# PRESIDENTIAL COMMISSION ON THE HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC

## HEARING ON CARE OF HIV-INFECTED PERSONS

The Hearing was held at the
INTERSTATE COMMERCE COMMISSION BUILDING
HEARING ROOM B
12TH AND CONSTITUTION AVENUE, NW
WASHINTON, D.C.

Thursday, January 14, 1988

**COMMISSION MEMBERS PRESENT:**

**ADMIRAL JAMES D. WATKINS (Ret.), CHAIRMAN**

**COLLEEN CONWAY-WELCH, PH.D.**

**RICHARD M. DeVOS**

**KRISTINE M. GEBBIE, R.N., M.N.**

**FRANK LILLY, PH.D.**

**JOHN CARDINAL O'CONNOR**

**BENY J. PRIMM, M.D.**

**PENNY PULLEN, M.D.**

**CORY SERVAAS, M.D.**

**WILLIAM B. WALSH, M.D.**

**POLLY L. GAULT, EXECUTIVE DIRECTOR**

**COMMISSION MEMBERS NOT ATTENDING:**

**JOHN J. CREEDON**

**THERESA L. CRENSHAW, M.D.**

**BURTON JAMES LEE, III, M.D.**

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## PANEL SEVEN

SPECIAL ISSUES
DENTAL CARE

## PROCEEDINGS

**MS. GAULT:** Ladies and gentlemen, members of the President's Commission, my name is Polly Gault. I serve as the designated federal official and in that capacity it is my privilege to declare this meeting open. Mr. Chairman.

**CHAIRMAN WATKINS:** Good morning. This is the second day of a set of hearings over three days on which we will address the extremely important subject of care of those afflicted with the HIV or AIDS. We put this set of hearings at the very front end of our deliberations on the Commission because we know its great importance to the American people, and certainly those persons with AIDS. We have, acting as Chairman, Dr. Colleen Conway-Welch, Dean of the School of Nursing at Vanderbilt who has extensive experience in care and I felt it would be very appropriate for her to act as Chair for these particular hearings so I will turn over the first of our panels this morning to Dr. Conway-Welch.

**DR. CONWAY-WELCH:** Good morning and welcome. I would like to take the opportunity to recognize the work that the staff has put in on these hearings over these three days, and to underline the fact that much of it occurred over the Christmas and New Year holidays and we are very grateful to them for their assistance. I would also like to point out that most of the panelists also had to be involved over the holidays in preparing their presentations and we are most grateful for the wonderful cooperation that we have received from all the panelists that have come to us on these hearings.

I would like to briefly spell out the format that we will be using today. Our focus on care is addressed along the following lines. Yesterday day we looked at outpatient care issues and inpatient care issues and hospital systems. We are going to continue to look at service delivery issues and then address areas of concern that special needs populations have regarding care. We are also going to be investigating the psychosocial aspects of the HIV epidemic on patients and their families as well as on the care givers themselves and, of course, cost and how we pay for this undergirds our concerns as we address this issue. The panelists have been asked to submit background information to the Commissioners and have been asked to construct their testimony in forms of summaries or recommendations and we appreciate their efforts in that area. We have asked the panelists to confine themselves to brief opening statements and summaries and then we will have the opportunity to be able to involve ourselves in questions and answers with our experts. I appreciate the time and effort that has gone into constructing testimony along those lines. In some ways that is even more difficult.

We will then proceed with questions and answers and we will start with Dr. Sundwall and Mr. Morrison's testimony with Ms. Pullen, on my right. She will be asked the first question. I would ask the Commissioners to confine themselves to one question because we have a wealth of material and I am anxious that everyone has a chance to be heard.

I would like to introduce Dr. David Sundwall. He is the Administrator for the Health Resources and Services Administration. Dr. Sundwall, good morning.

**DR. SUNDWALL:** Thank you very much. Before I give my prepared remarks, Admiral Watkins, let me compliment you on the staff you have put together for this Commission. I worked with a number of these people on the Hill, including Miss Gault and others and I can assure you, that you have some of the finest talent in health policy in this city. I commend you for your efforts in gathering such a talented and capable staff to assist you in this important work.

**CHAIRMAN WATKINS:** Thank you very much.

**DR. SUNDWALL:** I would like to thank you for allowing me to appear before the Commission again to present some of the activities of our Agency.

**DR. SUNDWALL:** You have asked that I present an overview of federal initiatives conducted by my agency in the fight against the acquired immune deficiency syndrome, and also provide some recommendations for your consideration.

As our name indicates, the Health Resources and Services Administration is devoted to developing resources to fight particular problems in health. Thus, our AIDS initiatives are designed to help alleviate the inadequacies of both health resources and services by moving the care and treatment of persons with AIDS, with AIDS-related conditions, and with human immunodeficiency infection into the mainstream of our primary health care system. In the time allotted, I will briefly describe the HRSA AIDS activities and discuss the recommendations we would ask you to consider. These recommendations arise not only from my work in the Agency and our three main programs, but also from the Intragovernmental Task Force on AIDS Health Care Delivery, a committee which I chaired during the past year at the request of Dr. Robert Windom, the Assistant Secretary of Health.

In addition to the work with the Task Force, HRSA has three major AIDS initiatives. First is the AIDS Regional Education and Training centers, or, ETC's, I am not going to discuss today because Dr. Sam Matheny, our AIDS Coordinator at HRSA, will be talking with you tomorrow about our efforts to train health professionals in these centers. I will only emphasize that the need for AIDS related training for health professionals will continue, and must be met through both private and public actions such as these federally funded ETC's.

Our other initiatives are AIDS service demonstration grants and the AIDS Drug Reimbursement Program. I will review these for you briefly. First, under our AIDS service demonstration program, we have to date awarded $25.3 million to support 13 projects. These are located in metropolitan areas with the highest incidence of AIDS.

These projects are important because they address a critical challenge we must face in caring for AIDS patients, and that is coordinating medical and related services into an organized system of care. Grant recipients are required to do the following: They must identify unmet service needs and take steps to address those needs; they must provide optimal integration of community resources through effective coordination; ensure continuity of services through effective case management; and reduce the overall cost of providing medical services for AIDS patients by providing alternatives to hospital care. In addition, because minorities are disproportionately represented in AIDS cases, grantees are required to focus on the needs of minority populations.

As the service demonstrations progress, we will look at the ways in which service and administrative components are linked. For example, the service components of our projects include ambulatory care such as counselling, psychological support and diagnostic services, residential or in-home care which may embrace long term care facilities, hospice services and home care services, case management services, linkage with hospital care, non-medical support services such as running errands or shopping or cleaning for non-ambulatory AIDS patients, and pediatric services where appropriate.

The administrative components of these projects are designed to reach out to the community and integrate care, resources and relationships. For example, area advisory committees and linkages with other AIDS programs at the national, state and local level (for example, the Robert Wood Johnson Foundation) are vital to our achieving the integration we need in AIDS care.

I would like to emphasize that it is not our intent to support the development of a separate system of care for AIDS patients. In fact, it is just the opposite. We intend to mainstream the care of persons with AIDS into our existing health care system. Added information on each of these funded projects has been provided for the record for these hearings. Commission members may already have read about our demonstration projects in the December issue of <u>Health Link</u> magazine which I will share with you here. This magazine is published for health educators and providers. HRSA supported the distribution of approximately 15,000 copies of this special issue devoted to AIDS.

Our last project is the AIDS drug reimbursement program. Last year, Congress reacted to the need of low income AIDS patients who were unable to purchase the newly-approved drug, AZT. The importance of AZT is that it appears to prolong the life of some individuals with AIDS and it is currently the only drug so proven. The Congressional appropriation of $30 million was designed as a one-time source of funds to be awarded to states and territories to reimburse for drugs approved by the FDA as prolonging life for AIDS patients. Low income individuals, as defined by the individual states, not covered by state Medicaid programs or other third party payers or whose state Medicaid program does not provide this drug coverage are eligible to participate.

HRSA is responsible for distributing these funds to states and as of November of this past year, grants had been awarded to all 50 states. Grant amounts were based on the percentage of AIDS patients in the states as compared with the national figures for AIDS patients as of July 2, 1987. For those states with fewer than ten AIDS patients however, a minimum award of $30,000 was made.

Now let me briefly give you our recommendations. We have four that we would like you to consider.

Number one: Increase and improve education for health professionals in the diagnosis, care, and counselling of HIV infected individuals. This critically important need can be met in part through emphasis on curriculum development and training, distribution of education materials and an emphasis on continuing education, including the provision of the most up-to-date, accurate materials available on the care of persons with AIDS. Among those materials, we recommend that a document prepared by our Intragovernmental Task Force on the treatment of AIDS patients, which is titled "Evaluation of Adult Patients Infected with the Human Immunodeficiency Virus," be distributed to all health professional organizations for distribution to their membership. We also want to be sure that staff in federally support health care projects, such as the community health centers operated through HRSA support, are appropriately trained in the diagnosis and management of AIDS patients. We are beginning to address that issue.

The second recommendation: Encourage the expansion of intermediate and long term care facilities which can accommodate the needs of AIDS patients. The Intragovernmental Task Force I chaired recommended that a program of the Department of Housing and Urban Development, specifically their 232 FHA program for mortgage insurance for nursing homes and related facilities, be used as a mechanism to provide for alternatives to hospitalization for AIDS patients. In addition, in December 1987, Congress appropriated $6 million in grant funds for the construction and renovation of non-acute care intermediate and long term care facilities for AIDS patients. We believe that the shortage of non-hospital facilities for AIDS patients is one of the most acute service delivery problems associated with this epidemic. and we would urge your leadership in addressing the issue. The efforts already underway which I have just described are only the beginning and we need commitment from the states in addressing the problem.

The third recommendation is that the Commission should examine the financing system supporting the care of AIDS patients. The Intragovernmental Task Force spent considerable time examining financing programs related to AIDS patients. We concluded that there was lack of uniformity in private insurance, in Medicare disability provisions and the differences among state Medicaid programs. This produces significant problems associated with the treatment and services available to AIDS patients. We would urge the Commission to focus its review on the financing system as it relates to these issues.

Our last recommendation is that we would encourage increased support of health services research related to AIDS and HIV-infected individuals. Our task force was repeatedly struck by the shortage of data and health services research related to the care of AIDS patients. While the National Center for Health Services research is now making headway in this area, we recommend the Commission consider approaches to further stimulate research.

It has been my pleasure to provide this information for you, and I would be happy to answer any questions you might have.

**DR. CONWAY-WELCH:** Thank you, Dr. Sundwall. Next, I would like to introduce Mr. Cliff Morrison. He is Deputy Director of the AIDS Health Services Program of the Robert Wood Johnson Foundation. Good morning.

**MR. MORRISON:** Thank you. Thank you, Mr. Chairman, and I wish to thank all of the Commissioners for providing us with the opportunity to present before you today.

The AIDS Health Services Program is a national initiative of the Robert Wood Johnson Foundation which began implementation in January of 1987. The program is supported by grants totaling $17.2 million to nine projects and eleven communities around the United States. The AIDS Health Services Program grants were provided to support the establishment of specialized, comprehensive health and supportive services for persons with HIV infection. The projects are intended to ultimately serve as models for large, urban, mid-sized urban, suburban and rural projects. The goal of the program is to help bring needed medical and supportive services to persons suffering from HIV infection in the United States by one, emphasizing community-based out-of-hospital care; two, demonstrating that care can be provided to persons with HIV infection more humanely and at a reduced cost; and, three, providing resources to help relieve the burden that caring for persons with HIV infection has placed on many urban hospitals and health care systems in the absence of alternative community-based services.

The Robert Wood Johnson Foundation, a national philanthropy, has awarded more than $800 million in grants since 1972 to improve health care in the United States. The Foundation is committed to serving underprivileged and underserved populations, and attempting to provide assistance to groups that have had difficulty to gaining access to health care in the United States.

Technical assistance and direction for the program is being provided by the Institute for Health Policy Studies of the University of California, San Francisco. The Director of the program is Dr. Mervin F. Silverman, former Director of Health in the city and county of San Francisco. The principal investigator for the program is Dr. Philip R. Lee, professor of Health Policy and Social Medicine and Director of the Institute for Health Policy Studies, University of California, San Francisco, and also President of the San Francisco Health Commission.

The program is also assisted by staff at the Foundation at Princeton, New Jersey, under the direction of Dr. Paul Jelenick, Senior Program Officer. A National Advisory Committee, consisting of experts and leaders in health care and the care of persons with HIV infection from around the United States, have played an active role in the initial review of applications, selecting applicants during the review process, participating in project site visits, monitoring the ongoing operation of the program and providing technical assistance and expertise to the program and the individual projects.

