the drug laws to assist law enforcement in the prosecution of violators. However, even with the great strides that we have made on the supply side, the fact remains that this country still faces an enormous drug abuse problem.

The reasons that this district does a land office business in narcotics prosecutions, the reason that in the last fiscal year, law enforcement seized in excess of 30,000 kilos of cocaine and the reason that more and more illicit drugs are being cultivated is the extraordinary demand in this country for illegal narcotics.

My job would be made much easier if demand were reduced. You must remember that traffickers are motivated by greed and the enormous amounts that the American people are willing to pay for

drugs. Doing away with demand removes the traffickers' incentive.

Equally important, the societal cost from drug trafficking has been and is continuing to be well documented. The cost in terms of the breakup of families, the collapse of successful careers, the impact on the quality and cost of manufacturing are givens. What is now added is a new cost -- the spread of this virulent disease.

What we all have to focus on, and what I do not answer for, is how to deal with this demand problem. I am not only referring to the lack of space in drug abuse clinics but also how to stop people, especially our children, from beginning with experimentation. In other words, how do we prevent the first step on the road to addiction. I believe that this issue is appropriately within your mandate because the prevention of drug addiction will prevent the spread of AIDS among drug abusers.

I will be happy to answer any questions you may have.

Thank you.

ORIGINAL

TESTIMONY OF THE FLORIDA STATEWIDE HEALTH COUNCIL

TO THE

PRESIDENTIAL COMMISSION ON AIDS

NOVEMBER 12, 1987

Terrence Collins, M.D.
Associate Professor of Community Medicine
University of Florida
Health Officer for Columbia and Lafayette Counties
President
North Central Florida Health Planing Council
Gainesville, Florida

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of
The Statewide Health Council

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Staff

George A. Schmidt, Ph.D.
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Ronald R. Brown, Ph.D.
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Kathryn J. Nixon
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Shirley J. Hecht
Administrative Assistant

(2) STATEWIDE HEALTH COUNCIL.--The Statewide Health Council is hereby established as a state-level comprehensive health council which is advisory to the department. The Statewide Health Council shall be composed of the 11 chairmen of the local health councils, two members appointed by the Governor, two members appointed by the President of the Senate, and two members appointed by the Speaker of the House of Representatives. At least one of the two members appointed by the Governor, the President of the Senate, and the Speaker of the House of Representatives, respectively, shall be a health care consumer or a health care purchaser. Appointed members of the council shall serve for a 2-year term commencing on January 1 of each odd-numbered year. The Statewide Health Council shall:

(a) Advise the Governor, the Legislature, and the department on state health policy issues, state and local health planning activities, and state health regulation programs;

(b) Promote public awareness of state health care issues;

(c) Consult with local health councils, the Hospital Cost Containment Board, the Department of Insurance, the Department of Health and Rehabilitative Services, and other appropriate public and private entities, including health care industry representatives regarding the development of health policies;

(d) Review district health plans for consistency with state health goals and policies;

(e) Prepare a state report, which includes the evaluations by each local health council for its respective district, on the adequacy, appropriateness, and effectiveness of state funds distributed to meet the needs of the medically indigent;

(f) Assist the Department of Community Affairs in the review of local government comprehensive plans to ensure consistency with policy developed in the district health plans; and

(g) Conduct any other functions or studies and analyses falling under the purview of the mission, goals, and objectives above.

AS A GENERAL PREMISE, ACCESS TO APPROPRIATE HEALH CARE IS CONTINGENT UPON ACCESS TO SOME COMPONENT OF THE HEALTH CARE FINANCING SYSTEM -- BE IT PRIVATE INSURANCE EITHER THROUGH GROUP OR INDIVIDUAL POLICIES, OR A PUBLIC PAYMENT MECHANISM SUCH AS MEDICARE, MEDICAID, OR IN SOME STATES, PROGRAMS SPECIFICALLY ESTABLISHED TO MEET THE NEEDS OF THE MEDICALLY INDIGENT WHO DO NOT QUALIFY FOR THESE OTHER PROGRAMS. WITHOUT A PAYMENT MECHANISM, ACCESS TO APPROPRIATE, QUALITY HEALTH CARE IS DIFFICULT TO OBTAIN UNLESS THE HEALTH CARE FACILITY OR AGENCY IS PREPARED TO ASSUME THE COST OF TREATMENT AS PART OF ITS BAD DEBT OR CHARITY CARE.

THOUGH ESTIMATES MAY VARY, PRIVATE INSURANCE HAS PAID FOR APPROXIMATELY 40 TO 65 PERCENT OF THE MEDICAL CARE FOR PERSONS INFECTED WITH HIV. FACED WITH THE PROSPECT OF RAPIDLY ESCALATING COSTS, THE INSURANCE INDUSTRY IS SEEKING WAYS TO BETTER SCREEN INDIVIDUAL APPLICANTS, ASSESS RISK AND PRICE PREMIUMS ACCORDINGLY, OR REFUSE INSURANCE TO HIGH RISK APPLICANTS. AT THE SAME TIME, STATE LEGISLATURES AND INSURANCE DEPARTMENTS ARE CONSIDERING REGULATORY METHODS TO INSURE CONTINUED ACCESS TO HEALTH CARE THROUGH PRIVATE INSURANCE. SEVERAL STATES FORBID THE INSURANCE INDUSTRY FROM ASKING ABOUT PRIOR AIDS-RELATED TESTING, OR USING AIDS RELATED TESTS DURING THE APPLICATION PROCESS, THE BROADEST RESTRICTIONS BEING PLACED IN THE DISTRICT OF COLUMBIA.

THE USE OF AIDS-RELATED TESTS AND INQUIRIES INTO THE TEST HISTORY OF APPLICANTS FOR INSURANCE HAS RAISED CONSIDERABLE CONTROVERSY. THE INSURANCE INDUSTRY NOTES SEVERAL ARGUMENTS SUPPORTING ITS USE OF THESE TWO PROCEDURES IN THE UNDERWRITING OF INDIVIDUAL LIFE AND HEALTH POLICIES, INCLUDING: THE ISSUE OF FAIRNESS TO ALL APPLICANTS; THE RELIABILITY OF THE ELISA-ELISA-WESTERN BLOT SERIES; THE INCREASING PERCENTAGE OF HIV INFECTED INDIVIDUALS WHO GO ON TO DEVELOP AIDS OR ARC; ADVERSE SELECTION, THE THREAT OF UNCONTROLLABLE FINANCIAL LIABILITY; AND THE BASIC PRINCIPLE UPON WHICH THE INSURANCE INDUSTRY IS BASED, DETERMINATION OF RISK. ADVOCATES FOR HIV INFECTED INDIVIDUALS, ON THE OTHER HAND, ARGUE FOR THE PROHIBITION OF TESTING BASED UPON SUCH ARGUMENTS SUCH AS DISCRIMINATORY USE OF THE TEST; CONCERNS OVER CONFIDENTIALITY, AND POSSIBLE ADVERSE EFFECTS IN EMPLOYMENT, HOUSING AND OTHER FACETS OF LIFE; DIMISHED ACCESS TO THE HEALTH CARE DELIVERY SYSTEM; DISINCENTIVES TO THE VOLUNTARY TESTING PROGRAM; GENERAL PUBLIC POLICY CONCERNS AND THE PREDICTABILITY OF HIV RELATED TESTING.

THE STATEWIDE HEALTH COUNCIL RECOGNIZES THE VALIDITY OF MANY OF THESE CONCERNS AND HAS ADOPTED AND RECOMMENDS TO YOU THE FOLLOWING POLICY COMPONENTS:

- THE DETERMINATION OF HIV SEROPOSITIVITY SHOULD NOT BE USED AS THE BASIS FOR ADVERSE UNDERWRITING DECISIONS ON AN INDIVIDUAL'S APPLICATION FOR INSURANCE OF ANY TYPE INCLUDING HEALTH AND DISABILITY FOR CONDITIONS THAT ARE NOT RELATED TO THE HIV INFECTION.

- INVOLUNTARY TERMINATION OF INSURANCE COVERAGE FOR A PERSON WHO IS DIAGNOSED WITH AIDS OR ARC UNDER THE CONTEXT OF A PRE-EXISTING CONDITION SHOULD BE PROHIBITED.

- TESTING FOR THE PURPOSE OF OBTAINING INDIVIDUAL LIFE, HEALTH, AND DISABILITY INSURANCE SHOULD NOT BE PROHIBITED BY LAW, BUT THIS TYPE OF TESTING SHOULD BE RESTRICTED TO THE USE OF THE MOST ACCURATE SERIES OF TESTS, WHICH IS CURRENTLY THE ELISA-ELISA-WESTERN BLOT SERIES.

- GUIDELINES SHOULD BE DEVELOPED SO THAT THE INDUSTRY'S USE OF THIS TEST IS APPLIED IN A NON-DISCRIMINATORY FASHION, I.E., REQUIRED UNIFORMLY OF ANY APPLICANT WHOSE MEDICAL HISTORY

INDICATES THAT THERE IS A SUFFICIENT AND APPROPRIATE REASON FOR REQUIRING SUCH A TEST; THAT THE TEST WILL BE ADMINISTERED ONLY AFTER INFORMED WRITTEN CONSENT OF THE INDIVIDUAL TO BE TESTED; THAT THE TEST BE ACCOMPANIED BY APPROPRIATE COUNSELING; THAT THE RESULTS OF SUCH A TEST WILL BE STRICTLY CONFIDENTIAL, DELIVERED IN PERSON TO THE INDIVIDUAL TESTED, AND NOT BE INCLUDED IN ANY INDUSTRY DATA BANK. TESTING FOR PURPOSES OF GROUP INSURANCE SHOULD NOT BE PERMITTED.