An evaluation of the AIDS Health Services Program has also been funded by the Foundation. The evaluation is being conducted independently by the Centers for Long Term Care, Gerontology and Health Care Research at Brown University, Providence, Rhode Island. The Director of the Evaluation is Dr. Vincent Moore. The focus of the evaluation will be on the key health services and policy questions regarding the impact of the program on the problems that it seeks to resolve. All of the nine projects are participating in the evaluation process.

The funding for the four-year program is being divided into two 24-month grant cycles. The funding for the second 24-month period will be contingent upon performance under the first grant and the potential for the project to be sustained after the foundation support has concluded. The criteria developed by the Foundation and program staff to select the nine projects have been frequently requested by federal, state, public and private granting agencies and organizations.

The AIDS Health Services Program emphasizes out-of-hospital services and each of the projects has organized and developed comprehensive networks of out of hospital or community based services for persons with HIV infection. These comprehensive networks emphasize the utilization of creative approaches to health care delivery at the community level with less emphasis placed on the traditional institutional and medical model systems for care.

The network concept formed the basis for the AIDS Health Services Program utilizing the experience from San Francisco which is a model community based system that seeks to avoid hospital care whenever possible. The model emphasizes strong coordination and a belief that community based systems are not only more efficient but more cost effective as evidenced by San Francisco Developing, the most coordinated system in the United States with the lowest cost per patient.

**DR. CONWAY-WELCH:** Mr. Morrison, would you be able to go to your recommendations so that we have more than enough time for questions for you?

**MR. MORRISON:** Certainly.

**DR. CONWAY-WELCH:** Thank you.

**MR. MORRISON:** The AIDS Health Services Program wishes to make the following recommendations. We would like for the Commissioners to consider encouraging communities to develop coordinated planning efforts for dealing with the HIV epidemic in their locality. Planning should involve input from community groups and an advisory committee that reflects the unique demographics of a given area.

Secondly, we would like to emphasize creating networks for out of hospital or community based systems of care, encourage communities to deliver consortia, service delivery organizations, utilizing the models already in place in the existing national demonstration projects. This can be done by using local resources, expertise, and advisory groups that reflect the individual communities.

The third recommendation is to provide the encouragement and incentives for philanthropies to become more involved in developing service delivery programs for persons with HIV infection. Thank you very much.

**DR. CONWAY-WELCH:** Thank you very much, Mr. Morrison.

**DR. CONWAY-WELCH:** I would like to open the panel for questions now, beginning with Ms. Pullen.

**MS. PULLEN:** Mr. Morrison, when we were in Florida there was testimony concerning the network of services in the Miami area which indicated that at least in some instances, there are physicians who are affiliated with non-network facilities who found difficulty in providing access of their patients to the network facilities. What kinds of provisions have been made in the San Francisco network to overcome that problem, or has it been a problem there?

**MR. MORRISON:** I think it has been a problem, but it has not been the problem but it has not been the problem that it has been in other areas. The Department of Public Health in San Francisco made an effort from the beginning to coordinate with all of the different agencies and organizations within the community. All of the local physicians, all of the local, private hospitals, were encouraged to participate in meetings and groups where people could share ideas and basically to coordinate the system itself within San Francisco. The city also set up almost immediately an AIDS coordinating committee which met on a monthly basis, and representatives from almost all of the private institutions in the city and a number of private physicians attended those meetings as well. In fact, I believe they still are going on.

**DR. CONWAY-WELCH:** Dr. Lilly?

**DR. LILLY:** Dr. Sundwall, as a professor in a medical school, I am particularly interested in professional education and so I am wondering, with respect to your first recommendation for training of health care professionals, in our medical school over the last few years now, we have provided very strong, thorough education about AIDS and the students see AIDS patients constantly throughout their training so I am not worried about the younger generation of physicians. In the high incidence areas, such as New York City, a large percentage of the physicians have learned about AIDS, know what there is to know, though even in New York CIty there are some who are undereducated on the subject, we came to that point of having our physicians well educated very late. How can we face this problem in the less concentrated areas of our country where the epidemic is going to go to places where it has not yet and the people need to know about that?

**DR. SUNDWALL:** This is an enormous problem, one which the federal government cannot handle alone. As I indicated, tomorrow, you will hear from Dr. Matheny in more detail about our educational training centers. We have now funded four, New York University, Ohio State University, the University of Washington in Seattle, and the University of California at Davis. These regional centers will provide outreach educational services in their communities and in the States they serve. We expect to fund more ETC's this year so we will have a total network of 11 regional centers in the coming fiscal year. As laudable as that is, we suspect that these continuing education programs, will each reach about 1,000 health professionals each year. That is just a beginning. I am pleased that the AMA is holding a national conference here in Washington in March, specifically related to AIDS education such cooperation professional organizations and the government, meanswe can eventually reach a substantial number of health providers throughout the country.

**DR. CONWAY-WELCH:** Ms. Gebbie?

**MS. GEBBIE:** Dr. Sundwall, if I were to guess I would probably say a dozen times in the last 20 years we have had demonstration projects around a particular population group or a particular disease in which a limited number of cities or counties or states have been able to show that if you coordinate the care and organize it better and use other facilities, people like it better, the care is more efficient, it saves hospital days, and all of the things we heard about yesterday. I do not remember any of those where we have sustained the change or made it universal once the demonstration project is finished. What sense do you have that this one is going to be any different?

**DR. SUNDWALL:** That is a tough question. As I was just discussing with Christine Brady, sometimes reason does not prevail in health policy. We have a very diverse, pluralistic health care system. I believe the problem is, in part that the public, expects to be able to choose from a broad array of health care services. Unless we have a change in public attitude towards health care, I do not thinks we can really affect broad scale change in our system. However, when we are faced with the needs of certain populations, we are forced to take steps. Those populations can include those who do not have access to resources at all because of inability to pay or those blocked from access such as the AIDS patient, those such as the medical technology dependent child, with multiple handicaps requiring such complex care that it requires management or they will to be locked in a hospital for the rest of their lives or else be barred from care.

I would hope that we might learn some lessons from what we are doing in these AIDS programs and that these will ultimately benefit larger segments of our population.

**DR. CONWAY-WELCH:** Dr. Walsh?

**DR. WALSH:** I would address a similar question to you, Mr. Morrison. First, I think you should be commended. Robert Wood Johnson us one of the few philanthropies which has decided to invest in AIDS, and you mentioned that one of your purposes is to encourage other philanthropies to do that, and the Foundation world was singularly unresponsive to it. In part, however, I think that they have been frightened by the same things that Dr. Gebbie has brought up, that demonstration projects, be they Robert Wood Johnson or federal, have a pretty steady track record of once the project is over, nothing is done, by the community, to sustain it, they simply look around for another sponsor.

Do either of you have any answer for this because this is a significant aspect of our potential recommendation. An awful lot of money has been put into demonstration projects, both privately and publicly, and the result is dismal. How do you evaluate whether it is worth keeping them up? You keep doing them. You have been doing demonstration projects at Robert Wood for 20 years I guess, and all sorts of things, but with the consistent degree of the community really not justifying your confidence. In other words, you have kept trying. It is commendable. What do we do?

**MR. MORRISON:** I think that that is an extremely valid question, and in the case of the AIDS Health Services Program, each of the nine sites were chosen based on their ability to continue once the Robert Wood Johnson Foundation ceased funding, and within the first year of implementation, almost all of the projects have started developing long term plans on how they will be able to do that, and at this point in time we feel very good that most of these projects will be able to carry on once the funding is ceased at the end of the four year period.

**DR. WALSH:** But that is all dependent on somebody else's funding. They are really not ready to fund themselves. That is what I mean. I mean, that is the difficulty.

**DR. SUNDWALL:** Let me add something if I may. Maybe we should not be too pessimistic about our lack of success in encouraging case-managed care. I am not responsible for the Medicaid program. That is in Health Care Financing but I am aware that in the Medicaid program, a system of managed care is encouraged. However, certain requirements must be met before states can receive their federal match. I think you would find nationwide, increasing evidence of the fact that this encouragement works. I think, Ms. Gebbie, you might agree that in Oregon, there probably are such efforts at the state level in Medicaid. We are also evaluating our demonstration projects, and I hope that we have a persuasive case, at the end of a couple of years, that can convince cities or counties or state governments that when they put public money into a treatment program, this is the best way to get the biggest bang for their buck.

**DR. WALSH:** Great. I am glad to hear their optimism.

**DR. CONWAY-WELCH:** Thank you, Dr. Walsh. Dr. Sundwall, I would like to ask you a related question to care. One of your many responsibilities includes the Division of Nursing in the Public Health Service, and I am aware that nurses are a logical resource for counselling patients, particularly around testing issues, and that nurses who have graduate education in psychiatric nursing would be an obvious resource for those positions. I am also aware of the fact that psychiatric nurse training has moved out of the Division of Nursing into NIMH and that NIMH is focusing its dollars on research to the point where there is no money available to support nurses who are interested in getting graduate education in psychiatric nursing. I also appreciate the fact that the Division of Nursing is very aware of that problem. Do you have any comments as to how that might be able to be addressed in the future or how agency cooperation could be gained to do something about the fact that there is no money for psychiatric nursing education?

**DR. SUNDWALL:** Your question is timely. The federal government is in the process right now of completely reassessing its role in training health professionals in general. Just coincidentally, the authorizations for health professions training (that includes doctors, allied health, pharmacists and nurse training) under Titles VII and VIII of the Public Health Service Act expire this coming year. This will require that Congress reconsider what is the appropriate role of the federal government. As you know, these programs have been very successful in training increasing numbers of doctors,nurses and dentists and the whole range of health professionals. In fact, we have more health providers now than we have ever had. Some people think we have a surfeit of providers in the aggregate, but the AIDS epidemic, and the pressures of caring for a growing number of elderly people, are forcing us to reconsider what health professions needs are going to be in the future. I believe that Congress, with perhaps some recommendations from you, should reassess the numeric deficiencies of particular kinds of providers, not just in caring for AIDS patients, though we will have to look at that need as part of in the bigger picture.

**DR. CONWAY-WELCH:** Thank you, that is helpful information. Mr. DeVos?

**MR. DEVOS:** I have one question for you here, Doctor. On the matter of the AZT money that you have granted, how long will that last, and what will you do when that is gone?

**DR. SUNDWALL:** Congress authorized last summer a one-time appropriation. They appropriated one amount of money to assist low income patients needing AZT. It will be up to them to determine if more funds should be made available. We will give them some assistance in that we have to provide a report to Congress on how that money was distributed and if it was effective. Our AIDS Office will, over this coming year, gather information from the states and then report to Congress, but it was not intended to be a ongoing program in the legislation.

**MR. DEVOS:** Have you spent that money already?

**DR. SUNDWALL:** Yes. In fact, sir, I am very proud to tell you that the Agency distributed those funds less than a month after the President signed the bill. That happened because the people that work in that area have done their homework and contacted the states well in advance of the bill becoming law. Of course, the reason was that we did not want HIV infected people to languish over some bureaucratic snafu so we ensured that the money was distributed to the states very, very promptly. Mind you, there has been some irregularity on the part of the states in getting that money distributed to people in need, but at the federal level, it was very quickly distributed.

**MR. DEVOS:** I have become known in this group as the heavy on costs and expenditures and the reason I do that is probably the same as why you do. Mr. Morrison here represents the other side. On the first side we have somebody who is a provider of cash, and whenever somebody is asked to provide cash, voluntarily, through an Agency or a philanthropic Agency, they require some good justification. But in my view, and I think the view of most people, the American citizens are going to ask for some real justification to help people with AIDS. You know, the AIDS community is very interested and they come by here with their wish lists, but the rest of this country is sitting out there saying, it is not my problem. So one of the things I want to make sure we do is that when we go to them, when this Commission goes to them, we have some real numbers to show we are spending our money well and wisely and as economically as possible to get the job done. That is not always done, but that should be our goal and therefore I have got to keep asking the questions that I am sure kind of become a drag here.

I am intrigued with Mr. Morrison's view that we have got to involve the private sector. Now, he speaks of philanthropies in one of his recommendations and getting them to give more but you know, we have got to figure out how to get corporations to give more, along with foundations that are established and organized to give money away. I think the companies and the individuals gave sixty or more billion dollars away last year in this country.

The private philanthropies, corporate giving, individual giving, is a huge amount and will go a long way but only if we have solid numbers to talk about. How do you propose getting this greater input? We have not seen it so far from a lot of foundations, and I want to salute you for the work you are doing. You are a pioneer on that role.

**MR. MORRISON:** Well, thank you very much. We do believe that perhaps with a little bit more direction from the federal government in terms of encouraging other philanthropies to become involved, that this could possibly help in that area. I think that there are probably any number of other ways that it could be approached but I think that that is definitely a good one to begin with.

**MR. DEVOS:** Well, there is such a temptation around here to say, let Uncle Sam do it. Uncle Sam's money is somebody else's money. The government does not have any money unless it steals it -- I mean, takes it from somebody first. They steal it in the sense they have a power to steal but they do appropriate it out of somebody else's pocket, and somebody has got to give it up so somebody else can have it, and we have just got to remember it comes from somebody else's energies. The money is made by people at work.

So there are resources there, and I love your view on community but until we develop a sense of community in the local community where the companies in that community and all the ethnic groups in that community get involved because they figure this is going to effect them all are we going to make it. We can do that nationally or we can try to, but if we cannot make it work in a town, in a medium sized American city where the people who are involved work in your company or are hurting in your company and you see them at your church, we are not going to make it nationally and so I salute your effort. Any recommendations you would have as to how and why you got involved might help us as a model that we could use to reach out to other private foundations to get funding and involvement in the battle.

**MR. MORRISON:** I think it is also important for us to point out that we do have six of our projects that overlap each other, and that has been a great help in those communities and I think that we all looked at those communities very carefully and saw a lot of potential, we saw a sense of community there in the beginning. That is why we are there I believe, and we feel that the efforts there have already been very fruitful, but that is a short period of time.

**MR. DEVOS:** There is a sense of frustration that it is almost beyond us so a lot of people just say, its too big, we cannot handle it. But if I look at my town of Grand Rapids and say, let us say we are going to have 100 cases, and when we look out and project it, it will be 200, and say, that is a manageable number. We can deal with that, and the community, every community dealt with their problem, it is probably manageable. When it becomes manageable in the minds of people then you get participation. There is a long gap between hopelessness and when it is hopeful. So whatever information you have for this Commission that will help the American communities become example of coming together, will help to solve this in every town. You are not going to solve it in this town. This city will solve its problem, but every community has got to deal with its problem locally so I salute you for what you are doing.

**MR. MORRISON:** I think that also with both programs, we have encouraged the communities that we are in but also other communities to start doing planning and coordinating at this point in time because then that is the opening. That allows us then to come in and to offer assistance to them because it shows an effort on their part that they are trying to do something themselves.

**DR. CONWAY-WELCH:** Mr. Chairman?

**CHAIRMAN WATKINS:** On a follow up, Dr. Sundwall, I will not take time here to ask you to answer this, but I would like you to supply an answer for the record. I think as an Administrator, you can give us this information. I would like you to tell us from the time of the appropriation of the dollars to support AZT until the funds got to the states, and I would like you to do the analysis within the states as to when they got it, what they did with those dollars, and how much have gone to the patients, to the people with AIDS because that is what is important. You get an A for getting the funds to the states rapidly. But that is not the issue. The issue is where does it go from there, how well has it been handled and so forth. I think it will be good to know just that little sequence of events, if you could give it to us. If you only use the seven states most affected by the virus and see what they did with it. We would like to know that because we have seen other indications where appropriations and allocations simply have not been picked up and employed in a manner that got it right down to the person with AIDS. I think that is what we have to know. Can you do that tracing for us?

**DR. SUNDWALL:** Yes, sir. We are in the process of that.

**CHAIRMAN WATKINS:** There is no discrimination connected with that. You can probably run that for us. We would like to know the answers to that, and if you can find out if the moneys have not been spent in a way to ensure that AZT got to the persons with AIDS, we would like to know why. There may be some valid reasons in some cases, there may be some hurdles there that we can knock down and so those are the kinds of things we need.

**DR. CONWAY-WELCH:** Thank you. Dr. SerVaas?

**DR. SERVAAS:** I am wondering, in following up Rich DeVos's comments about communities, if AIDS patients go back to their small communities to die, and this is what I have heard around small towns in America, is there any reason why we cannot give them good care in their home towns when they have gone to San Francisco or New York and gotten into drugs. Are not a lot of these people already displaced? They have gone to the big cities. Is the care so complicated, in AIDS, I do not believe it is, it is like syphilis, the great imitator, they get all kinds of diseases, can we not have a community taking care of these AIDS patients, and encourage them to leave the congested urban centers where they can be taken into the hearts of the people in Grand Rapids? I think when people know AIDS patients, it makes a big difference.

**DR. SUNDWALL:** I could not agree with you more. We really do not need to replicate our federal programs in every city in the country. All we intend to do is demonstrate how you can pull resources together with local, city, county and state governments to provide care where there are significant numbers of AIDS patients. It is hard to find good news in the AIDS epidemic, but some of the most heart warming things I have heard are stories of the compassion and care that local communities and families have showered on people suffering from AIDS. There are many stories to the opposite effect but the good ones show that in many instances, people are taken back home and cared for most compassionately.

I would recommend for the Commission's reading, if you have not seen it, a book entitled, Good-Bye, I Love You, by Carol Lynn Pearson, a Mormon mother of four children whose husband, after their divorce acquired AIDS and came home to die. This is a very touching story about how her family, her church, everybody opened up to care for this individual. That is just one example, that we need to capitalize on and talk about instead of just the dreadful cases that do exist when people are denied access to appropriate care. I think these good examples can be encouraged and that there is an enormous capacity in the country to care for these people in our current health care system and among families.

**DR. CONWAY-WELCH:** Thank you, Dr. Sundwall. Dr. Primm?

**DR. PRIMM:** Dr. Sundwall, first I would like to thank you for your kind letter of gratitude that you recently sent to me and then I would like to ask you a question concerning community health centers. It has been reported in the

January 18, 1988, Newsweek that possibly AIDS, a worse case scenario by the Hudson Institute out in Indianapolis, that if present trends continue and that the educated and the more affluent begin to change their behavior patterns, that AIDS is going to become a disease of the underclass, of which I am witnessing particularly in my communities.

I just visited a clinic in Bel Glade, Florida, a health clinic that, by the way, Mr. Morrison, there is a program there sponsored both by the Robert Wood Johnson Foundation, the Health Department of Palm Beach County and certainly also the National Institute on Drug Abuse, a consortia, something that I like to see in small towns as Dr. SerVaas was talking about right here, a consortia or an effort, a combined effort on the part of foundations, on the part of our federal government, on the part of local government to do something about the devastating problem in that community, a joint effort.

I am wondering about the 600 or so community health centers that you fund around the country that have not been included in this consortia of say, medical schools and health departments in other places or have not been targeted for funding so that they could reach out to this underclass, these people who are mandatorily tested, for example, in the Job Corps who are summarily discharged when they are tested and sent back to their communities with no resources whatsoever. People, for example, who come out of the prison who are mandatorily tested or sent back to their communities and have no real health care source to go to immediately.

It would seem to me that community health centers would be that office, that health office that could care for these individuals returning, as Dr. SerVaas talked about that would reduce the cost considerably of them going to hospitals and other major institutions for care. They could have early medication, be followed very closely if they are HIV positive. For example, in Bel Glade, there was not one, and I want to repeat this, not one piece of educational material supplied to that health center from either NIDA nor the Robert Wood Johnson Foundation that I saw, nor the CDC, and I was quite concerned about that, and that was just a visit last week. I would like you to comment on that and enlighten us on that please.

**DR. SUNDWALL:** I am very pleased you mentioned our community health centers because that represent a relatively silent effort by the government. As Dr. Primm has said, we fund 600 community health centers throughout the nation at a cost of about $400 million a year. Those are primarily designed to serve the poor and the underserved in urban and rural areas. This has been an ongoing effort since the late 1960's and it is something that I think quietly and competently goes about providing an awful lot of needed care.

These centers have not, in general, been involved in AIDS care to date, though some have. We do have one commendable effort in New York at the Lutheran Community Health Center, which does have an AIDS initiative. I also believe that they are potential for ambulatory care for a number of minorities. About 60 percent of the people we serve in those centers are minorities, and it is a natural place where we might reach out to them, both to private health education and treatment. We are beginning that.

We do have collaboration between the educational training centers and our community health centers and starting this year, we will focus on more involvement. We have requested support from the Administration for the resources to help all of the providers in those community health centers understand AIDS care and counselling and better.

**DR. PRIMM:** You have already spent $25 million supposedly this year or the year of 1987 and only five of those community health centers were targeted as recipients of some of those dollars. It would seem to me out of $25 million at 600 health centers and the possibilities that they offer to solve some of the problems and the scenario that some of that money could be sent to those centers almost immediately rather than planning on the future. That is what I would like to see happen if possible.

**DR. CONWAY-WELCH:** Thank you. Mr. Creedon?

**MR. CREEDON:** I would like to come back, if I may, to the question raised by Dr. Walsh and that is, if you look out at the number of AIDS cases that we expect to have over the next few years, it is obvious that the hospitals will not be able to accommodate them, nor is it necessary for periods of time during their care that they be in a hospital so it is very important, I think, the work that you are doing to develop other approaches to out of hospital care of these models. I guess I have a question as to whether there is a method or a structure within the government now for objectively evaluating these different models, and then disseminating information concerning them to all of those who should know about it, and possibly having some leverage to have them introduced and if there is no such structure now, should there be a structure and if so, what kind of a structure?

To some extent, you know, we have talked about should there be a czar in charge of the war against AIDS and if there were a czar then presumably he or she would develop a structure for making sure that models with respect to how to care for people, information about them does get disseminated and implemented to the extent that you can appropriately implement them, recognizing that a certain amount of pluralism is desirable. So, is there a structure, should there be a structure and if so, what kind?

**DR. SUNDWALL:** We have built into each of our efforts, whether it be the training and action of health professionals or our demonstration projects, an evaluation component of those to see what works and what does not. Clearly, everything does not work and we are learning as we go along.

**MR. CREEDON:** But there you are evaluating your own efforts rather than somebody else evaluating them.

**DR. SUNDWALL:** That is correct, though, in fact, we have contracted for an outside evaluation. It is not our intent to make ourselves look good, rather we hope to get objective information through contracts with universities or outside groups. I think, the important part of your question is, how can we share those findings with others; how can we disseminate the information. I do not believe there is a need for another organizational structure to disseminate such information. The Public Health Service, already collaborates with many groups including state and territorial health officers, Council of Legislatures, and National Association of Governors. I have a contract right now with the National Association of Governors on maternal and child health and we are working well together. I believe there are many avenues we can use to get this information out. I think the important thing is to make certain that we keep our attention on the effort to get the information out. I think we can do it, we just have to make certain that we are committed to do that in a timely fashion.

**MR. CREEDON:** As Dr. Walsh said, frequently these models are developed and then they never get used, and it may not be because the information does not get out, but somehow there is just inertia in implementing them. I would think the federal government has a lot of leverage, especially with respect to the Medicaid program to make sure it does get done. There could be some pressure, legally or otherwise to encourage it.

**DR. SUNDWALL:** Well, they are certainly encouraged through Medicaid. I know Dr. Roper will speak to you in this sessions. The Health Care Financing Administration is encouraging states to apply for waivers so they can conduct case managed services for AIDS patients through Medicaid programs. Anyway, I continue to believe that we do not need yet another organizational focus in the government through which we share the information. Maybe we do need to look at ways to leverage the states or local communities to look at alternatives to hospitalization.

**MR. CREEDON:** Thank you.

**DR. CONWAY-WELCH:** Thank you, Dr. Sundwall and Mr. Morrison. We would like to move on to the next panel then. We appreciate --

**CHAIRMAN WATKINS:** Let me close it out. Dr. Sundwall, first I would like to point out how important your Intergovernmental Task Force effort was. It is timely for the Commission. It is extremely important. It hits right at the heart of what we have been focusing on yesterday, today and tomorrow. It is extremely important that you pick up from this a sense on the part of the Commission that we want to see these things come to fruition. We want to see them move in some orderly process, learning the lessons, building up because what you have done here is you have laid a template for society, for health care delivery in all areas.

While AIDS becomes an important catalyst to bring these issues it to our attention and get things moving, it could have tremendous ramifications and not necessarily overwhelming expenditures for the federal government so we would like to have some comment from you right now as to what you think the Commission could do, very specifically, to insure that these kinds of recommendations from the most competent people we could bring together in the country. You have done the work now, and it looks very good to us, and it sounds like a nice composite of what we have been hearing during these sessions. To give us a feel for what you think this Commission can do to take these things and move them forward, not just by throwing dollars but by setting the tone. We have talked a little bit about the cooperative effort and how important we think that is between public and private sector. It is something that we can do, I think, in this Commission, and perhaps even in our interim report to the President in February -- give your organization and those who have been working in the field, including the grass roots people out there who are yearning for this kind of effort, a chance to come out in a very positive way that says, no, we are not going to let this gather dust on the shelf. This is not just another study that people can just pick away at and throw a few million dollars at. This is something for the entire country. So what can we do?

**DR. SUNDWALL:** I would be pleased to provide for you a copy of the final report of the Governmental Task Force Report I just received yesterday from Dr. Windom, the Assistant Secretary for Health. As I have mentioned I, chaired that Committee at his request. He established the Committee and I reported to him. I am very pleased that he feels as you do. That is, he does not want to thank me for it and put it on the shelf or publish it. Rather he has, in fact, assigned responsibilities for every recommendation to either my agency or the CDC or to Alcohol, Drug Abuse and Mental Health. He can, in fact, assign us tasks, and he has done that throughout the Public Health Service. He has recommended to the Health Care Financing Administration when appropriate or to the Agency on Human Development, a role for that agency in child care as it regards pediatric AIDS. He believes just like you do that we have to implement these things and he has asked for a timetable so I appreciate your holding our feet to the fire and we will share that document with you from Dr. Windom and in fact give you some dates that we might implement what we are talking about.