- SINCE CURRENT PUBLIC HEALTH MEASURES TO DEAL WITH THE SPREAD OF AIDS DEPEND HEAVILY UPON THE VOLUNTARY TESTING PROGRAM, THE BENEFITS OF WHICH HAVE NEVER BEEN QUESTIONED, AND BECAUSE INFORMATION OBTAINED FROM INQUIRY INTO AN APPLICANT'S PRIOR TEST HISTORY MAY HAVE LIMITED ACCURACY, INQUIRY INTO THE PRIOR AIDS-RELATED TEST HISTORY OF AN APPLICANT FOR INSURANCE OF ANY TYPE, EITHER DURING THE APPLICATION PROCESS OR DURING AN INVESTIGATION CONDUCTED BY THE INSURER OR AN INSURANCE SUPPORT ORGANIZATION ON BEHALF OF AN INSURER, SHOULD BE PROHIBITED.

- LEGISLATION SHOULD BE UNDERTAKEN TO INSURE THAT CONFIDENTIAL INFORMATION CONCERNING HIV INFECTED PERSONS THAT IS HELD BY INSURANCE COMPANIES AND INSURANCE SUPPORT AGENCIES BE PROTECTED FROM THIRD PARTY ACCESS, INCLUDING UPON SUBPOENA OR ANY OTHER METHOD OF DISCOVERY EXCEPT UNDER RARE ND SPECIFIED CIRCUMSTANCES.

- FEDERAL LEGISLATION SHOULD BE ENACTED TO PREVENT DISCRIMINATION ON THE BASIS OF AIDS OR HIV SEROPOSITIVITY IN EMPLOYMENT, HOUSING, SCHOOL ADMISSION, PUBIC ACCOMODATION, AND THE PROCUREMENT OF GOODS AND SERVICES.

THE ABILITY OF THE INSURANCE INDUSTRY TO USE AIDS RELATED TESTS FOR THE PURPOSES OF INDIVIDUAL HEALTH INSURANCE WILL INEVITABLY RESULT IN AN INCREASING NUMBER OF INDIVIDUALS WHO CANNOT PURCHASE PRIVATE INSURANCE TO COVER THE EXPENSES OF THEIR HEALTH CARE NEEDS. THE STATEWIDE HEALTH COUNCIL SUPPORTS THE CONCLUSION REACHED BY THE COMMITTEE ON A NATIONAL STRATEGY FOR AIDS OF THE INSTITUTE OF MEDICINE AND THE NATIONAL ACADEMY OF SCIENCES WHICH STATES:

". . .SOCIETY HAS AN ETHICAL OBLIGATION TO ENSURE THAT ALL INDIVIDUALS RECEIVE ADEQUATE MEDICAL CARE. THIS IMPLIES THE OPPORTUNITY TO MAKE PROVISION FOR, OR OTHERWISE BE ASSURED, THAT

THEIR FUTURE HEALTH CARE COSTS WILL BE COVERED. THOSE WHO CAN AFFORT IT SHOULD PAY PREMIUMS SO THAT THEY ARE INSURED, BUT THOSE WHO CANNOT HAVE A RIGHT TO EXPECT PUBLIC PROVISION."

THEREFORE, THE STATEWIDE HEALTH COUNCIL MAKES THE FOLLOWING ADDITIONAL RECOMMENDATIONS:

- THE ESTBLISHMENT OF RISK POOLS, SUCH AS THOSE ALREADY DEVELOPED IN ELEVEN STATES INCLUDING FLORIDA, SHOULD BE ENCOURAGED THROUGH FEDERAL LEGISLATION AND FUNDING SO THAT INDIVIDUALS UNABLE TO OBTAIN CONVENTIONAL INSURANCE CAN PROVIDE FOR THEIR HEALTH CARE NEEDS. ELIGIBILITY REQUIREMENTS SHOULD BE STRUCTURED SO THAT ANY HIV INFECTED INDIVIDUAL IS IMMEDIATELY ELIGIBLE FOR ENROLLMENT.

- FEDERAL INCENTIVES SHOULD BE DEVELOPED TO ENCOURAGE STUDIES BY THE STATES TO DETERMINE THE FEASIBILITY OF IMPLEMENTING A PROGRAM OF SUBSIDIES FOR PREMIUMS AND/OR DEDUCTIBLES TO INDIVIDUALS PARTICIPATING IN SUCH RISK POOLS.

- LOSSES TO STATE RISK POOLS SHOULD BE SHARED BY ALL HEALTH INSURANCE PROVIDERS, INCLUDING THOSE

WHO ARE SELF INSURED WHO ARE CURRENTLY EXEMPT FROM PARTICIPATION BECAUSE OF THE EMPLOYEE RETIREMENT AND INCOME SECURITY ACT OF 1974.

- AS A FINAL COMMENT, IT IS OBVIOUS THAT THE CARE AND TREATMENT FOR THOSE INFECTED WITH HIV IS GOING TO BE COSTLY AND THAT BOTH THE PUBLIC AND PRIVATE SECTORS WILL BEAR A SIGNIFICANT SHARE OF THE COSTS. WHAT IS UNRESOLVED IS THE PROPORTION THAT EACH WILL SHARE, AND WHETHER GEOGRAPHICAL AND URBAN AREAS THAT HAVE BEEN AFFECTED THE HARDEST BY THE AIDS EPIDEMIC WILL SHARE A GREATER BURDEN OR WHETHER THE COSTS WILL BE MORE EVENLY DISTRIBUTED WITHIN THE INDIVIDUAL STATES OR THE NATION. WHILE THESE QUESTIONS DEMAND EXAMINATION AT THE FEDERAL LEVEL, THEY ALSO COME AT A TIME WHEN BUDGET CONSIDERATIONS ARE FORCING CUTS IN MANY SOCIAL SERVICE AND HEALTH CARE PROGRAMS AND THERE IS HESITANCY TO ACCEPT NEW AND PERHAPS COSTLY COMMITTMENTS. INCREASED FUNDING, HOWEVER, IS NOT NECESSSARILY THE TOTAL OR ONLY SOLUTION TO THE PROBLEMS ARISING FROM AIDS. MORE THAN EVER BEFORE, THE FEDERAL AND STATE GOVERNMENTS MUST TAKE AN ACTIVE LEADERSHIP ROLE IN DEVELOPING A COMPREHENSIVE AND INTEGRATED PLAN TO DEAL WITH

ALL ASPECTS OF AIDS, A PLAN THAT DIRECTS THE ANGER OF THE NATION AND OUR STATE TOWARD THE DISEASE RATHER THAN TOWARD ITS CARRIERS. FINALLY, AS GOVERNMENT DIRECTS THE RESOURCES OF THE NATION IN COMBATING AIDS. IT MUST FOSTER THE FORMATION OF NEW TYPES OF PUBLIC-PRIVATE PARTNERSHIPS SPECIFICALLY TO BRING ABOUT MORE CREATIVE RESPONSES TO THE PROBLEM OF CARE AND FINANCING FOR THE HIV INFECTED, AS WELL AS FOR ALL THE UNINSURED IN NEED OF HEALTH CARE.

ORIGINAL

TRANSCRIPT OF ORAL TESTIMONY FOR THE PRESIDENTIAL COMMISSION ON THE HIV EPIDEMIC

BY: REV. DR. JAMES J. McCARTNEY

NOVEMBER 12, 1987
1:30 P.M.
MAILMAN CENTER FOR CHILD DEVELOPMENT
MIAMI, FLORIDA

Mr. Chairman and Members of the Presidential Commission on the HIV Epidemic:

As a citizen of Florida, I thank you for holding your hearings here today in Miami and look forward to this opportunity of presenting some thoughts for your reflection. My name is Father James J. McCartney and I am the System Ethicist for the Allegany Health System and the Director of the Bioethics Institute at St. Francis Hospital. I am also adjunct professor of Moral Theology at St. Vincent dePaul Regional Seminary in Boynton Beach, Florida and professor of Jurisprudence and Ethics and Social Policy at the St. Thomas University School of Law. I also am a member of the Clergy Advisory Committee of the Health Crisis Network, a local agency which serves persons with AIDS and their families and friends. In my remarks I will focus on seven areas where I believe the federal government has responsibility to provide funding and leadership. These include research, education, compiling epidemiological information, assisting other governments, ensuring care, providing housing, and balancing privacy rights over against protection of public health.

1.) RESEARCH: We all know the overwhelming statistics that are currently used in projecting the AIDS crisis for 1991. We know that in the United States alone, it is estimated that over 270,000 cases of full-blown AIDS will have occurred by 1991 and over half of these persons will have died. We know that at least 1.5 to 2 million people are currently infected with the human immunodeficiency virus (HIV). We know that while the cost of care is dropping, nonetheless we can safely say that it costs between $10,000 and $15,000 a year for the average care of someone with full-blown AIDS. We must now add into this another $8,000 per year for those on AZT (Retrovir). All this information puts a tremendous burden on the federal government to try to find both a cure for and a vaccine to prevent this disease as quickly as is humanly possible. Thus the National Institutes of Health should provide funding for basic research in virology with a special focus on retroviruses that will help understand the physiological mechanism of HIV even better. The NIH should also be empowered to conduct clinical trials as expeditiously as possible on new anti-

viral agents with the hope of inhibiting virus growth and eventually bringing about a restoration of the immune system. I believe we must see controlling HIV as the number one health priority for years to come.

2.) EDUCATION: The federal government must continue under the direction of the Surgeon General to provide effective, timely education about the cause of AIDS and its transmission. This should be done in cooperation with state and local governments but should also include such tactics as paying for television time during such widely viewed shows as football games or the Cosby Show. The very effective advertising that the military has developed over the years could be a good model here. The government has a responsibility to provide information about all the different ways in which the spread of AIDS can be slowed and stopped, even while pointing out that some methods are more effective than others.