**CHAIRMAN WATKINS:** Thank you very much.

**DR. CONWAY-WELCH:** Thank you very much. I would like to welcome the panel this morning. We are addressing psychosocial issues of patients and families and care givers surrounding the HIV epidemic. I am pleased that Mr. Morrison can put on his other hat, and we thank you for staying. I would like to apprise the panel of the fact that we are asking you to limit your comments or recommendations or summaries to a five minutes period because we want to have time for questions and answers afterwards and I would like to alert the Commissioners that we will start this time with questions and answers with Mr. Creedon. Mr. Morrison?

**MR. MORRISON:** This panel discussion is on psychosocial issues. Many of the psychosocial support systems that exist today for working with persons with HIV infections were not in place before the epidemic. By modifying, adapting and expanding these systems, additional service components can be added to assist in meeting the present needs. There is really no better place to observe this phenomenon than in San Francisco.

There tends to be a widespread belief that the San Francisco model or many of the community based support systems that have been developed there are not applicable to other cities or communities. It is important to emphasize that this is only partially true. If we examined the types of systems in place in San Francisco, we can begin to see that many components can be duplicated, modified or adapted to other areas of the country.

It is true that San Francisco, being your neat, very small city, multi-ethnic, with numerous concentrated neighborhoods, the major group affected by HIV infection in the city has, from the beginning, been homosexual and bisexual men. Both the gay community and the medical establishment responded quickly. The gay community organized itself and began working with the traditional health care system to deal with these issues.

The most significant point here is that community groups and bureaucratic systems such as the Public Health Department, again communicating with each other and accepting responsibility, the Department of Public Health and San Francisco

General Hospital were willing not only to work with the community groups, but also, for the first time, to work more closely with community-based service agencies. There are a number of these agencies that we have used as examples I think throughout these hearings such as SHANTI, San Francisco AIDS Foundation Hospice and a variety of other community and church groups which we do want to emphasize.

This needs to be pointed out because the impact of communication and planning and a willingness by all concerned to do both. This occurred because the traditional health care establishment was willing to admit that it could not solve the problems alone. This initial act, which was more symbolic than anything else gave a clear message to historically disenfranchised groups, that message being, we accept clients for who they are and we are willing to work with them, allowing them to be part of the decision making process. This approach, as simple as it sounds, allowed individuals and groups to feel that they were more involved and that they validated and that they had some control over their own lives.

The San Francisco Model, which developed over time, is constantly changing and evolving. The most important feature was that the responsibility was shared at every level from the mayor's office down to the individual seeking health care services. This is not necessarily an easy approach, but it can be facilitated by utilizing planning, coordination and collaboration.

The model depends heavily on psychosocial support systems from a non-traditional perspective and in this model, it began with massive volunteerism. Community volunteers first began working with groups such as the SHANTI project, providing emotional peer support in the area of death and dying, then on to other support services such as financial assistance, practical support, housing and advocacy. Volunteers began joining a wide variety of patient advocacy and service organizations including hospice, community advocacy and church groups as well. This gave San Francisco an edge early in the epidemic and has resulted in a model to make communities take responsibility and action locally and not wait for the state or federal government to act for them.

Volunteerism itself can be very helpful and significantly influence the aspect of cost containment. However, in our experience, we realize that communities cannot totally depend on volunteers for the delivery of services. Even in San Francisco, the recommendation has been to utilize volunteers when and where possible to start programs, but plan from the beginning that eventually most of these activities will have to be assumed by salaried or professional staff. It should be emphasized that this can still be a major cost saving for communities, particularly during the early phase of the implementation.

Churches and religious groups historically have provided the best models for volunteer programs and activities and at this time more and more of them are becoming involved with the epidemic. Over the past several years, church groups have developed supportive services for people in their own neighborhoods or in relationships with such organizations as hospice. An excellent example of church involvement is in New Orleans where the entire system, the New Orleans AIDS project, is administered through the Associated Catholic Charities, the organization that historically in that city has responded to local needs, and that project, I would like to add, is also funded through the Robert Wood Johnson Foundation.

When these kinds of services are developed, coordination of training, supervision and ongoing development need to be addressed to prevent duplication and to standardize the services being delivered. This approach can also be utilized with a different mix of clients as well, but it becomes even more important as the numbers of HIV infections among substance abusers, increase. For example, as the number of substance abusers increase, the need for more training and the involvement of more mental health care providers with specific expertise in substance abuse issues becomes necessary.

Creating these pools of volunteers and professionals enables the system to provide a number of psychosocial support systems to individuals in a variety of community settings. This can result in reducing the dependency on acute care institutions and help to contain the cost of providing care to persons with HIV infection. The institution setting, both in inpatient and outpatient areas, the need for psychosocial support services, is extremely obvious, and we would like to make a number of recommendations. Actually, there are quite a few, and if you like, I will go into them. Otherwise, we can just go on to the other presentations.

**DR. CONWAY-WELCH:** If you could highlight the recommendations, that would be helpful.

**MR. MORRISON:** Okay, the recommendations are to modify, adapt, and expand present psychosocial support systems which include home care, hospice and mental health services in the institutional setting and in community; secondly, create additional psychosocial support services with organizations such as SHANTI, organizations such as Health Crisis Network in Miami, Gay Men's Health Crisis Center in New York, AIDS Project, Los Angeles and the San Francisco AIDS Foundation. Church organizations such as exist in San Francisco and New Orleans could also be helpful.

Next, encourage the development of system-wide planning and coordination utilizing community groups and the local resources. Next, provide incentives for the development of volunteer groups in communities and coordinate the training, supervision, ongoing development and standardization of services whenever possible and also encourage the integration of volunteer services into existing organizations.

Also, develop a continuum of services emphasizing development of psychosocial team of counsellors, social service providers, case managers, volunteers, and educators, to deal with the specific populations with specific needs. Utilize mental health professionals with specific expertise in working with substance abuse issues when planning those services. Provide incentives for projects to develop and implement coordinated case management systems and also develop support systems for care providers in the institutional setting and in the community. Support systems will decrease burn-out, attrition rates of staff, and assist in containing cost.

Also provide for ongoing training for staff in institution and community settings on issues of life style, substance abuse, breathing and the issues of death and dying. Encourage health care systems to examine attitudes towards substance abuse, specific life styles, and non-traditional family structures, also develop specific programs utilizing the stated model for women, children, and HIV-infection in persons within the correctional systems. That is all of our recommendations.

**DR. CONWAY-WELCH:** Thank you, Mr. Morrison.

**DR. CONWAY-WELCH:** I would like to introduce Dr. Richard Johnson. Dr. Johnson is the Eisenhower Professor of Neurology and Professor of Microbiology and Neuroscience at the Johns Hopkins Hospital in Baltimore. I would like to add that Dr. Johnson is an internationally recognized expert on the effects of the HIV infection on the brain and that we specifically asked him to be here today to respond to concerns and questions and answers that the Commissioners have regarding that issue and recent reports that have come out that between 40 and 50 percent of individuals who are infected with the HIV virus but are otherwise asymptomatic, do in fact have cognitive deficits.

I would like to ask Dr. Johnson if he would want to comment on that now, or if he would like to wait until the question and answer period.

**DR. JOHNSON:** Either way you would like, Dr. Conway-Welch.

**DR. CONWAY-WELCH:** Why don't you start off?

**DR. JOHNSON:** All right. Early in the AIDS epidemic, it was not appreciated that infects not just the immune system, but the nervous system as well. What we regarded early on as apathy and withdrawal and depression in retrospect was dementia that was being missed. In 1985, only been 2.5 years ago, the virus was recovered in the brain and, spinal fluid, viral RNA was demonstrated within the cells in the brain, the DNA was found in the brain, and the virus was also reclassified as a lentivirus, a sub-family of retroviruses, all of which cause chronic brain disease.

In the last 2.5 years, over a half dozen different neurological diseases very clearly have been related to HIV, and many others that have been postulated. The full spectrum of the disease caused by HIV has not been defined. Some occur early in the course of the infection, even at the time of sero conversion. Some are transient, some are very rare, some are very frequent. The most important is the so-called subacute encephalopathy or AIDS dementia that occurs, in over 50% of patients and, the pathological substrate is present in 80 to 90 percent of patients at the time of death. Dementia may be the presenting sign of AIDS in 10 percent of patients with AIDS. So the dementia is the most frequent complications and the most devastating. It starts, with apathy and withdrawal, and ends with mutism, paralysis, incontinence and blindness.

Many of the questions need to be answered. How early can the signs of dementia occur? One of the first issues we tried to address in a prospective study, (the MACS study, funded by NIAID) was how early and how frequently the early course of the infection is the brain infected? Is this a terminal event or a late event in the disease? From the prospective studies of gay men as they sero convert, we know that over half of them have evidence suggesting infection of the nervous system in the first two years, even though they are asymptomatic, perfectly healthy, normal men in all respects. They have normal neuropsychiatric exams and they have normal psychological tests, which means that there can be quiescent, totally asymptomatic infection of the brain, and, in fact, there frequently is.

MACS is a combined study of 5,000 gay men between Johns Hopkins, Northwestern, Pittsburgh, and University of California Los Angeles. A subset of 1,800 are in the prospective neuropsychiatric study. Despite infection rates, neuropsychiatric deterioration at a time when they are asymptomatic, appears to be very, very rare, so that early loss of mental function does not appear to be as prominent as might be assumed in the recent report that received publicity, where they were suggesting testing people in critical occupations. The MACS study has not been totally analyzed, but certainly to date, it would certainly not warrant those kinds of recommendations.

I think this problem of dementia does bring up other issues. It certainly brings up major issues in the therapy of the disease. Can the drug get into the central nervous system? In fact, since we do not know where the virus is in the central nervous system, we do not even know what part of the central nervous system we are interested in. We need a great deal more basic information.

The second one is the health care issue. As drugs may be devised that will clear systemic infections and, indeed, as now is possible, we do much better in the treatment of opportunistic infections, we may have a rising tide of younger, demented patients needing care.

**DR. CONWAY-WELCH:** Thank you very much, Dr. Johnson. I would like to introduce Mr. Joel Grey. Mr. Grey has been invited, as a person with AIDS, to share with the Commission, concerns about psychosocial support and care as they have impacted him or his family, colleague and so forth. Thank you very much, Mr. Grey.

**MR. GREY:** Thank you for your time. I am also a nurse and I am a nursing student at the University of Iowa. Before I begin, I would like to give my recommendations, and basically they are four. Before we can even address psychosocial issues in rural areas, we need to look at these issues.

One, an issue of legislated confidentiality and anti-discrimination on a national level in the use of the HIV antibody test on health care.

Number two, increase funding for information, education and risk reduction in all areas.

Three, expanded support of biomedical research programs, clinical services, and community services.

Four, federally funded and sponsored anti-drug and treatment campaign.

In rural areas, the AIDS epidemic cannot be based on statistics and numbers. To address the psychosocial needs of people with AIDS and their families involved, it requires an aggressive and thorough attack based on problems and solutions found by the experiences of other cities and states. For states that will be instituting laws such as mandatory testing and contact tracing, the rights of confidentiality and anti-discrimination of every individual must be protected. The continues to be countless numbers of individuals being tested for the HIV antibodies, not only without their consent, but without pre-imposed test counselling, resulting in continued suicidal ideation and attempt.

Even without testing, individuals who are soon to be at risk, primarily gay men, are being fired from their jobs, terminated from life and health insurance, and evicted from housing. Examples of some of this discrimination will be in your packet. Funding for education, counselling or research at this time is generally based on the incident of cases in a given area. Prevention of the spread of HIV, this is a significant problem. As of December 14, 1987, we have had 81 cases documented in the state of Iowa. These statistics do not reflect the number of people with AIDS that are in Iowa, but how can we acknowledge the number of people who are diagnosed elsewhere and returned to Iowa to be with their families? How can we educate family and private practitioners who do not use AIDS as a diagnosis to protect himself or herself and others from the negative response and fear in small communities? And how do we provide support for families and friends who have lost a loved one due to AIDS, while we still deny that AIDS is even a problem for people in Iowa and rural areas.

Yet, how can we expect people with AIDS to be visible and vocal about the difficulties about living with AIDS when in doing so, it only draws more discrimination to the people who are already suffering from great devastation of isolation, stigma, and loss of dignity and respect. Long term care for the chronically and mentally ill has always been problematic and negligent, even before AIDS became an issue. Recently, 80 long term care facilities were surveyed as to how they would treat a person with AIDS in their facility. Out of 50 institutions that responded, none would accept a person with AIDS at this time.

Local and family practitioners need to be educated about current medical information and treatment of people with AIDS. It is not enough to prescribe AZT for a person with AIDS. Physicians need to take the next step in understanding what to do with a person who is asymptomatic and HIV antibody positive with a T-cell count of 700 versus a person who is HIV

antibody positive and also presents with night sweats, weight loss, lymphadenopathy and maybe a cell count of less than 200. Due to the vast psychosocial needs of a client, a physician needs to be aware of how to direct a client to local support systems and social services for funding and support. We are one of the states where AZT gets to the state level of funding. We have $43,000 in the state level that does not get to the people that need the drugs.

Also, in Iowa, we have physicians that are readily able to prescribe anti-depressants, sedatives, tranquilizers and pain killers as an ineffective and irresponsible treatment for people with AIDS. Although AZT and other experimental drugs are being conducted throughout the country, AZT is the drug currently recommended for treatment of AIDS, but it does not help all persons with AIDS. In Iowa, information about drug trials are inaccessible and, for the most part, nonexistent. And for people who are unable or choose not to use AZT, there are no alternative therapies and treatment, let alone funding for treatment including AZT.

Living with AIDS in rural Iowa has significant differences than living in larger cities, such as San Francisco and New York City. Access to health care and support services has always been a problem for our rural population. With AIDS, health care almost always requires hospitalization since visiting nurses and home health care personnel are unable to accommodate all the needs of a person with AIDS and their family members. We do not have intermediate housing or hospice homes for people to stay while they are in larger cities to get treatment. Even in a well-educated city like Iowa City, our equipment distributors for home health care will not rent equipment if it is known that the client has AIDS. Such services and support must be readily available as we continue to have people with AIDS in rural areas and as more and more sons and daughters come back home to be with their families and to die.

My final point is about substance abuse. Because of my involvement with AIDS, I have been asked to resign my position two weeks ago at a treatment center because it is a conflict of interest. Treatment centers need to be discussing AIDS, even though they do not have a lot of clients that are HIV antibody positive or presenting with AIDS symptoms. It is imperative that funds be made available to educate the people in our country who choose to use drugs and alcohol. For substance abusers who are seeking treatment, accessibility to programs is increasingly difficult, with waiting lists of up to six months. For those who continue to use, education and information needs to be readily available and provided by people who are sensitive to these individuals.

I would like to close with just an example of how living with AIDS in Iowa can be. For a farmer named Tony who has AIDS, who, along with his wife and three children live in a town of about a population of a little over 2,000. Over a six month period, he was diagnosed with AIDS three times, and then told that he did not have AIDS. His finances were a nightmare, and when a call went out for financial support from local churches, nothing came back. His SSD finally had to be determined out of state due to the confusing medical records.

Since then, his children have been harassed and ridiculed by peers and teachers. A local social worker asked Tony not to be a Cub Scout leader for fear of putting the Cub Scouts at risk of getting AIDS.

The closest support group in counselling is 50 miles away, yet five blocks from where he lives, a woman recently lost her son to AIDS last year, and next door to her is a family who has a local cousin who also has AIDS. Fifteen miles away in an even smaller town has been a person who returned to Iowa to be with her family and to die, yet all of these people are 45 to 50 miles away from the closest hospice, AIDS support group or services.

We have even people travelling further for support and to address the needs of these people in rural areas, we need to have funding down to the grass roots level, not to be stuck at the state level or a federal level. We need it now because what we do today will prevent those people from 1993, 1994 and on from getting AIDS. Thank you.

**DR. CONWAY-WELCH:** Thank you very much, Mr. Grey. I would like to introduce Dr. Susan Tross. Susan is on the psychiatric service of Memorial Sloan-Kettering Cancer Center. Dr. Tross, thank you for coming.

**DR. TROSS:** Thank you. As you have heard, my name is Dr. Tross. I am a psychologist who has been working with AIDS and HIV infection since 1983 at Sloan-Kettering and since July of 1987, I have been working with Dr. Dejarlais and Dr. Freedman from Narcotic and Drug Research, Inc., to bring AIDS education and prevention information to poor, hard-to-reach, inner city adults and youth who are IV drug users or who may be their sexual partners. When, as with AIDS, the stake is death, it is easy to lose sight of these salts on quality of life faced by those who are struggling with survival but for the young mother with AIDS who is afraid to hug her children, the drug user who have been thrown out of his home, or the gay man who can not longer turn to his parents, these human issues in AIDS and HIV infection are all to real. I would like to highlight some of the key mental health issues that beg for programmatic attention.

First, HIV disease must be understood as a chronic illness, which, at each juncture in its course, poses the threat of emotional crisis. The hidden patients in the HIV era are the ambulatory, intermittently dysfunctional people, with intermediate forms of the disease like AIDS-related complex. In our psychiatric studies of gay men with AIDS with no physical symptoms, we found the greatest degree of emotional distress in men with ARC, 70 percent of this group had a current psychiatric disorder as contrasted with 54 percent of the AIDS group and 35 percent of the healthy group. These men uniformly describe themselves as walking time bombs, living in limbo under the burden of persistent catastrophic fear about developing AIDS. These studies have not been done with IV drug users, but we can only expect these problems to be magnified in a population whose material and social resources are generally weaker.

Number two, Dr. Johnson has very aptly pointed out that the neurological complications of AIDS have psychiatric manifestations. I only want to emphasize that the Sloan-Kettering point of view really also does have reservations about the recent study that was done and the disproportionate attention it was given.

Number three, HIV testing must be understood as a major psychological stressor which bears the liability of severe emotional fall-out. Anyone who has had to notify a frightened and confused young man or woman or his or her sero positivity knows the anguish, the despair and the hopelessness conferred by this moment. A special, tragic case of this is the young woman who learns that her baby is sero positive. It will probably be at this juncture that suicidal risk will prove to be greater than at other stages in the course of HIV and it will also probably be at this point that the risk of dissolution of important interpersonal relationships will prove to be the greatest. In a study of IV drug users notified of their sero positivity, four out of five couples in which the sero positive partner initiated condom use, split up after this occurred. Further, if one appreciates the fact that both drug use and sexual activity sometimes serve as important modes of tension release, then it is easy to see how HIV testing without adequate emotional readiness could actually lead to relapse to drug or unsafe sexual practices through the mechanism of stress response.

Number four, the psychological impact of HIV disease reaches far beyond the index patient to the significant others, the care takers, the dependents and many others in the patient's social network. As these people lose their entire network to AIDS, they are vulnerable to the multiple liabilities of bereavement, burn-out and traumatic concern with their own health.

My recommendations addressing these problems are as follows. First of all, because we are dealing with hard-to-reach populations, living on the edge of the mainstream, innovative approaches are needed to delivery service effectively. First, the establishment of dedicated, multi-disciplinary AIDS units that are attached to existing community service sites, and I emphasize community, so that we are able to bring the services to this population rather than the population to the services. These sites should include drug treatment programs, medical clinics, community hospitals, family planning clinics, sexually transmitted disease clinics, and other sites which already attract the populations we are committed to reaching.

Two, commitment to grass roots, self-help, community-based modalities of health care which better reflect the informal patterns of help seeking in the hard-to-reach populations we are trying to reach.

Three, and very important, is the provision of more treatment slots for IV drug users to enable motivated IV users to get off drugs. Those slots do not exist for them now.

Four, augmentation of the functions of the HIV testing and counselling programs so that they themselves are the loci of prevention and referral activities.

Four, establishment of dedicated, inpatient, psychiatric and extended care facilities that are equipped to deal with the problems of AIDS dementia in particular. It is very hard to place an AIDS patient with dementia in any kind of extended care facility in most states.

Five, the initiation of routine staff training programs in general hospitals and outpatient clinics to make the community health provider comfortable and familiar with the issues surrounding HIV disease.

Six, establishment of hospice programs to provide back-up for patients and the families of patients dying at home.

And seven, finally, the recruitment of minority health professionals for programs targeted at minority populations to assure the greatest possible participation in health care services. Thank you very much for the opportunity to talk to you.

**DR. CONWAY-WELCH:** Thank you, Dr. Tross. Before we go on, I would like to remind the Commissioners we will begin questioning with Mr. Creedon. I would like to introduce Carolyn B. Robinowitz, Deputy Medical Director of the American Psychiatric Association. Thank you for your time this morning.

**DR. ROBINOWITZ:** Thank you. As you heard, my name is Carolyn Robinowitz, and I am Deputy Medical Director of the American Psychiatric Association, the medical society representing more than 34,000 psychiatrists. I also direct the APA AIDS education project which is now a year old. We very much appreciate this opportunity to appear before the Commission and to outline not only our ongoing AIDS education efforts but some of the policies that we have developed, particularly related to confidentiality and disclosure as they effect the HIV positive person.

As many of the public policy issues involve a conflict between the rights of the infected individuals and society's interest in containing the epidemic, we have not yet emerged a definitive public health strategy but we need to look at issues based on protection based on discrimination.

With regards to the time constraints, I will not repeat some of the comments already made about the psychological aspects except to underscore the importance of involving the medical community including psychiatrists. Presentation with dementia, apparent depressions that may be dementia as well as the secondary depression related to the knowledge of an impending terminal illness, very often become presenting signs or entry into a health care system for a patient. A health care system is woefully ill prepared to address the psychosocial or the medical needs of many of these people, and in addition, people are then subjected to the various discriminations that occur in terms of health insurance, life insurance, loss of jobs and so forth. We have many documented cases of people who simply were tested and as a result of testing, not the results of testing but admitting to testing, lost their jobs, lost their health insurance and so forth.

Furthermore, in a recent article in JAMA confirms this, the amount of pre- and post-test counselling and follow up is minimal as is often informed consent to the persons who are often subjected to a different risk, another risk, which is a risk of testing itself and its results.

Finally, and in relation to testing, a very important issue is dealing immediately with the sequelli of testing. In addition to the depression that may accompany the results of a positive test, there are many family unity issues as you have already heard. All of these demand and require involvement from the various health care professionals who often do not bring these issues up, and someone may be estranged from family, family of origin and be unable to return, particularly to rural communities where they fear the discrimination they will find or the family response to admission or drug use and/or sexual activity.

Let me talk for a moment about confidentiality and disclosure because that is one of the points that have not yet been covered. Before I do that, I want to alert you to some very useful activities that the American Psychiatric Association is engaging in. We are working with our 76 local district branches. These are psychiatric societies and community agencies and university departments of psychiatry to develop educational programs for the health care providers.

While they are aimed primarily at psychiatrists and psychiatric residents of both the mental health community, psychologists, mental health nurses and social workers as well as the other medical community, are involved in looking at the psychosocial aspects, the neuropsychiatric aspects of HIV infection and trying to develop a community more able as well as willing to care for HIV infected persons. Although this project is just getting underway, what we have been impressed with has been the strong links between the national organization developing some expertise and some training materials, some of which I will submit for your record and further review, but also the kind of community involvement brings together practitioners and persons in the community who might not otherwise have this kind of contact. We feel this is very important.

**DR. CONWAY-WELCH:** Dr. Robinowitz, if you could highlight the issues on confidentiality because later this spring, there will be three days of hearings on issues related to confidentiality, discrimination testing, etc. So if you could highlight those points and then move to your recommendations.

**DR. ROBINOWITZ:** Right, and I will submit for the record the more extensive position statement.

**DR. CONWAY-WELCH:** That would be very helpful.

**DR. ROBINOWITZ:** There are several issues. One relates to a physician's duty to warn an unknowing and potentially endangered person of any HIV sero positive individual who places that person at risk for HIV infection. We all agree, I think, that the factors which much be weighed include the confidentiality of the individual physician-patient relationship as well as the physician's responsibility to the community at large. We know that if the physician-patient relationship is interfered with and that if patients are not confident that issues discussed with their physicians are private and will not be divulged, then we run into difficulties. AIDS, ARC, HIV-positive, sero-positivity, are very stigmatizing conditions in our society, as much are mental and emotional disorders and compounding the stigma, of course, is the presence of the disorders in groups that already experience considerable stigma and therefore there is considerable suspicion among persons at risk and persons who are sero positive that this information will be used against them. This threat is not only to patients and to people with whom they interact, but it also threatens the collection of public health information and threatens the likelihood of persons even going to get care early on or to find out about their positivity.

We feel that the employment decision should be based on reasonable medical judgments, a person's availability and ability to work, and not the prejudiced attitudes or stereotypes, and we are going to assist in opposing legislative attempts to overturn the high court's ruling on our line and in supporting legislation granting statutory protection both to victims of AIDS and individuals testing positive of the HIV.