3.) COMPILING EPIDEMIOLOGICAL INFORMATION: The Centers for Disease Control (CDC) must continue to compile epidemiological information about the disease. Therefore the federal government should require that all HIV positives be reported anonymously to the CDC for epidemiological tracking. The CDC should also develop other relevant statistics which will help us to understand the spread of the disease and those most at risk.

4.) ASSISTING OTHER GOVERNMENTS: Because AIDS is a world-wide pandemic, the United States has a moral responsibility to assist other governments in coping with this disease. This can be done by sending the latest research information to other government-based health agencies for their use. The United States should also build into its foreign aid budget funds which will help foster basic care of people in those countries most afflicted, especially in central Africa and the Caribbean.

5.) CARE: The federal government, through grants and contracts, must ensure the possibility of treatment for all HIV positive persons, and not allow the market to allocate resources as is done in other areas of health care. Access to basic health care must be seen as a human right and not as a commodity since we are talking here about unbelievable suffering and debilitation. The federal government must do all in its power to make sure all the citizens of the United States receive a basic decent minimum of health care, especially in the context of AIDS.

6.) HOUSING: One of the most urgent needs in this region, and, I suspect in others, is adequate housing for those who are in the last stages of AIDS and who need round-the-clock support without the aggressive type of care usually rendered in hospitals. What I have in mind in this regard is something similar to an in-patient hospice care facility. While I believe this is primarily the responsibility of local and state governments, nonetheless the federal government could help in this endeavor by providing funds, possibly through the Department of Housing and Urban Development, to inititate some of these projects and to promote the very efficient, cost-effective philosophy of hospice in the rendering of terminal care.

7.) BALANCING PRIVACY RIGHTS OVER AGAINST PROTECTION OF THE PUBLIC HEALTH: The federal government, as well as other levels of government, must constantly be weighing personal privacy rights over against protection of public health. In this context I will offer ~~three~~ 4 concrete suggestions for the moment:

A.) The federal government should regulate insurance companies so that they cannot refuse insurance for persons who are HIV positive. We must make sure that there is some safety net provided for HIV positive persons, otherwise the care for these persons will be paid directly through the tax monies used for indigent care.

B.) The federal government must enforce legislation which prevents job discrimination on the basis of HIV positivity alone. I believe the federal discrimination statutes in this regard are adequate, but the Justice Department must be instructed by this panel to enforce those statutes efficiently and fairly.

C.) The federal government should enact legislation to protect doctors nationwide from liability when they communicate HIV positivity information to an at-risk sexual partner. This is one case in which I believe personal privacy must yield to the rights of third parties not to be harmed. Right now there is much confusion among physicians as to what their ethical and legal responsibilities are in this regard.

D.) The federal government, while it has the right to screen persons entering military service for anything whatsoever, including HIV positivity, also has the obligation in this context to ensure privacy and confidentiality of those tested. This has not always been the case. The commission should do all in its power to ensure that those who have information about the HIV

status of military recruits or anyone else whom the federal government tests, use those results in an ethically responsible way. Strong and effective legislation should be enacted to prevent the disclosure of this information to unauthorized persons.

In closing I would like to thank the members of the Committee for allowing me to present this testimony. I will include with this transcript the recent pastoral letter on AIDS issued by the Bishops of Florida. I will also include a section of AIDS in South Florida: A Plan for Action issued by the Health Council of South Florida in April of 1986, namely, the Fourth Section on Legal on Ethical Dilemmas on which I worked as a member of the task force established by the Health Council.

Thank you again for being with us today.

PASTORAL LETTER ON AIDS

The Catholic Bishops of Florida

"The joys and hopes, the griefs and anxieties of the people of this age, especially those who are poor or in any way afflicted, these, too, are the joys and hopes, the griefs and anxieties of the followers of Christ." (Gaudium et Spes, 1) Indeed, Our Lord Jesus teaches us: "This is how all will know you for my disciples; your love for one another." (John 13: 35) He tells us that on judgment day He will reward the good by assuring them, "As often as you did it for one of my least brothers, you did it for me." (Matthew 25: 40)

An affliction that is bringing devastating grief and anxiety to the people of our age is the epidemic of AIDS (Acquired Immune Deficiency Syndrome). Victims of AIDS must receive the support of clergy, religious and lay members of the People of God, the followers of Christ.

Victims of the disease often die terrified, lonely, disowned and disconsolate. Their families endure suffering and embarrassment.

Experts tell us that within the next two years most of us will be touched personally by the dread disease through the death of a friend, relative, neighbor or co-worker. The third largest concentration of AIDS in the United States is in our State of Florida.

All of this presents an urgent challenge to those who aspire to be followers of Christ. By our compassion, we follow the Christ who was so compassionate to those in distress, who healed the leper, who wept at the tomb of Lazarus.

We must reject prejudices based on the previous conduct of some victims by recalling the Lord's injunction, "Let him who is without sin cast the first stone." If we are to be truly followers of Jesus, we are called to be in the vanguard in offering what help, what comfort we can to the victims and their families. We need to help provide a better understanding of the disease and how it is contracted, to allay groundless and uninformed fears of infection that cause the cruel isolation of victims. We should be

comforters of families and advocates for governmental aid. Above all, we have to bring the spiritual and sacramental ministry of strength, comfort and hope to the sufferers. Let us be mindful that "The one who is seriously ill needs the special help of God's grace in this time of anxiety, lest he (she) be broken in spirit and subject to temptations and the weakening of faith." (Introduction to the Rite of Anointing and Care of the Sick)

In an effort to respond to this call, we the Bishops of Florida have adopted the following policies for ourselves, our clergy, religious and faithful, as we seek to be true to Jesus living among us. These have been prepared after consultation with pastoral, medical, psycho-social and legal authorities.

1. We commit ourselves to assuring that the victims of AIDS and their families experience the comforting love and hope of Jesus through the ministry of the Church. We call for prayers for the victims and their families, and for the discovery of a cure for the disease.

2. In addition to providing initial orientations to our clergy, religious and lay ministers and educators concerning the pastoral, medical, psycho-social and legal issues related to AIDS, we shall continue to provide information and assist in training programs.

3. While adhering fully to the moral principles of the Church, our social and educational agencies are asked to develop particular policies along two lines: a) to provide, in a manner appropriate to the age involved, education concerning AIDS virus and its transmission, and the formation of a compassionate attitude towards persons with AIDS and their families; and b) to discern the circumstances which will least restrict the admission of clients, students or employees in keeping with sound public health policies and the recommendations of the National Centers for Disease Control (CDC).

4. We recognize that our Catholic health facilities are doing their best to extend their capacities for caring for AIDS-related patients. Some of our agencies, however, are frustrated in their efforts by serious medical, legal and insurance considerations. Nevertheless, we must be true to the healing and reconciling ministry of the Church.

Therefore, if persons who use the services of the diocesan agencies or employees of the dioceses are discovered to be AIDS carriers (HIV-positive), or if they develop opportunistic infections associated with AIDS-related complex (ARC), or develop full-blown Acquired Immune Deficiency Syndrome (AIDS), they are to be treated compassionately and without discrimination. Appropriate care shall be taken, however, that others are not put at risk for HIV infection or infection by other communicable diseases. Such appropriate care, although presently restricting in many situations, will involve the ongoing review and adaptation of the recommendations of the CDC, insurance regulations, and professional medical and nursing standards. Every effort shall be made to maintain confidentiality. In a morass of complications, attention must be centered on the welfare of people—both the sick and the well.

5. We will collaborate with others in advocacy with local, state, and national civic leaders and agencies on behalf of more adequate funding for research, medication and care for those afflicted with the AIDS virus. We recognize that the present assistance is woefully inadequate. Such help is needed because no one civic region, church organization, or medical center can sponsor and support the acute and long-term care facilities, programs, hospices, social and educational services that are so desperately needed.

6. To ensure that our response to the many dimensions of the AIDS crisis continues, the pastoral care for AIDS patients and their families will be assigned to a designated person or office in each diocese. Working within the official structure of the diocese, this designee will coordinate present and future initiatives for patients with AIDS and their families, and serve as liaison with other public, private and religious groups.

We rededicate ourselves to proclaiming the Church's teaching concerning the sanctity of marriage, the virtue of chastity, and the obligation to respect our bodies as gifts of God and temples of the Holy Spirit. It is of note that the federal and state

agencies dealing with the problem of AIDS today advocate the secular values of sexual abstinence, long-term committed monogamous relationships and the avoidance of drug abuse. For it is indeed through promiscuity, homosexual activity and drug abuse that the AIDS virus is frequently spread. To be a Catholic is more than to avoid specific sins, it is to accept fully the presence of Christ, and to manifest our love for God and for all who are made in His image. Thus, as part of our educational efforts, we will call on our people to make this an occasion for grace, conversion and healing, so that our Christian community might assist the sufferers to discover a merciful and compassionate God.

In conclusion, we express once more our grief and anxiety for those who are suffering from the affliction of AIDS and for their distraught families and friends. We thank the members of the clergy, religious and laity who, in the spirit of Christ, have attempted to bring the love of Christ to this catastrophic situation. We commend the members of the medical, nursing and social service professions for their dedication and leadership in facing this crisis.

We ask the support and prayers of our people for their brothers and sisters who are enduring the pain, rejection, discrimination, despair and guilt which so frequently accompany this dread illness. During this Marian Year, we entrust our united efforts to Mary, Sorrowful Mother, Healer of the Sick and Comforter of the Afflicted.