Now, we know that since limited confidentiality inhibits limited self-disclosure, we feel that it is very important that we limit breaking confidentiality to very special and unique circumstances and that as much as possible, the person should be informed in advance of the limits of confidentiality so that the person can make an informed consent within the situation itself. A policy allowing for other breaches of confidentiality except in very extreme situation, and I want to emphasize the extremity, might be counter-productive in discouraging people from agreeing to voluntary testing and contributing to the spread of the disease. I would like to emphasize that we are opposed to mandatory testing. We feel that this has an opportunity for further stigmatizing and does not necessarily deal with the changes in health care providers' behavior as well as individuals' behavior necessary to prevent the spread.

For example, it has been suggested that all patients admitted to psychiatric hospitals be tested. On the other hand, even if that were done, that would not guarantee identification of all persons who might be HIV positive because of the lapse of conversion and it could encourage unsafe behavior on the part of staff who might not take the appropriate care that should be taken with all patients, not simply with those who test positive. Rather than go into more of the detail, I will answer questions later.

**DR. CONWAY-WELCH:** We would appreciate whatever you can submit to the record. That would be very helpful.

**DR. ROBINOWITZ:** Thank you.

**DR. CONWAY-WELCH:** Did you have recommendations, Dr. Robinowitz, that you wanted to make.

**DR. ROBINOWITZ:** Let me give a few brief recommendations that have not been touched upon. Obviously, we feel it is very important that there be research mandated for behavioral research as well as the immunologic and viral research, particularly in terms of drug abusing behavior and its treatment as well as prevention. We feel that other behavioral issues related to sexual behavior need also to be addressed. Our major recommendation was for education of health care providers, a full spectrum of health care providers, counsellors, through physicians in terms of learning more about the disorder, its transmission, its treatment and in particular also learning about the psychosocial and neuropsychiatric aspects, the appropriateness of psychiatric treatment when anti-depressants for example are in fact needed as opposed to when they are superfluous and inappropriate and we also need to develop more long term facilities for the care of what is an increasingly young population with dementia who are not being cared for in other facilities.

**DR. CONWAY-WELCH:** Thank you very much. We would like to introduce Ms. Lois Wagner. Ms. Wagner is a registered nurse and she is speaking on behalf of the Vanderbilt AIDS project.

**MS. WAGNER:** Thank you. I am a nurse clinician and a member of the Vanderbilt AIDS Project Steering Committee. I also serve as Chair of the Project's Committee on Counselling. The Vanderbilt AIDS Project is a multi-disciplinary, university-based educational research and service program of the Vanderbilt University Medical Center. The Counselling Committee of the Vanderbilt AIDS Project was formed to provide analysis and recommendation to the Director of the Vanderbilt AIDS Project regarding the current status and future direction of the Project's Counselling Program. The Committee is composed of nurses, social workers, physicians and chaplains.

The Committee conducted an analysis of patient and institutional needs in relation to psychosocial care of persons with AIDS, not only in terms of current service delivery but in anticipation of projected need. This analysis revealed a number of needs in the area of psychosocial care of persons with HIV infection.

It was found that professional staff had a need for AIDS education, information, and counselling services to be readily available within their institution, that there was a need for specialized psychosocial counselling services for persons with HIV infection and their significant others, that there was a need for specialized multi-disciplinary teams within institutions to provide such services in addition to and in compliment with existing services and that these services need to be in place and ready for implementation before an institution faces a high case load of HIV related illness.

Meeting these institutional needs is a significant challenge. The analysis strongly suggests that they can be most successfully met by an organized, comprehensive and most importantly multi-disciplinary approach within institutions. The recommendations for meeting the aforementioned challenges are as follows. That institutions establish professional teams, knowledgeable in AIDS, which are available to provide or supplement existing psychosocial care in the form of individual, or group counselling for patients with HIV infection and their significant others. They should also be available to provide for the educational, informational, and counselling needs of staff and to serve as a centralized coordinating team dealing with the myriad of AIDS issues which arise within institutions.

It is felt that nurse-social worker teams would be ideal for this type of approach. These professionals should preferably be trained at the master's degree level and been exposed to some AIDS-specific curricula. It is further recommended that rural areas with smaller and more scattered case loads consider pooling resources and establishing regional teams.

Two, that AIDS continuing education be provided on a regular basis to all staff and that this education be updated periodically. Staff should also have available to them a mechanism to obtain emotional support for themselves in the form of individual and group counselling or support groups as needed.

Three, it is recommended that institutions establish formal networks with community organizations, universities and public health agencies in order to prevent duplication of services and promote adequate utilization of all available services in the provision of psychosocial care in any given region.

Four, it is recommended that institutions have programs of ongoing psychosocial research and program evaluation.

Five, where appropriate, it is recommended that student interns from all disciplines be exposed to settings which require the psychosocial care of persons with HIV infection. This will enhance the general level of knowledge regarding AIDS among new health care professionals, and would serve as an additional resource for institutions.

Six, finally, it is recommended that institutions remain apprised of trends regarding the numbers of cases both within the institution and surrounding region so that services can be planned and implemented accordingly. Some institutions may feel the need to hire additional personnel in order to implement these recommendations. Some may feel it is sufficient to reallocate, at least at first, existing personnel. The number and cost of additional personnel will vary according to institutional needs and regional differences, both in terms of case load and salary scale. This makes it difficult to give precise figures.

There is, however, a potential for cost saving. Properly trained staff or student interns exclusively involved in counselling and coordinating care of persons with AIDS will more likely be aware of and be able to utilize more fully the entire network of institutional and community services. As has been demonstrated to be the case in San Francisco, the availability of such services facilitates shorter hospital stays, improved psychosocial care and enhanced quality of life for persons with HIV infection. Thank you.

**DR. CONWAY-WELCH:** Thank you, Ms. Wagner.

**DR. CONWAY-WELCH:** I would like to open up the panel for questions from the Commissioners. I know the Commissioners share my frustration with being limited to one question each, and I would ask if we could move rapidly through one question each and then we will go around again. Mr. Creedon.

**MR. CREEDON:** I would like to address my question to Mr. Morrison although Dr. Tross and Ms. Wagner might also want to comment. Three or four years ago as we were struggling, and we are still struggling with the problem of the use of drugs, especially among high school and young adults, there was a program that was developed called Chemical People. It was a two hour television program that was aired throughout the nation, and the first hour was devoted to the scope of the problem, the fact that people deny that there are drug problems in their schools and so forth. Then the second hour which was a week later, was devoted to how to form a community-based organization involving the leadership of the community in an effort to deal with the problem.

It seems to me what you are talking about to some extent is getting different parts of the community, a multi-disciplinary approach to dealing with the AIDS issues. I guess I am asking the question as to whether something similar might be done in this area. Now, I am not sure that we would be addressing it to the public as such, but perhaps to other groups, but whether a program could be videotaped and made available or put on educational TV or whatever which first discussed some of the problems that you are trying to deal with in the multi-disciplinary approach, and then secondly made specific suggestions as to how a community-based approach could be mounted.

**MR. MORRISON:** I happen to agree with you completely. I think it is an excellent suggestion. I think that in local areas, that this kind of approach has already been used, and I am sure that there are other members of the panel that could probably bear out those examples so I completely agree with you. I think it is a very good idea.

**MR. CREEDON:** Maybe the Robert Wood Johnson Foundation would even finance the development of the TV programs.

**DR. CONWAY-WELCH:** Thank you, Mr. Creedon. Dr. Primm?

**DR. PRIMM:** Dr. Johnson, one of the most pressing problems that I see that we face in our nation is the understanding of medical data and the proper interpretation, and whether the media interprets things accurately and reports them accurately out to the public in our nation. That does not happen. Both you and Dr. Tross have indicated your displeasure at the interpretation of how dementia among HIV infected and certainly AIDS patients would impair them for certain occupations, and even the Army or the Department of Defense has indicated that they would remove people from certain jobs that require particular skills because of this great fear.

That has caught on and in New York it has been rumored that the Department of Transportation and the subway system, etc., the Metropolitan Transit Authority all are looking at this precedent as the way to go themselves. What have you and Dr. Tross and Dr. Robinowitz and all the other members of the panel, what do you propose to do to try to straighten out some of this interpretation that you all now are terribly concerned about?

**DR. JOHNSON:** Thank you, Dr. Primm, for asking that. I think it has to be balanced. The fact is you can have psychiatric or even motor control symptoms as the first symptoms as AIDS. You can also have them as the first symptoms of a hundred other diseases. Many of these we can test for.

Part of the problem I think the military has had that once they had the information for other reasons, then you are in a position of should you give these people, but if they had, for instance, residual alcohol levels in the morning on those same people, if they had EEG's on these people showing a slowing of alpha rhythm, if they cat scans showing a loss of cortex, which is present in a very high percentage of people over 55, I am in that group now, I think we would be in the same position. I think it needs to be kept in perspective.

The major causes of lack of judgment in a job I think are probably alcohol and premature aging of the brain, (atherosclorosis) and drugs including prescription and over-the-counter drugs. These are far greater problems than AIDS, and they can be tested for.

I was very upset with the suggestions in the Washington Post that we should start testing airplane pilots. I was asked a question by one of the reporters that wouldn't I rather have my 747 pilot HIV negative? Yes. I would also rather have him over age 30 and under age 55, very well trained, not have had a single drink for the last week, not an antihistamine or analygesic and a lot of other things I could put on that list. Often, it is the way these questions are posed.

I think we need to keep the nervous system infection in perspective. We do not have answers to many of the questions. On the other hand, we do not overreact because it happens to be related to AIDS rather than more common problems in our society.

**DR. CONWAY-WELCH:** Thank you. Dr. SerVaas?

**DR. PRIMM:** Dr. Tross was going to respond. She is in New York with the people in the Division of Substance Abuse Services.

**DR. CONWAY-WELCH:** Dr. Tross, would you care to respond?

**DR. TROSS:** I do want to say that in terms of how we can respond, I think that it is a myth that one single neuropsychological test can solve the more important problem of making sure that neurology, psychiatry, psychology, are represented in comprehensive care, and that can be done in the work place through the mechanism of employee health services every bit as well as it can be done everywhere else. I think it is these kinds of recommendations to test and remove are oversimplified, reductionistic, unrealistic solutions to a problem that is more complicated than that.

**DR. CONWAY-WELCH:** Dr. Robinowitz?

**DR. ROBINOWITZ:** Just to add to Dr. Tross's comment, I think that we need to address the population fear that sponsors such kinds of recommendations where it is the fear of the disease and the person who may have it and since there is a feeling often of helplessness, people tend to overreact and so there is a kind of remove, extrude, isolate, which occurs in many areas and can become really devastating.

**DR. CONWAY-WELCH:** Thank you. Dr. SerVaas.

**DR. SERVAAS:** I address my question to Dr. Johnson. I was wondering if there have been any studies on the neurological problems in the hemophiliac population? I understand from the National Hemophiliac Foundation that they have 10,000 AIDS positive hemophiliacs and that almost 95 to 100, almost all of the severe hemophiliacs are now AIDS positive, that of the 10,000 hemophiliac AIDS positive, 9,950 have suffered no discrimination so that there are 50 cases where they have. These are a young population, a lot of school children. Would this not be an ideal population to, since we would probably know about when they were inoculated with the factor A that caused their AIDS, would that not be an ideal population since they are not discriminated against evidently, they are all out of the closet because everyone knows that the hemophiliacs are AIDS positive, couldn't we do some neurologic studies with that population?

**DR. JOHNSON:** Yes, I think that is a very good idea. The studies that have been done have been almost exclusively with gay populations who are certainly under social pressure at the present time. There are essentially no prospective studies of HIV children or HIV-positive mothers. For example, it is not known whether the neuropathies that occur in adults occur in children. There is not a prospective study of neurological disease in IV drug abusers. That is difficult to do, but there have been suggestions that the neuropsychiatric complications differ by route of inoculation. We just do not know at this point. We need a lot more studies.

**DR. CONWAY-WELCH:** Dr. SerVaas, Dr. Jenko who will be a witness this afternoon is also going to be speaking on hemophiliacs so hopefully he will be able to add to that. Mr. DeVos.

**MR. DEVOS:** I was going to ask Dr. Johnson a question but I am 61, and I cannot remember what it was.

(LAUGHTER)

**DR. JOHNSON:** I have forgotten the answer.

(LAUGHTER)

**MR. DEVOS:** I have a question on behalf of the chairperson for you, Ms. Wagner. She wants to flesh that one out a little bit for example, on your project. How much is your budget? What is your source of funding? What are your future funding plans? I am the cost-heavy guy on this panel, and I am trying to dig out what these things cost and who is going to pay for them.

**MS. WAGNER:** I cannot really tell you exactly what our budget is. I am really not directly privy to that. We need to speak to the Director about that. Our funding has really been departmental in a way. The Vanderbilt AIDS project was born out of the Center for Clinical and Research Ethics and was supported through that mechanism. Recently, we have received some funding through administration which has been a tremendous help. We have also been about doing a lot of grant writing for funding. A lot of our effort has been purely voluntary. People who work within the institution who are interested in AIDS have volunteered to become involved with the Vanderbilt AIDS project, work on their committees and that kind of thing and actually have done a lot of the counselling that has been done and troubleshooting that has been done within the institution.

We now do feel a need to hire some staff. We recently hired a half time education coordinator, a half time counselling coordinator, but we still are woefully lacking in funds to really institute the kind of program that we need.

**MR. DEVOS:** I am impressed continually with the health care people and how they are eager to get involved with some of these things. I salute them and you.

**MS. WAGNER:** Thank you.

**DR. CONWAY-WELCH:** Thank you, Mr. DeVos. Dr. Walsh.

**DR. WALSH:** I would address this to either Dr. Tross or Dr. Robinowitz or both of you. I am going back to this problem of testing and confidentiality and so on because you raised the question. One question on which I will make a very brief comment is that the ARC patients feel they are walking time bombs, and I wonder how they are going to react when we honestly define AIDS as one disease, an immune deficiency disease, whether it is in the ARC stage or the AIDS stage because that is really an artificial bridge, and you are going to have to handle that when it happens.

There are no great arguments with anyone about confidentiality or mandatory testing and the problems of violation of either of the two that could occur. The individuals who have had sexual encounters and who fear to be tested, even though they may have had a sexual encounter with a high risk behavior individual, I wonder whether there are any techniques that you have developed psychologically or psychiatrically or whatever because you must be seeing patients like this also, and need to persuade them of the efficacy of getting tested.

The second part of the same question is that in those patients who are tested positive in which confidentiality is a real problem, have you developed any techniques whereby you can convince them of their responsibility to at least assist you in contact tracing because the confidentiality problem is not a serious one for people with AIDS. I mean, they are already helping one another, everyone knows. But it is that sero positive patient who is potentially infectious or probably is infectious, and again we get back to public health or the health of the public.

Without violation of any of these things, is there a way in which the physician can be taught to persuade these people that there may be a sense of obligation to follow both the one who is in fear, having had exposures and I have run into some fairly prominent people who have been in that position and who absolutely refuse to be tested even for their own peace of mind, and the other group to assist us in more, in as one of our previous witnesses called, containment of the disease. What techniques have you developed and have you had any success with them?

**DR. TROSS:** I think that the key word, the key operative factor in testing is counselling, and I just want to refer to one theory in psychology, the fear of communications theory which says that if you have too little anxiety or if you have too much anxiety, you do not perform the preventive health behavior change, whether it is smoking cessation, whether it is alcohol abuse cessation or whether it is some of the practices that are being recommended as safer sexual practices.

What counselling can accomplish if we have the resources to do it is that persuasion process. There are very valuable instances in which testing can be helpful, but you have got to make sure that you are sitting with an individual who can process the information you are telling him or her, who can figure out a way to tell their partner such that the partner will not retaliate in some terrible way. If we are dealing with IV users, and we are in a situation where are telling the partner is going to make the spouse pull financial support out of a home that is being supported by one person with many children, we are obviously creating another emergency so I think that in the situation where we have adequate pre- and post-test counselling, there are experimental programs going on now in drug treatment centers.

We are running one at Beth-Israel in New York, and there is another one I know about in Chicago where we are able to bring couples in, an IV person and their non-using partner, to do testing together but this is very different from contact tracing. We are empowering the person who is the patient to come in with the partner, and we have two counsellors simultaneously so we can have an individual discussion and we can have a couple discussion. But this takes planning and resources, and I think ultimately it is cost effective because I think we do get better results that way.

**DR. ROBINOWITZ:** I think what this highlights is the difference between an active, effectual counselling process and an education process. I am reminded, for example, of the Maryland students who, when surveyed, had high degrees of knowledge, but almost no change in sexual behavior and because of a belief of immortality that exists in that age group, were not so careful of their behavior in spite of their knowledge.

I think the same thing is true in the counselling process. It really has to be a process. In many situations, we have discovered that counselling really is giving someone some information or pushing or forcing them to get tested and telling them what the options are, and it really has to be an emotional interchange where the person can address the fears, and sometimes you can prolong this process over a considerable amount of time until the person's anxiety can be more allayed and they become more comfortable with the notion of being tested while at the same time paying attention to other risky behaviors in which they may be engaging, and we have see this with people who had transfusions prior to testing, and who became exceedingly anxious when information was published and it suggested that they get tested and we saw a number of very anxious people who suddenly felt very stigmatized, very much at risk and were almost paralyzed by their anxiety.

So, the first step is not dealing with the testing or HIV infection per se, but simply dealing with the anxiety of the situation and what is arouse. The other thing is the adequate follow up. When testing is accompanied by adequate follow up, there is a much higher likelihood, particularly if there is a limited number of people at risk, of good follow up, of safer behavioral practices. The problems we run into, again, are the people, and we are seeing more of this in communities where they are less involved in psychosocial support networks, where they do not necessarily have a close relationship with someone else, whether sexual or IV drug contacts are more frequent or numerous and less with identifiable people, then you have a much more difficult time getting them in for testing and even if you do get them in for testing, the kind of being able to work with them because these are people who have often been disappointed by the treatment system and do not necessarily see it as being particularly helpful, and that is where you need very strong, multi-disciplinary teams.

I think a lot of this is going to come from the physicians who are very often the first contact points, and who may be the worst at this. The general physician who really has not had much experience and is very uncomfortable even asking a sexual or drug alcohol history, never mind them pursuing it. So that you really need a very basic physician education. The folks who have been in the counselling business tend to do this more comfortably, but they are often not in the line of contact unless there is a program.

**DR. CONWAY-WELCH:** Mr. Grey?

**MR. GREY:** As with substance abuse, the majority of people that still use substances will not be seeking treatment so we are only addressing a small percentage of that population. The same with the people who should come in and get testing that might be positive. The majority of those people will not be seeking the testing or the counselling so we have to provide the methods of getting that to the people to counsel them because it takes two people to put somebody at risk, not just the person who might be coming in for the testing so that pre- and post-test counselling, the post-test counselling needs to be given to the general public because not everybody will seek that system to find out the information to stop the spread.

**DR. CONWAY-WELCH:** Thank you, Mr. Grey. Ms. Gebbie?

**MS. GEBBIE:** I think we are all becoming better at devising long, complicated questions. We have heard testimony earlier about the need for more behavioral research. We have heard more on the biomedical research side about some of the problems connecting funding with the projects, and people finding out where good projects are. I would be interested in hearing from actually any member of the panel of either specific behavioral topics that need to be researched that are not being researched, or particular weaknesses or strengths in the process of connecting those of you who have brilliant ideas to be researched with what money might be out there, that whole system, because clearly the behavioral side is a critical piece of this epidemic that cannot be neglected.

**DR. ROBINOWITZ:** If only we had three hours for the answer. I think there probably are three areas that come to mind for me. One is, how one can interface with sexual behavior in the adolescents and young adults. Maybe one should say children, adolescents, and young adults in terms of getting the cognitive information translated into changed behavior, difference between knowledge and action and feelings and that is a big topic area and there are lots of specific things under that.

The second is other kinds of risk taking behavior, in particularly drug and alcohol abuse, and for HIV, of course, the drug abuse, IV drug use, both the research on drug seeking behavior, drug using behavior and how one can interact with that becomes very important so that is a whole broad area for research.

A third is, and this begins to get into the biomedical, but it is my segue for me in thinking of the neuropsychiatric, is the brain involvement and brain behavioral involvement at different stages of infection, in different population groups and also in children at different stages because we are able to follow children over some time, and the relation to stress because there certainly seems to be some evidence that stress influences immune function and we also would be interested in knowing its influence on neurologic, neuropsychiatric function.

I think it is not so much getting funding, although there are lots of ideas that do not actually get funding, but making sure there is sufficient funding available for those projects that have been peer reviewed and seen as reasonable and having an impact. We have been fortunate, there has been federal funding. There certainly needs to be more in that because I think the basic research in the long run is going to have a lot to do with the particularly behavior change.

**MS. WAGNER:** I think another particular area that I would like to see looked at are some of the cultural determinants of health seeking behavior. I mean, the various subcultures within our society in the United States, and also what people believe about their health, their health beliefs, how that affects their health-seeking behavior.

**DR. TROSS:** I think the most important kind of work that needs to be done behaviorally is face-to-face, hands-on street level intervention. Unfortunately, a lot of the people who have the technical know-how to obtain a research grant are not the people who are at the outreach level, who are the ex-IV drug users who are prepared to relate to people on the street so I think one of the most important things that the funding mechanisms can do is to try to marry a good, well-placed, community self-help organization with some technical assistance, either in the local community or in the agency giving the funding itself, to enable the people who can access the populations but who do not know how to conduct research to team up with the people who know how to conduct research.

One of the most important problems in obtaining funds is the lag time. If you write a grant right now for a deadline, even if your review is favorable, you are not going to get those funds for another year, and this epidemic is so changeable and so aggressive that often you have to reformulate what you have actually been lucky enough to get funded. So I would certainly say that the most important thing in the current mechanism to try and change is to expedite the funding process whereby if somebody does get a favorable review, they can start now.

**DR. JOHNSON:** That has been done by a recent act of Congress demanding a six-month turnaround time on AIDS-related research. It is being implemented right now.

**DR. CONWAY-WELCH:** Dr. Lilly.

**DR. LILLY:** Actually, I thought that Christine Gebbie had taken my question away from me, but I wanted to ask it specifically of Dr. Johnson with respect to the basic biomedical aspects of the neurological problem. You referred at one point to lack of information on a particular area there, and I wonder if you could develop a little bit just what are the main problems that we really need to know in this area of the neurological aspects and are we addressing those, are we trying to fill in those gaps. I know we are trying. Is our effort adequate?

**DR. JOHNSON:** How does the virus get in, how early and why? Does it come in with cells? Is it cell free? Does it cross just at what point? Where is it during the latency period? Why is it not cleared and how could it be cleared? I could go through a series of questions like that, all of which we do not have the answer to.

**DR. LILLY:** Is this any indication that there are different strains of the virus, some of which are more prone to cause neurological involvement?

**DR. JOHNSON:** There have been studies showing different growth characteristics of the viruses. That come out of brain, and those that come out of blood. However, we do not have any bioassay system. So we cannot put it back in an host animal and test out how virulent it is. One of the problems we are faced with is that the only natural host for HIV is man. The only brain in which this virus causes disease is the human brain. You are therefore either stuck with doing studies of humans which is difficult, time consuming and expensive or studying animal models which are not the same virus and may have considerable differences. Until recently there has been a lack of good animal models.

I think there is interest in the federal government for putting up more funding for research. On the other hand of good investigators are committed to research they have been doing in the past. They have programs studying arthritis or whatever it may be that they are invested in, they are funded and if they are good and they are going to stick with it. Therefore, we need to bring in new people who are smart and young, which we could do, but that requires training money which we do not have. We can try to get some old converts like myself, but there are not many around. In neurological and psychiatric area, we need more really good, very bright young people, totally committed to research in this area. I think they will come, but this is going to take a few years. This is going to be a natural evolution. They do not appear, as the full neurologist-virologists de novo.

**DR. CONWAY-WELCH:** Ms. Pullen and Mr. Creedon? Dr. SerVaas?

**DR. SERVAAS:** My question is to Dr. Johnson. Dr. Richard Price, I think he is at Sloan-Kettering, has an incidence in his practice of 25 percent of AIDS patients first presented with neurological symptoms and nine percent I believe that died before they had anything but psychiatric and neurological symptoms. Is that in line with your experience?

**DR. JOHNSON:** Well, retrospective data always gives you different numbers than prospective data. That is, if you look at charts at the end, it does not look bad. You always have different data if you look prospectively. Some retrospective data has been as high as 20 percent presentation with neurological disease. I think prospective data that is now being accumulated is going to be below ten percent, but somewhere around the ten percent range.

**DR. SERVAAS:** Are there good studies that show differences in the drug population, the gay population and the hemophiliac?

**DR. JOHNSON:** The studies are virtually all of gay populations. There are some studies now being done of the HIV positive children. There are very few studies of the drug abusing population. I am not aware of any published neuropsychiatric studies of that population.

**DR. CONWAY-WELCH:** Mr. DeVos? I had a comment and a question, following up on Dr. Tross's discussion about the people who are doing the eye-to-eye counselling are not the people who have grant writing skills. I think that Ms. Wagner pointed that out in that right now this AIDS project in a city that does not have an enormous AIDS problem yet is being funded out of medical center funds of a medical center that has a large problem with uncompensated care as most do around the country, and that that puts their future in a very precarious position because they never know, from day to day what sort of medical center funds will be available and if one of the issues is educating people who have more involvement in the clinical area to actually find the hooks to get money, to get funding, to write the grants and if you write a grant that is of C+ quality, how do you get it up to A+ quality because that is what you have to do to get a good priority number.