Edward A. McCarthy
Archbishop of Miami

Thomas V. Daily
Bishop of Palm Beach

Thomas J. Grady
Bishop of Orlando

John J. Nevins
Bishop of Venice

W. Thomas Larkin
Bishop of St. Petersburg

Agustin A. Roman
Auxiliary Bishop of Miami

John J. Snyder
Bishop of St. Augustine

Norbert L. Dorsey, C.P.
Auxiliary Bishop of Miami

J. Keith Symons
Bishop of Pensacola-Tallahassee

Date: October 23, 1987

Florida Health Coalition, Inc.
(Formerly: South Florida Health Action Coalition, Inc.)
Suite 201 • 3625 N.W. 82 Avenue • Miami, Florida 33166 • Telephone: (305) 592-4936

ORIGINAL

TESTIMONY

TO THE

PRESIDENTIAL COMMITTEE ON

AIDS

AT

JACKSON MEMORIAL HOSPITAL

MIAMI, FLORIDA

11-12-1987

PRESENTED BY:

JOHN N. SFORZA, EXECUTIVE DIRECTOR

ZOA LANGLOIS, CHAIRPERSON OF THE AIDS SUBCOMMITTEE

I have been asked to address this committee on the economic concerns of employers.

We all recognize the impact AIDS has on the very fiber of our society, not withstanding those issues I will address only the economic concerns of employers faced with a Public Health problem, fast becoming a corporate health and economic problem.

Employers are presently attempting to cope with the financial and administrative toll of AIDS. A toll which we count in human misery, death and dollars.

AIDS is a worldwide problem, here in the United States, Florida ranks third behind New York and California in the number of AIDS cases.

So we are on the frontlines against an enemy with the potential of affecting the Quality of Life so severely, that each of us will be affected whether or not we contact the virus.

The Miami Herald reported earlier this spring that "No one knows the total cost of the problem in Florida". It is true that costs will vary from patient to patient, but the July 30th issue of Medical Benefits reported that the center for Disease Control places the total cost, from diagnosis to death, in the range of $60,000 to $100,000 per patient. These costs reflect the typical hospital treatment for the entire course of the illness. These are direct costs to an employers health care plan. Other costs can be assumed to emerge which can be defined as direct or indirect.

These include but are not limited to:

- Health Care Insurance Premiums - As employer plans experience AIDS related expenses, costs are going to increase, perhaps so much so that smaller employers may not be able to provide health coverage.
- Life Insurance coverage usually provided by employers will also have a serious effect on the cost of doing business, and some will question the value of providing traditional employer paid Group Life Insurance for their employees.
- Disability Benefits, whether they are insured plans such as LTD or salary continuance plans sponsored by employers, will be affected by the potential of prolonged absences of the victims of this disease and their family members. Temporary replacement or productivity losses will result in loss of revenue to all businesses,

These are just a few of the direct costs associated with the Business Community. Other costs do exist which will have a negative effect on all businesses, they are the indirect costs.

These include but are not limited to:

- Employee educational costs associated with the prevention of AIDS, as well as, the costs associated with Safety Information regarding AIDS in the workplace.
- Public Relations costs, regarding public safety of the product. A concern shared by all food processing and distributing businesses.
- Marketing costs of products. Our society is changing.. As the fear of AIDS ends the so called Sexual Revolution, advertising costs will be affected.

Uncollected Health Care costs associated with uninsured AIDS patients will be passed on to the insured population via increases in treatment fees charged to insured or paying patients.

These are just a few of the business community's concerns.
If employers are going to survive this potential national disaster there must evolve a coordinated Federal, State, and local reponse to manage health services and the health financing crisis posed by the escalating AIDS epidemic. The assessment, development and implementation of a comprehensive service delivery system for care of AIDS patients in a cost effective manner must be achieved. Additionally, insurers and employers who are hit especially hard by AIDS claims must be able to protect their solvency through an AIDS insurance pool.

Lastly, while the medical community is working hard to find a cure and vaccine to eliminate this terrible disease, government and businesses should focus their efforts on prevention.
Prevention can be accomplished through educational programs. Government is needed to sponsor large scale preventative programs and as a main source of information, business is needed to sponsor localized preventative programs. But this is very costly to the Business Community, an extra tax incentive should be offered to the corporations that provide AIDS prevention programs for employees and dependents and the Community at Large.

FILE COPY DRAFT

David Berger

COMMENT OF AMERICAN IMMIGRATION LAWYERS ASSOCIATION ON MEANS TO IMPLEMENT STATUTE ADDING HIV INFECTION TO LIST OF DANGEROUS CONTAGIOUS DISEASES

PRELIMINARY STATEMENT

The American Immigration Lawyers Association (AILA) is a professional organization of over 2500 attorneys engaged in the practice of immigration and nationality law. AILA is strongly committed to the fair and humanitarian application of the immigration laws of the United States. We are also concerned about the spread of dangerous contagious diseases in the United States by prospective immigrants. Since Acquired Immune Deficiency Syndrome (AIDS) is one of the most devastating medical diseases in this country, we, of course, support the objective of attempting to limit its spread. The means chosen, however, must be rationally related to the achievement of that objective, particularly where those means may jeopardize the rights of non-citizens to become U. S. permanent residents and of U.S. citizens to be united with their non-citizen relatives.

The proposed regulation regarding HIV infected individuals issued by HHS on June 8, 1987 has been superseded by the recent enactment of PL 100-71, the Supplemental Appropriations Act of 1987. This statute directs the President by August 31, 1987 to add human immunodeficiency virus (HIV) to the list of dangerous contagious diseases contained in §212(a)(6)

of the Immigration and Nationality Act. Since the statute is wholly silent on the means with which to implement this action, we direct our Comment to what those means should be.

I. FOR PERSONS OUTSIDE OF THE COUNTRY, MANDATORY HIV TESTING SHOULD BE REQUIRED ONLY IF THE ELISA AND WESTERN BLOT TESTS ARE AVAILABLE TO IMMIGRANTS AND REFUGEES

The proposed rule of HHS issued June 8, 1987 recognizes that the ELISA test, by itself, is unreliable for identifying persons with the HIV infection.* The test was developed in 1985 to screen blood intended for surgical or emergency use. It is oversensitive by design, on the theory that exclusion of some noninfected blood is preferable to the inclusion of infected blood. A large number of persons tested will produce results that are seropositive and false. Accordingly, HHS has proposed that a positive result on the ELISA test must be supported by results from the Western Blot test or a similarly reliable test. In fact, because of the problem of false positives, it is "standard procedure" to confirm positive results by repeating the ELISA test and then confirming a second positive result with the "western blot" test. Schatz, "The AIDS Insurance Crisis; Underwriting or Overreaching?", 100 Harv. L. Rev. 1782, 1784 (March 1987); Clifford, "AIDS and Insurance; the Rationale for AIDS Related Testing," 100 Harv. L. Rev. 1806, 1812, 1813 (March

* We attach as an appendix a brief background review of AIDS, the HIV infection and the available tests.

1987); New York Times, June 9, 1987, p. C14; Washington Post, July 23, 1987, p. A3.

Many countries, especially third world countries, do not have facilities to administer both the ELISA and Western Blot test. Interview with Carolyn McCloud, M.D., Institute of Tropical Medicine, University of Miami; Washington Post, July 15, 1987, p. A14. An HHS requirement, therefore, that all HIV testing be completed in the alien's home country will uncounscionably bar the entry of all prospective immigrants and refugees (including those who are healthy) from every country without such testing facilities. In support of its proposal precluding testing at the port of entry, HHS states only that it "would create great hardship on those aliens found to be positive." That may be, but the hardship is far less than the admission bar inherent in the HHS proposal.

Finally, even if all prospective immigrants and refugees are given the opportunity to take the Elisa test twice and the Western Blot once, the danger of false positives remains, especially if the tests are administered to low risk populations. Schatz, 100 Harv. L. Rev. supra at 1784-85; Francis, "The Prevention of AIDS in the U.S." 257, #10, JAMA 1357, 1395, March 13, 1987: Washington Post, July 23, 1987, p. A3. For this reason, AILA favors the provision of parole or similar status for

all those who agree to enter an educational and counseling program. See pp. 5-6 infra.

II. FOR PERSONS WITHIN THE UNITED STATES ELIGIBLE FOR LEGALIZATION, TESTING FOR HIV INFECTION SHOULD BE REQUIRED ONLY IF WAIVERS OF §212(A)(6) ARE ISSUED TO APPLICANTS WHO ENROLL IN A COUNSELING PROGRAM

The legalization program enacted by the Immigration Reform and Control Act of 1986 was intended to bring qualified illegal aliens into the mainstream of U.S. society. To encourage legalization applicants to come forward, the statute promises them confidentiality, imposing stiff criminal penalties upon INS officials who breach that promise §245A(c)(5). Any punishment of legalization applicants testing HIV positive by deportation, detention or quarantine would violate this confidentiality protection of IRCA and completely undermine a central purpose of the amnesty program.*

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* Such possible punishments are not fanciful. As Senator Simpson, a principal author of IRCA, stated concerning the recently enacted statute on HIV infection (Cong. Record, June 2, 1987, p. S7415):

> Then do you exclude them and deport them to a country that will not take them? Then what are we talking about? Leaving them here illegally in a status with a communicable disease? That is a possibility. Or, are you talking about detention or areas where they will be kept quarantined? That is really where we are headed here.

The objective of any testing program is to identify infected aliens to prevent the spread of AIDS. Any mandatory testing program of persons in the United States which penalizes those found infected will surely be counterproductive: to avoid identification as HIV carriers, potential legalization applicants will avoid the tests altogether or will disappear upon being found HIV positive. They will thus be driven further underground with the likely consequence that the disease will spread to others.

AILA believes that this catastrophic result need not occur. Under IRCA, the INS may waive the exclusionary grounds set forth in §212(a)(6) in the "public interest", for "humanitarian purposes" or to promote family unity. §245A(d)(2)(B)(ii).* Since the statute does not define these terms, the INS surely may issue such waivers to carry out the legalization statute's objective of encouraging applicants to come forward as well as the public interest of minimizing spread of the disease. We would urge that waivers be issued whenever the alien agrees to enter an education and counseling program. Such a program could provide the individual with information about AIDS and how the virus spreads, and could convey the means and perhaps also the motivation to avoid spreading the virus.

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*The same criteria govern the issuance of waivers for refugees §207(c)(3).

AILA believes that this affords the best possible means of limiting the exposure of the American public to AIDS from non-citizen sources.

In addition to the beneficiaries of the general legalization program, Congress intended in IRCA to legalize Cubans and Haitians who have similarly lived on the edge of American society for more than five years. Since a disproportionate share of Haitians are afflicted with the HIV infection, it is especially important that any testing program be implemented in a fair and rational manner. As with amnesty applicants in general, AILA favors the grant of waivers for all Cuban-Haitians who agree to participate in an educational counseling program. We read the combination of IRCA's §§245A(d)(2) and 245A(f) to permit the issuance of such waivers.

AIDS is probably a unique medical problem; although no cure presently exists, the spread of the virus can be lessened through education and behavior modification. We believe that enforcement of this new ground of excludability should be directed toward a positive result by encouraging legalization applications with a carrot rather than a stick strategy. This approach would limit the spread of the disease by providing HIV positive persons with both the incentive to file legalization applications and with the education and counseling required to prevent the further spread of the virus.

DRAFT

III. FOR OTHER PERSONS WITHIN THE UNITED STATES, HIV TESTING SHOULD BE REQUIRED ONLY IN CONJUNCTION WITH GRANTING STATUS ANALOGOUS TO EXTENDED VOLUNTARY DEPARTURE

The same considerations described in section II above apply to other persons within the United States aspiring to permanent residency. To require HIV testing and to penalize the infected with deportation, detention or quarantine will drive those individuals underground. Just as with persons eligible for legalization, potential adjustment applicants with the disease should be induced to undergo education and counseling. Accordingly, AILA strongly urges that persons who test positive not be deported or punished. By virtue of the "prosecutorial discretion" inherent in §103 of the INA or by analogy tothe "extra-statutory" remedy of extended voluntary departure, the Attorney General should permit those afflicted with HIV infection to remain in the United States.

There are additional moral and practical considerations for this position. In all likelihood, HIV positive applicants presently within the United States became infected here because the virus has at most a six month incubation period. Francis, supra at 1359, Clifford, 100 Harv. L. Rev. supra at 1812. The United States presently leads the world in the number of reported AIDS cases, and due to American global mobility, the U.S. has gained an international reputation as a net exporter of AIDS. Should the U.S. require testing without the waivers and

safeguards discussed above, that action may be replicated worldwide, or could cause a quarantine war with other nations. The cost to U.S. trade would be extreme and the loss of freedom of movement would be catastrophic to U.S. citizens. Such international retaliation can be avoided by a fairly administered program of comprehensive testing whose purpose is solely to educate and counsel the victims of this dread illness. AILA belives that only such an approach can reconcile the humane objectives of our immigration laws and the health protections mandated by the AIDS disease.

DRAFT

APPENDIX

Since the recognition of AIDS in 1981 there have been 36,514 cases reported in the US, of these 21,155 have been fatal. (1). The Public Health Service (PHS) estimates that 270,000 Americans will develop AIDS by 1991. (2). The present majority medical opinion states that a virus, human immunodeficiency virus (HIV) is strongly associated with, and is probably causative of, AIDS. The disease has been present in localized areas of central Africa for several decades, and during the past two decades has spread through Africa, the Caribbean, Western Europe and the US. (3). Epidemiological authorities generally believe that the present AIDS epidemic is the result of infections that occurred in the 1970s and early 1980s before the pathology and means of transmission were identified. (4).

It is generally believed that HIV transmission is the product of sexual contact, blood borne transmission (shared needles or transfusions) and by perinatal transmission either in utero, during birth or via breast feeding. (5). There is a minority view that claims the virus is transmitted by enviromental agents such as mosquitos, particularly in tropical areas including the Carribean and Belle Glade, Florida. (6). There is another recent and will documented minority view that HIV is not the actual cause of AIDS but that HIV is associated with AIDS, and that the cause lies with some entirely different microrganism. (7).

Blood tests for AIDS were developed in 1985 as a response to contaminated medical blood supplies. At present AIDS is not directly tested, rather the AIDS precursor virus, HIV, is identifed by the presence of HIV antibodies in the bloodstream. There are three tests in use: the ELISA, which is oversensitive and produces numerous false positive results (8), the Western Blot test which is said to eliminate most false positives (9), and a third test which is used only for clinical purposes. The combination of two ELISA tests followed by one Western Blot test is considered to be 99% accurate. (10). However, the figure is debated, and more importatly, the meaning of seropositive results is still unclear. Positive test results and the development of AIDS are two separate events: estimates that a person who tests seropositive will develop AIDS range from 6.4% in five years to 34% in three years. (11). The Centers for Disease Control (CDC) predict that 20% to 30% of those who test positive will develop AIDS within five years. (12). Others estimate those who test antibody positive have an even greater chance of developing full-blown AIDS beyond a five year period. (13). Another opinion holds that all of these figures apply only to high risk individuals who, by their acts, make themselves vulnerable to a wide range of virus infections which will strike opportunistically, but that non-high risk individuals, by reducing their exposue to infections, have a much greater chance of <u>not</u> developing AIDS. (14). There is much disagreement concerning the medical significance of seropositive test results. Lawrence Altman, MD, writing recently for the NY Times on why some infected men do not develop AIDS stated: "But scientists agree that there is no way to predict what the ultimate outcome for virus carriers will be. Only time will provide the answer. Doctors have no

way to advise infected individuals about their chances of developing AIDS. Government officials have only scanty data to use in planning for the economic, social and other problems AIDS will cause." (15).

It is not fully understood if seropositive test results indicate that a person is infective as well as infected. HIV integrates in the host's genes and can presumably stay latent. Consequently, because the virus at some time may convert from a latent to an active status, all antibody positive persons should be considered potentially infectious for reasons of safety. It has been found that in actuality only about 65% of antibody positive persons have had recoverable virus circulating in their blood at any given time. (16). At this stage of scientific development, tests are not sophisticated enough to indicate whether a seropositive test equates with infectiousness at some times or at all times; the question will only be clarified by additional studies. (17).

As well as a debated scientific phenomemon, AIDS is a formidable agent of political action and social-cultural reaction. The spectre of a national or global AIDS plague is so powerful that a reaction, AIDS hysteria, is now a broadly recognized factor which must be considered. C. Everette Koop, US Surgeon General, has termed the hysteria a form of fascism: "This is a vital issue because many people are afraid that there are 'fascists' who in the name of testing intend to implement a private agenda of persecuting drug addicts and homosexuals. Some even talk of tatooing AIDS patients, or worse, quarantining them. This would not only be a massive infringement of civil rights, but it would also be impossible to implement and, if implemented, ineffective at combatting the real problem." (18).

Probably because AIDS became known as a disease that was sexually transmitted by social groups popularly believed immoral or of low social status. AIDS is a disease that carries a stigma of fault or blame. In making any analysis of AIDS, its effects on society, or of government policies towards the disease, a sharp eye must be kept on factors of hysteria or blame.

Presently there are two schools of thought concerning what this society should do to protect itself from those who are already infected. There is the mandatory testing school which implies that seropositive individuals, once identified, will face some form of mandatory restraints on their behavior. Secondly, there is the school of thought which argues that voluntary testing, combined with rigorous public education and counseling of the infected will effectively control the disease.

DRAFT

Notes

1. NY Times, "AIDS Test Ordered for US Prisoners and Immigration," at 1.

2. 101 Public Health Report, 341 (1986), at 345.

3. 29 Science 1352, (1985), Morgan: "The Epidemology of AIDS-Current Status and Future Reports," at 1353.

4. 257, N° 10 JAMA 1357, (3/13/87), Francis: "Prevention of AIDS in the US.

5. Id., at 1358.

6. Conversations with Mark Whiteside, MD and Carolyn McCloud, MD of the Univ. of Miami Institute of Tropical Medicine, week of June 22-26, 1987. See also, NY Times, (7/1/87), "Mosquito Found to Carry AIDS but Not Pass it on," at 9.

7. 47 Cancer Research 1199, (3/1/87), Duesberg: "Retrovirus as Carcinogenss and Pathogens: Expectations and Reality," at 1211.

8. 100 Harv. Law Rev. 1782, (March 1987), Schatz: "The AIDS Insurance Crisis: Underwriting or Overeaching?" at 1784.

9. NY Times, 6/9/87, "AIDS Test Ordered for US Prisoners and Immigration," at 1.

10. Staff: "The AIDS Epidemic, 201 (1985) (citing Dr. Robt. Gallo of the Natl. Inst. of Health).

11. 316 N. England J. of Medicine 61, (May 1987), Polk: "Predictors of AIDS Developing in a Cohort of Seropositive Homosexual Men," at 64.

12. Schatz, Id., at 1784, (see note 8).

13. NY Times, 6/30/87, "Doctor's World: AIDS Mystery," at 23.

14. See note 6. Also see Duesberg, Id., at 1214, (see note 7).

15. NY Times, 6/30/87, Id., at 23, (see note 13).

16. Francis, Id., at 1359, (see note 4).

17. Id.

18. Am. Medical News, (published by AMA), 6/26/87, "Dr. Koop Calls for AIDS Tests Before Surgery," at 1.

James Sammone

FILE COPY

FIGHT FOR LIFE PROJECT

aids coalition endowment
(305) 896-9093

aids coalition endowment

(305) 896-9093

RATIONALIZATION

"FIGHT FOR LIFE" project grew out of the necessity for HIV infected individuals to take the responsibility for their own health care. This responsibility stems from the lack of effective treatment strategies by the government, medical communtiy and pharmaceutical companies.

We are entering our 7th year of this epidemic and still we have only one approved drug. AZT. This horrendous situation stems only from lack of cooperative communication bewteen the three previously mentioned agencies and the lack of serious urgency to deal with the disease on their part. We cannot wait any longer for those entities to solve our problems. We must do what we can to inprove our chances for survival while attemping to adjust to handle epidemics in the future.

In the near future, it's inlikely that the three entities will resolve their affairs in the extraordinary state of emergency -- we must step in and undertake the situation ourselver.

"FIGHT FOR LIFE" project hopes to enroll approx. 20,000 participants by the end of fiscal year of '88'. Each participant will be required to show proof of their HIV infection and submit monthly data to the Research Dept. in ACE, Inc.

University Central Florida's Dept. of Medicine will correlate this data and will submit to the Research Committee for evaluation.

"FIGHT FOR LIFE" project will be the largest undertaking in research and therefore can monitor the largest number of pharmaceutical combinations in the nation and in the shortest period of time. By the end of the first fiscal year, more information will have been compiled on approx. 30 experimental drugs than the NIH will in a five-year period.

"FIGHT FOR LIFE" project will provide brochures discussing the proper use of all avenues that the participants wish to investigate, but in no way will the project at any time handle the sale, supply, shipment or purchase of any unapporved drug.

The "DEATH" drug trails initiated by the pharmaceutical companies are designed to prove the efficiency of their drug while unnecessarily exposing the placebo groups to progression of the disease. HIV patients will no longer have to be guinea pigs for the prarmaceutical companies.

Testing the efficiency of numerous drugs while saving lives is the responsibility that ACE, Inc. has undertaken in a vision of saving lives in our future.

We encourage your comments, criticism and involvement. Contact the "FIGHT FOR LIFE" project at the AIDS COALITION ENDOWMENT (ACE, Inc.) at (305) 896-9093

C
A E

aids coalition endowment
(305) 896-9093

FIGHT FOR LIFE PROJECT

PURPOSE - to encourage HIV'S to take greater control of their lives through education, self-awareness, and pharmaceutical availabilities. To monitor the response of various positive approaches to control as determined by the affected individual in an effort to optimize the effectiveness of current available pharmaceuticals (singularly or in combination). The data gathered in a nation wide approach will be corelated by ACE INC. (Fight For Life, Research Group). The conclusion reached by the Research Group will be used to alter national health care priorities. (Statistical data need not be obtained exclusively from living participants or those using pharmaceuticals).

RESPONSIBILITIES

FIELD DATA COORDINATORS

1 Interview HIV's
2 Coding (HIV's, Doctors, areas)
3 Disclaimer Form (ACE)
4 Medical Release
5 Monthly Data Sheets
6 Administrative Fee
7 Purchasing Program

PROJECT COORDINATORS

1 Collect Data
2 Educate Coordinators
3 Program Development
4 Provide Pharmaceutical Information
5 Alter National Health Priorities

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(305) 896-9093

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Proposed Budget
Fight For Life Project

Computer Costs (1st year)		
Scan Tron Sheets	=	$35,000
$1,000 initial	=	1,000
Program (input)	=	750
Computer Time	=	3,600
Sub total		$41,350
Administrative		
Director	=	$35,000
Assistant Dir.	=	27,000
Statistician	=	30,000
Secretarial	=	20,000
Sub total	=	$112,000
Office Expense		
Printing	=	$10,000
Postage	=	3,600
Supplies	=	2,700
Telephone	=	6,000
Utilities	=	1,750
Rent	=	7,700
Insurance	=	1,200
Travel	=	6,500
Sub Total	=	$71,850
Project Total	=	$225,200

AIDS ACTIVISTS TO ADDRESS PRESIDENT REAGAN'S AIDS COMMISSION

The following is the text of a speech to be delivered to the presidential aids commission in Miami at the Mail Man Center 1601 N.W. 12th Ave. 8th Floor Auditorium on Thursday October 12th Between 12:30 and 1:30 P.M. The speech will be delivered by James Sammone , President, Aids Coalition Endowment Inc.(ACE Inc.)

TEXT

I want to address this comm. both as the President of ACE.. but also as HIV POSITIVE PERSON, so that the comm. will view my statement not only as an organization but as a individual who has been infected with a life threatening disease. We want you all to see us as people not statistics. We are, your sons and daughters, your nieces and nephews, your bank teller, your grocery packers, your clergy, your health care workers, you military and your neighbors.

I realize those facts are frightening to some people and that is why it is of paramount important that this Comm. make the statement that this disease is not transmitted through casual contact. That should be your number one educational goal. It is only through its leadership that the American public will not react hysterical but in a rational and compassionate way. They look to you know for that statement, please, make it'

Once that leadership step has been taken it will then be important that some specific measures to end this epidemic be enacted.

We believe, that the Comm. Need recommend to the president and to the congress that a state of National Health Emergency Exists and that extraordinary measures need be taken.

We want you to feel our sense of urgency but not write us off as terminal. We fully intent to live with this disease. We take the responsibility for our own health and to do what ever is necessary to stay alive. We will do so. That is not a statement of the few but the the determined effort of the many

We are 7 years in to this epidemic which the government did not want to speak about for so many years because of its sexual nature. For that reason many thousands have died unnecessarily. We will die no more! With the inception of this National Health Emergency we will in effect declare war on aids. We must take that declaration as seriously as our last declaration of war during World War II. In that state of war extraordinary measures such as this country has never seen, took place. The most secret of which and the one project which ended the war was the MANHATTAN PROJECT.

We ask you know to endorse the "NEW MANHATTAN PROJECT ON AIDS", as has been advocated by the human rights campaigns and which ACE endorses. That project brought together the most learned mines of its time in an

effort, unsurpassed, in history. That is the kind of leadership that we need, now, from you to combat this health crisis.

We believe that unless that this project is not under taken in short order this epidemic will far exceed the Black Plague in international proportions. We also believe that you know that. Now the American public does also.

The Project need appoint one head with the authority to develop and initiate a national strategy, government agencies, the FDA, CDC, NIH, the Public Health Service and others which should be directly responsible to that one person. It is imperative should this appointment should come from the health Care Community and should be an AIDS expert, not another political appointment.

Time for the politics are over as is the time of bureaucratic haggling and disagreement. We are doing the dies while you are doing the arguing.

This project is what is needed. We are the experts like no others have been we need an expert such as Dr. Matilde Krim to head the project. You may not agree with her politics but you must agree with her expertise.

The appointment should be made from a joint committee of congress to avoid any more political appointments that waste the valuable time that we may have left. Please, we beg you to do this now!

ORIGINAL

TESTIMONY

Presented To

PRESIDENT'S COMMISSION ON AIDS

By

GARY JACOBS
PRESIDENT, HEALTH MANAGEMENT INC.
4620 NORTH STATE ROAD 7, SUITE 209
FORT LAUDERDALE, FLORIDA 33319

NOVEMBER 12, 1987

The cost of AIDS treatment in our society has created a myriad of conflicting options for the payor system, providers of health care services, the patient, and the patient's support system. It has caused employers, insurers, politicians and governments to react to the sensitive nature of the disease itself, along with the costs associated with it. As the payor system (both in the public and private sector) begins to respond, it is clear that humane and cost-effective care is necessary. Morally, each of us has rights, as people of a world community, to be treated fairly, equitably and honestly as we live on this earth.

Florida is in a unique position (as a state with the 3rd highest incidence of AIDS in the nation) to rally its public and private resources to battle this raging foe.

As the public sector becomes the initial focus of concern, we are beginning to see the response of mainstream corporate America. Initially education, training, and strategic planning has begun in the work place (in my opinion) as the first step. Effective case management, coupled with the above tactics, will be necessary weapons to allay the fears and build collective strength.

The insurance industry must implement programs and benefit plans in conjunction with the employer's response at the work place, as well as work with government, at all levels, to

effectively deal with this problem. Herein lies the challenge facing mainstream America. On what terms will employers and their underwriters cover the cost of AIDS treatment? What will be the response of state legislators and insurance commissioners in ensuring coverage? How will the public and private payor systems devise creative solutions?

Florida traditionally has been a low benefit area. Collectively-bargained health coverage is less pervasive in Florida than in the more traditionally unionized areas of our nation. Additionally, dependent coverage cost is usually assumed by the employee, thus forcing a decision of whether or not to cover one's family. If one elects not to cover the family, the potential cost of care will be borne by the public health care systems.

Florida does not have one dominant carrier. Thus, we have hundreds of carriers competing for business. Restrictions and pre-existing clauses rationally lower risk--yet risk protection cannot become a solution. Risk management, through carefully-developed treatment protocols and payment policies, must be implemented in order to contain the costs of AIDS care. Insurers of all kinds must enact case management methods, consistent with current medical protocols, in order to provide humane care in the most cost-efficient ways possible.

Effective case-management techniques may also cause our political institutions to amend rules, policies and laws which presently restrict care for AIDS patients to more costly settings. Under Florida's Medicaid system, without a federal waiver, AIDS patients that qualify for Medicaid coverage can only access providers and services presently covered under our state Medicaid program. This prohibits reimbursement for less costly alternatives and tends to use expensive in-patient care as the system of choice. Zoning at the local level must also be re-examined to foster the development of group living environments for AIDS patients. Reimbursement for such service must be assured, so that lower cost facilities can be developed to serve the special needs of this population. Coordination (through community-based networks) of licensed facilities must be achieved so that, on a county-by-county basis, all residents will be assured of the availability of treatment. Counseling must be an integral part of care from the point of pre-testing to ensure the emotional health of our people.

Through this approach we can build community-based treatment networks which will serve to care for their own residents, with payors assuming their responsibilities and rights, so that as a common community we can face this tremendous challenge together.

ORIGINAL

PRESENTATION BY REPRESENTATIVE ELAINE GORDON

LEGISLATIVE TASK FORCE ON AIDS

FLORIDA HOUSE OF REPRESENTATIVES

THANK YOU FOR THE INVITATION TO SPEAK WITH YOU TODAY. AS A MEMBER OF THE FLORIDA HOUSE OF REPRESENTATIVES FROM DADE COUNTY, I WELCOME YOU TO OUR COMMUNITY. AS A MEMBER OF THE LEGISLATIVE TASK FORCE ON AIDS, I UNDERSCORE OUR COMMITMENT TO WORK WITH YOU TO DEVELOP A STRONG AND EFFECTIVE NATIONAL POLICY TO STOP THIS TERRIBLE DISEASE.

MY PRESENTATION TODAY WILL FOCUS ON THREE AREAS; WHERE FLORIDA HAS BEEN LEGISLATIVELY ON THIS ISSUE; THE OBJECTIVES AND ACTIVITIES OF THE LEGISLATIVE TASK FORCE ON AIDS, AND THEN SOME RECOMMENDATIONS.

THE FLORIDA LEGISLATURE FIRST PASSED AIDS RELATED LEGISLATION IN 1985 WHEN IT ESTABLISHED STATUTORY AUTHORITY FOR THE ALTERNATIVE TESTING SITES. SINCE 1985, 30,000 FLORIDIANS HAVE BEEN ANONYMOUSLY TESTED AT THESE SITES AND APPROXIMATELY 12% HAVE TESTED POSITIVE FOR THE HIV ANTIBODY.

In 1986 we realized we needed to address the public health aspects of AIDS as well as other sexually transmissible diseases and we passed a comprehensive rewrite of our outdated venereal disease statute. This law, which seeks to strike an appropriate balance between the rights of the individual and the need to protect the public's health, strengthens provisions relating to confidentiality, and to reporting, investigating, examining and treating sexually transmissible diseases. Our law has become a model for other states with Illinois recently enacting an almost identical version. Also, in 1986 we passed a law requiring those who have been arrested for prostitution to be offered an antibody test and those who have been convicted to be given the test.

In 1987, Florida witnessed a phenomenon experienced in other state legislatures. Numerous bills relating to AIDS were filed. Most of these bills were referred to the Committee on Health Care, of which I am a member. Because of the importance of the AIDS issue and the need to have a thorough discussion of the various

AIDS RELATED PROPOSALS, THE HOUSE FORMED THE LEGISLATIVE TASK FORCE ON AIDS.

THE LEGISLATIVE TASK FORCE ON AIDS IS MADE UP OF 11 MEMBERS OF THE HEALTH CARE COMMITTEE. MEMBERSHIP IS BI-PARTISAN AND REPRESENTS A CROSS-SECTION OF POLITICAL IDEOLOGY. THE PURPOSE OF THE TASK FORCE IS THREEFOLD; TO RECEIVE AND EVALUATE TESTIMONY ON A VARIETY OF AIDS RELATED ISSUES; TO ACT ON VARIOUS INDIVIDUAL MEMBER BILLS WHICH HAVE BEEN REFERRED TO THE FULL COMMITTEE; AND TO DRAFT LEGISLATION AS A PROPOSED COMMITTEE BILL ON AIDS.

IN PREPARATION FOR THE 1988 LEGISLATIVE SESSION, THE TASK FORCE HAS ALREADY MET TO DISCUSS THE HEALTH CARE DELIVERY SYSTEM AND TREATMENT RELATED CONCERNS, EFFORTS TO EDUCATE ABOUT AIDS, POLICIES CONCERNING SCHOOL CHILDREN AND SCHOOL EMPLOYEES, AND ISSUES RELATING TO COUNSELING, TESTING AND CONFIDENTIALITY. FUTURE MEETINGS WILL FOCUS ON INSURANCE, DISCRIMINATION AND EMPLOYMENT RELATED CONCERNS AND PUBLIC HEALTH MEASURES.

ALTHOUGH IT IS TOO EARLY TO REPRESENT TO YOU A CONSENSUS ON THE APPROACH THE TASK FORCE WILL TAKE CONCERNING LEGISLATION I CAN SHARE WITH YOU A SENSE OF THE CHAIRPERSON'S DIRECTION.

FIRST, WE SEE THE NEED FOR FURTHER IMPLEMENTATION OF A COMPREHENSIVE AND COORDINATED STATEWIDE EDUCATION EFFORT. SECOND, WE MUST CONTINUE TO ENCOURAGE VOLUNTARY AND ANONYMOUS TESTING. THIRD, WE MUST REQUIRE THAT ANYONE WHO RECEIVES AN ANTIBODY TEST BE OFFERED COUNSELING AND FOLLOW-UP SERVICES. FOURTH, IN ORDER TO ENCOURAGE TESTING AND TREATMENT, CONFIDENTIALITY MUST ALWAYS BE GUARANTEED. FINALLY, STRONG NONDISCRIMINATION LAWS, PARTICULARLY IN THE AREAS OF EDUCATION, EMPLOYMENT, HOUSING, INSURANCE AND HEALTH CARE MUST BE ENACTED.

AS PART OF ANY STATEWIDE EFFORT IN THESE AREAS WE RECOGNIZE OUR RESPONSIBILITY AT THE STATE LEVEL TO ACT RESPONSIBLY AND RESPONSIVELY. IN ADDITION TO THE SUBSTANTIVE LEGISLATION WE HAVE ALREADY PASSED AND EXPECT TO ENACT IN THE FUTURE, FLORIDA HAS AUTHORIZED SUBSTANTIAL EXPENDITURES FOR AIDS. FOR INSTANCE, FOR FY 1987-88, WE APPROPRIATED APPROXIMATELY 12.5 MILLION FOR AIDS. HOWEVER, WE ALSO FIRMLY BELIEVE THE FEDERAL GOVERNMENT MUST ALSO SHOW A STRONGER DEGREE OF LEADERSHIP AND A FULLER COMMITMENT OF ITS FINANCIAL RESOURCES.

SEVERAL SPECIFIC RECOMMENDATIONS FOR FEDERAL ACTION COME TO MIND. THE IMPORTANCE OF EDUCATION CANNOT BE OVEREMPHASIZED. WE SHOULD EXPECT NO LESS THAN AN APPROACH WHICH TREATS THIS DISEASE IN A CLEAR, STRAIGHTFORWARD MANNER UNINCUMBERED BY RELIGIOUS OR POLITICAL OVERTONES. SINCE ONE OF THE PRIMARY WAYS THIS DISEASE IS TRANSMITTED IS THROUGH SEXUAL RELATIONS, WE MUST PROVIDE EDUCATION IN A FRANK AND OPEN MANNER EVEN THOUGH SOME MAY FIND SUCH DISCUSSION DISCOMFORTING. FURTHERMORE, THIS EDUCATIONAL

EFFORT SHOULD INVOLVE INDIGENOUS, COMMUNITY-BASED GROUPS WHO HAVE THE EXPERTISE AND EXPERIENCE TO REACH THE BROADEST RANGE OF OUR CITIZENS.

WE NEED A NATIONAL POSITION AND POLICY ON TESTING WHICH UNDERSCORES THE LIMITED AND, IN FACT, COUNTERPRODUCTIVE VALUE OF COMPULSORY TESTING. TOO MANY PEOPLE VIEW MANDATORY TESTING AS A "QUICK FIX" WHEN, IN REALITY, IT IS A "NO FIX."

THE FEDERAL GOVERNMENT MUST ADDRESS THE WIDESPREAD DISCRIMINATION FACED BY PEOPLE WITH AIDS. AS A STATE LEGISLATOR, I CAN APPRECIATE THE CURRENT DEBATE AS TO WHETHER ANTIDISCRIMINATION LAWS ARE BEST LEFT TO THE STATES TO ENACT, I BELIEVE AT THE VERY LEAST WE NEED MINIMUM FEDERAL STANDARDS THAT STATES WOULD HAVE TO MEET OR EXCEED.

MY REMARKS TODAY ARE FROM THE PERSPECTIVE OF SOMEONE WHO HAS BEEN INVOLVED IN THE SUBSTANTIVE AND FISCAL ASPECTS OF THIS ISSUE.

ADDITIONALLY, AS A TASK FORCE MEMBER, I HAVE HEARD MUCH OF THE TESTIMONY YOU HAVE AND WILL RECEIVE. I TRULY APPRECIATE THE MAGNITUDE OF YOUR EFFORTS AND COMMEND YOU FOR YOUR DILIGENCE.

ORIGINAL

PRESENTATION TO
PRESIDENT'S COMMISSION ON AIDS
MAILMAN CENTER AUDITORIUM
MIAMI, FLORIDA
THURSDAY, NOVEMBER 12, 1987

METRO-DADE COUNTY - LOCAL GOVERNMENT'S ROLE IN ADDRESSING AIDS

Presented by:

Sylviane Kaufman, Acting Director
Metropolitan Dade County Department of Human Resources
Office of Health Services

Thank you for this opportunity to appear before you today to speak about Metropolitan Dade County's involvement in addressing the AIDS crisis in this community.

Metro-Dade County government recognized the seriousness of AIDS and it's potential impact on this community dating back to 1982. The County's Health and Human Services Committee was concerned and committed to responding to the AIDS issues and fully supported all efforts by County departments. The County's early participation began with the initial planning efforts of the Health Council of South Florida and in the developmentof the AIDS Network of South Florida.

The County's Department of Human Resources, Office of Health Services and Jackson Memorial Hospital actually constituted the original AIDS "network." The Human Resources Health Center, a 150 bed superior rated County owned and operated skilled nursing facility pioneered the provision of skilled nursing care to AIDS patients in 1982 when no other nursing home in the nation accepted AIDS victims. This community based resource allowed the discharge from Jackson Memorial of AIDS patients who qualified for skilled nursing care. Appropriate treatment is provided in the nursing home at one-fourth of the hospital medicaid rate. Initially Human Resources Health Center responded to the medically needy and indigent segment of this population with an allocation of two beds, using existing staff and existing resources. As demands grew and in order to relieve the pressure on Jackson Memorial Hospital, and allocation gradually increased to 4, 6, 8 and currently 12 beds for AIDS patients. These beds operate at a 100% occupancy rate and on any given day 12-16 patients inappropriately occupy hospital beds at Jackson, awaiting placement at the Center.

Human Resources developed a treatment and staff education program that has received national recognition and has been used as a model throughout the country. It is still the only nursing home accepting AIDS patients in Dade County.

In order to defray the additional costs of caring for these very sick patients, the Office of Health Services aggressively sought and was awarded a special Medicaid rate, roughly double the usual Medicaid per diem. Further, all third party resources are actively pursued. Over two years ago, the County recognized the need to expand total AIDS bed capacity to 30 beds in keeping with the AIDS Network Plan and the Health Council's Plan. To accomplish this goal, the County successfully lobbied for State funds and was awarded $2.3 million dollars in the last legislative session to construct a 30 bed AIDS unit at the Human Resources Health Center. Architectural plans are being developed and the anticipated project completion date is July, 1989. The operating expenses will be included in the Dade County operating budget.

In addition to the skilled nursing services at the Health Center, the Department of Human Resources, Office of Health Services provides Home Health Care, including skilled nursing and homemaker services, medical management of diagnosed AIDS cases in the correctional system; social services, counseling, community education, inservice education for health care providers, and advocacy. Medical detoxification, assessment, referral and residential care to substance abusers with AIDS is provided through the Department's Office of Rehabilitative Services. Emergency financial assistance and independent living facility placement is provided through the Office of Emergency Assistance as part of the AIDS Network Residential Care component.

The County has played an active role in a nation-wide research project funded by the Centers for Disease Control (CDC). The State Department of Health and Rehabilitative Services, State Health Office and the Dade County Public Health Unit have been conducting a study on the transmission of Human Immune-deficiency Virus (HIV) among prostitutes in Miami. Over 95% of the women enrolled in the study have been recruited from the County's Department of Corrections and Rehabilitation at the Women's Detention Center. Project staff have been supported by Metro Dade's Office of Health Services, Prison Medical Services Program personnel without cost to the State.

The County's Community Action Agency provides 20 meals per day to AIDS victims in the community through a private sector agency, Cure AIDS Now. We anticipate this to be an ongoing service to AIDS victims.

One of the most recent Dade County government mandates was that AIDS education be provided to all 22,000 Dade County employees. The County Manager, with full Commission support, formed the Metro Dade AIDS Task Force. The County's Personnel Department has coordinated this effort with input from the Fire and Police Departments, the Labor Unions, the County Attorney, Affirmative Action, the Department of Human Resources and Handicapped services. The Task Force has developed a Train the Trainers Program on AIDS, which will kick-off the week of November 16, 1987. All County departments will have selected staff trained in AIDS education, who will in turn train all departmental employees. In addition, printed brochures on AIDS in English and in Spanish, will be provided to all 22,000 employees. Posters have been designed and 500 will be distributed to all County locations throughout Dade. Brochures and posters will contain numbers to call for further information on AIDS. Each pay check issued next week will contain the statement "AIDS-GET THE FACTS.." Continued information will he provided through articles in Metro-Dade Today, the bi-monthly County publication, through new employee orientation sessions, and through management seminars.

Much has been accomplished in the last six years as health care providers and community leaders have struggled to address the AIDS public health epidemic and its impact on Dade County. Dade County has stretched its resources to the limit in attempting to be responsive and will continue to do so. Although current effort is necessarily concentrated on those already affected by the disease, we firmly believe that uncensored and widespread awareness and AIDS education and prevention programs are probably the most cost-effective means of arresting the spread of this disease over the long term.

We believe that Metro-Dade County's massive undertaking in AIDS service delivery and education demonstrates a committed County government in the war against AIDS.

Thank you for your attention.

ORIGINAL

TO: The President's Commission on AIDS

FROM: Larry D. Capp, Ph.D

SUBJECT: AIDS In The Black Community

Good Morning. My Name is Dr. Larry D. Capp, Executive Director of the Metro-Miami Action Plan. I am a Clinical Psychologist and a Public Administrator.

The Metro-Miami Action Plan (MMAP) was developed to provide a catalytic process through which a broad range of activities would become directed towards the improvement of the quality of life in Dade County's Black Communities. Disparities in quality of life have been identified in several areas. These include Housing, Education, Employment, Criminal Justice, Health and Human Services, and Economic Development. The MMAP process stimulates existing organizations, both public and private sector, to make the elimination of these disparities a priority item in their daily work plans.

The MMAP process is guided by three major factions - community representatives, private sector leaders, and governmental entities. Each of these groups is actively represented on the MMAP Executive Board of Directors.

MMAP has been the catalyst for many positive developments during its relatively short history. These successes are helping to reduce the disparities that exist in Dade County.

Our Health and Human Services Action Committee views the AIDS crisis as a top priority. The challenge facing MMAP and the Black Community is the spread of AIDS in our community and the lack of educational information targeted to all segments of our community.

My presentation will cover two issues that I think the Commission should consider in its deliberations, followed by a concluding statement regarding AIDS in the Black Community.

Issue #1 - Lack of Educational Outreach Efforts Directed Towards The Black Community.

In the absence of a medical solution, the only effective way to halt the spread of AIDS is to discourage the behaviors which place people at risk. This will require public education on a large scale with special efforts targeted at Blacks, since this group is being affected disproportionately by the epidemic. Moreover, Blacks, many of whom require special considerations when developing health education strategies, cannot become effective stewards of their own health unless they have information adequate for this purpose.

However, at present, many Blacks are not being adequately reached by AIDS health information from the mainstream health care system. Many health education outreach programs have been ineffective in reaching the Black Community because the programs are not specific to the "at risk" audience they are trying to reach.

The bottom line is that if you are going to contain AIDS in the Black Community, you've got to have information that's targeted to that community that's understandable in a language that people can understand; and you have to use non-conventional resources to assist in the effort. A grass-roots level health education effort is needed. This involves intense out-reach by sensitive staff.

Some non-conventional forums present in the Black Community are game parlors, street corners and parks where teenagers hang-out; laundry rooms, shopping facilities, community centers where women of child-bearing age go and talk with each other; Churches, and most importantly community-based organizations who have the pulse of the community at their finger-tips.
We must acknowledge that there is a large population of people who either cannot or will not read brochures, and do not access conventional media programming.

Communication methods such as audio-visual educational materials and peer out-reach efforts are methods which have been used as a means by which to educate this group about the risks of HIV transmission

Special outreach efforts need to be directed at tenagers by becoming a part of the required curriculum of local high schools, or encouraging teenagers to put on drama projects that they themselves design, write and act out for their peers.

The thrust behind these efforts is to increase the knowlege and improve the attitudes of Blacks concerning AIDS prevention and detection, and to encourage the Black Community to adopt healthful behaviors and practices which reduce their risk of AIDS infection and transmission.

ISSUE #2 Housing For AIDS Patients/Known and Unknown

The National Centers for Disease Control have issued guidelines which clearly state that, except in certain well-defined instances, caring for or living or working with a person who has AIDS or who is HIV positive presents no health risks.

People with AIDS, already burdened physically, emotionally and economically by the disease, all to often are thrown out of their homes by family, roommates, landlords and neighbors. They have doctors, dentists, nurses, ambulance drivers and nursing homes refuse to provide them with medical care or services.They are often have problems at their jobs. Just recently in Arcadia, Florida, a family was burned out of their home and literally run out of town.

People with AIDS need a facility or home where they can live in dignity. This suggests that funds put into research and educational out-reach should also be put into facilities that care and treat AIDS patients. Funds should also be put into homes where the family is there to support the individual but lack the financial ability to do so. We must insure that no discrimination occurs in housing or other basic necessities of life for all AIDS patients and their families.

Conclusion: "Where Do We Go From Here"

Prejudice against racial and ethnic minorities homosexuals immigrants sexually active people and drug users interferes with our ability to respond to AIDS as a health crisis. This stigmatization of AIDS as "their" disease diverts our attention away from the very real social, economic, discrimination and health issues which affect us all.

We must destroy the myth that AIDS is someone else's problem. This myth assures the continued spread of both the HIV virus and the stigma associated with AIDS, while fueling the growing backlash against women and racial, ethnic and other minorities. We hope and pray that sooner or later this epidemic will be eliminated by the development of effective treatments and a vaccine. Until that time, we must courageously and responsibly accommodate ourselves to the reality of an epidemic, remodeling personal and institutional commitments as necessary. We must dedicate ourselves and our resources to support, to provide practical care and to provide sensitive educational efforts designed to reduce prejudice and to stop the spread of the disease. Thank you for having me appear and share my thoughts with you and may your efforts to address AIDS in this Country be most successful.