I know the Division of Nursing does regional demonstrations around the country on how to help people write grants and probably a lot more of that needs to be done to help provide that link. I am sure there are a number of community agencies that are desperate for grant money, either federal or private and simply do not have the people there with that expertise.

The other comment was to Mr. Grey. We are very concerned about the problem with AIDS in the rural underpopulated areas of this country, and the resources that are available, and how that whole care process can be better managed. Certainly, you have identified major problems in what is not a small town, to say the least. Would you have any comments in terms of linkages that could occur from the federal government or from the state government or large cities that might be able to address some of your concerns?

**MR. GREY:** Unfortunately, it sometimes takes statistics in an increased number of cases before somebody realizes that we are having a problem, and that goes all the way from the federal government down to a state level, and that many of these issues and problems that we are seeing at a state level, that we have a health department that does not want to address these issues, not only just in Iowa, but other states around us. We are being more negligent than some other states neighboring us.

But there are issues of education that need to be dealt with on the state level with the health department. Legislators have just put together a task force and they can work on getting that money that usually gets tied up into the bureaucracy and red tape on a state level out. AZT money does not always get out; you need a psychiatrist to do HIV antibody counselling, and the state is shuffling papers on a state level and does not get resources out to those test sites throughout the states or to the AIDS service organizations throughout the state.

Our state AIDS Coordinator was a person from the CDC that was not effective in what he was doing and very homophobic. Dealing with gay people was not his forte and they ended up transferring him to TB. Then we got another person so there is a lot of bureaucratic problems in trying to get from a state level down to a community level because it is not a way that they have had to work before, and the resistance and reluctance -- they are bull headed people in Iowa -- and they are not willing to change behaviors. Maybe we were not right, but it did work at the time. There are a lot of problems with it, and making that change is real difficult unless it comes administratively from the top on down. A lot of people are doing it voluntarily. We have no paid staffs to do it, and we need to get the community to service people getting those grants, too.

**DR. CONWAY-WELCH:** So the responsiveness of the health department is critical.

**MR. GREY:** Yes. Highly critical.

**DR. CONWAY-WELCH:** Thank you. Dr. Walsh?

**DR. WALSH:** I wondered whether you had any ideas or thoughts on the degree of support, both private and public, that is being given to behavioral research in this area. It seems to me that, without even counting Medicaid funding, there will be a billion dollars for AIDS in the next fiscal year, and unless I am reading it wrong, Dr. Johnson touched on it a little bit, an awful lot of it is just going down the traditional research tube to the "old boy" network because they really do not seem to know what to do with it, and we have had several witnesses who have raised the issues that both you and Dr. Robinowitz have raised in regard to needing more in the behavioral sciences because to me, that is the answer. It is going to be behavior modification will help us long before we find the answer to a cure or anything else. Do you have any idea of the proportionate amount of funding that is going in that direction or do you have any suggestions for us because as several of us brought up many times yesterday, one of our functions is to try to find out how to prioritize what support there is, from both public and private sectors so as to urge upon those sectors the best idea of where money should go. Do you have any comments on that that would help us?

**DR. ROBINOWITZ:** I think, general comments, and I would be pleased to respond more specifically in writing to you later, which I think might be more useful, but I think the behavioral issues often are stereotyped with the same brush that the behaviors are. The research in those areas tends to get seen as not important, and it has been a problem in the alcohol, drug abuse and mental health administration where the biological research, which is very important, tends to get reviewed much more comfortably than the behavior which is seen as soft, less easily measurable, less guaranteed, and I think that there are certainly suggestions in priorities and I will respond to that, but I think it very often is stigmatized as are the behaviors.

**DR. WALSH:** Well, I think it just seems to me that in grant applications as Ms. Wagner is trying to make and as our foundation makes from time to time, that when you get into applying for this type of grant that is not measurable quantifiably somehow, the grant reviewers do not know how to cope with it. Not only are they late in responding and, as you say, you have to change your thing a year later once you get it, but it is almost as if they are afraid of them and I just do not know the answer to it because it is so important in this particular behavior.

**DR. TROSS:** One initiative that has been taken in the NIMH I know, is that when a review is conducted by an ad hoc committee of people who are familiar with AIDS, then I think the review is much more sensitive to the problems of doing research with hard-to-reach populations and the need for, I mean there are sound quantitative and qualitative behavioral research methods. I think, though, that if you have people who are familiar with AIDS, they know about those methods, and they do not tend to look at your grant the way they would look at a grant involving 2,000 captive college students on whom you can do many things that you cannot do in the real world so I think that is a constructive suggestion. It is actually something in place that I think should be in place in every other agency that review grants.

Another thing is that I think that if service programs had evaluation components attached to them, we have done a lot of HIV testing and counselling in this country, and much of it went without even four cursory behavioral questions like what were your reasons for testing or how did you feel during the week before we gave you your results and did you tell anybody that you took the test. These are very simple questions that you do not have to have a Ph.D. to ask, but if the mechanism had been in place to require people providing service to do something like that, I think we would have better information now so that is another thing that I would suggest.

**DR. WALSH:** It seems to me that we have to find a way to do more of that. I just do not know what the answer is at this point.

**DR. TROSS:** I would very much like to submit something in writing as well to try and look at what is needed.

**DR. WALSH:** We would be very grateful.

**DR. CONWAY-WELCH:** Thank you. Ms. Gebbie?

**MS. GEBBIE:** Let me switch from the research back to the service. I was intrigued with your anecdote, Mr. Grey, about the isolated people in Iowa with difficulty getting access to service. I think for some time to come, we will have a lot of communities, even small communities within big cities where there is only one individual who has HIV infection or maybe two or three individuals who have problems, not big enough to sustain a unique AIDS service organization of some kind, and isolated from the next nearest one by distance or ethnicity or something. How important is it that persons with AIDS, coping with dying, coping with family support, coping with chronic disease, with all the things we are coping with, be served with AIDS-unique organizations? Is it feasible that they get served in other kinds of support groups that serve issues that share some of the common features. Is this a disease that really has to be cared for centrally, or should we also look at some models of support that might integrate in order to capitalize on the resources we have?

**MR. GREY:** Well, first of all it would benefit us to have a networking system where we have funds available to provide the phone services so that people have someplace to call for support and talking to people with AIDS such as the San Francisco AIDS Foundation has a PWA Hotline. The SHANTI project has a bunch of, a vast variety of information similar to other agencies throughout the country so we need to be able to have those types of services and the funds available for the people to go out to rural areas and make their personal one-to-one contact, to find out what the issues are these people need. Maybe it would have to be a social worker, maybe it could be somebody else, maybe an ex-user of IV drugs, whatever.

The second aspect is having like the SHANTI project and the Chicago House as different places where they have intermediate homes, similar to the system set up by the Ronald MacDonald Houses where chronically ill children have a place where the family and children can be, where they seek treatment but they do not have to stay in a sterile environment in a hospital. It is very impersonal. You get to stay in a house, a place where you can be in a home-type setting and have a quality of life sustained in a time of death and that you do not have to have the high costs. You have the family involved, and you have the medical care available and that people from rural areas would have that access, to come into a city or some intermediate place where that service would be provided.

It would also help in other chronic illnesses such as cancer and mental illness where people would have a place intermediately to go, being cost effective, where volunteers are incorporated and that other systems are helpful and beneficial.

**MS. GEBBIE:** So let me be sure that I understood your answer which is, for some things those AIDS patients need direct contact to other people with AIDS but you do see the possibility of some of those services being integrated across disease lines.

**MR. GREY:** Yes.

**DR. CONWAY-WELCH:** Dr. Lilly?

**DR. LILLY:** I am rather interested, Mr. Grey, in one point that you made. You gave the statistics on the incidence of AIDS in people diagnosed in Iowa. You made the point that a number of people come home there and that led me to the recognition that in fact as a resident of New York who has known a number of people who have developed AIDS, some fraction of those have, in fact, gone home elsewhere to be with their family to be taken care of, and I am just interested in wondering if you would sort of develop that business of how this works out.

**MR. GREY:** As I said, there were 81 cases as of December 14, 1987, in Iowa, documented of people with AIDS. However, I have worked with 80 different people myself that have AIDS, and that was even before these statistics were published. This is state-wide. I have only worked out of Iowa City which is a very small community compared to other major cities.

**DR. LILLY:** So a large number of these people were, in fact, diagnosed elsewhere so it would appear in the statistics but not in Iowa.

**MR. GREY:** Not in Iowa statistics and it is underreported cases of AIDS also, and a physician will not put AIDS down on a death certificate or a diagnosis to protect the family, himself and his practice that the fear that other patients he is seeing, if they found out he was treating somebody with AIDS, they would not go to him any longer. That includes dentists, that includes other health services.

That is very difficult to deal with in Iowa, and the families do not even have to come home. A person with AIDS does not have to come back to Iowa. What do you do with the family members who have lost a son or daughter who are still in Iowa that have no place to turn, no hospice system to work through bereavement. The people do not have to come back to affect a family or friends.

**MS. GEBBIE:** If I could just, a brief follow up comment on that. The states have pointed out several times the problem of using CDC numbers which are state of original diagnosis. For example, AZT money was distributed on that basis, yet almost all states, other than New York, California and Florida, have received patients coming home, sometimes it is almost as many as your locally diagnosed cases. It is a real problem in following the needs for service.

**MR. GREY:** Also on a state level, our statistics are stated higher than what the CDC records even though there is a delay in reporting to the CDC, our statistics continue to maintain a higher rate or number of cases compared to the CDC reporting so our funds are not as high as what they would be, even based on our health department statistics.

**DR. CONWAY-WELCH:** Ms. Pullen?

**MS. PULLEN:** This is a little bit off the care issue but it is a question that was raised in one of our hearings in December that I would just like to pose to you all as to whether any of you have any reaction to this. It was pointed out to us by some of our witnesses in December that they felt that it would be more useful for the CDC case reports to be categorized by high risk behavior rather than what has become known as high risk groups. Do any of you have any reaction to that suggestion?

**DR. JOHNSON:** I think one advantage of putting it in terms of behavior rather than groups is that by putting it in groups, people who are not in those groups assume they cannot get infected no matter what their behavior is. As the father of a number of Yuppie children, I have talked to them about their friends' attitudes are. They are not in risk groups. Drug abusers are junkies who take heroin, not Yuppies who pop coke with dirty syringes. Anal intercourse does not take place only between gay men, that between heterosexuals who think it is fun or a method of birth control among teenagers. I think it is very important to talk about behavior and I think it is important, I am not so sure it is important to CDC reporting, but I think it is very important when you talk to kids to talk about behavior. Otherwise they will assure that if they are not in these risk groups they are safe.

**DR. TROSS:** I agree. I think particularly with adolescents, there are a lot of adolescents in New York, males, who have sex with other men, sometimes for pay. They would not consider themselves gay and if you asked them on a questionnaire whether they are homosexual or gay, they would say no, and yet, of course, they are putting themselves at risk through that particular behavior. So I think also that in the IV user group, there is some degree of underestimating in the sense that if somebody does also, is also a homosexual, they would probably be reported under that category so that it minimizes the magnitude of the problem.

**MR. GREY:** This can also be seen in very conservative areas where there are gay men that are in marriages that will continue with homosexual behavior or sexual activity that is putting them at risk but yet come home and be with a family and putting that family member at risk and children, etc., on down the line, and that they do not consider themselves gay because they are in a conservative area. They will still maintain a marriage and a family life, depending on what the stipulations of what they are expected to be like, especially considering like farmers in Iowa or physicians in rural areas that do not have the liberal ideology that allows them to be who they really are.

**DR. CONWAY-WELCH:** That you very much. Mr. Chairman?

**CHAIRMAN WATKINS:** Dr. Johnson, I think your testimony for us this morning was extremely important for the nation as a whole, and I hope the good television cameras here caught it all. It is the kind of thing that I think this Commission can do a lot to feed back to the American public that there is balance and there is a calmness that we ought to bring to this situation and not allow the kind of perception that is generated by a single article which could move rapidly through this country and support those that have another agenda. It is extremely important we air this. I think your concise testimony was very important to us, and I believe that it is so important that we need to highlight it a bit more. I know we have an article that you have sent to the Commission on AIDS in the Brain that may be sufficient, I just do not know because I have not read it. But, if you would address the subject of the newspaper article that is floating around rather freely on the issue of neurological damage early and its identification as, perhaps, an early symptom that can be detected, and therefore could affect a variety of areas including safety in the work place, and a whole range of issues.

It is going to come up very often now, and we need to really have the professional input so would you send me a letter as the Chairman of this Commission specifically on that issue? You can lean on the other article, obviously, that you have already submitted to us, but I think it would be good to hit it head on, and I would like to have some feeling if you could give us a feeling of the consensus of that position from the professional relationships you have with other organizations. We will do what we can to air that position in its balanced form. So would you be willing to do that for us?

**DR. JOHNSON:** I would be happy to do that, Admiral Watkins. The data is being analyzed. There is also going to be a World Health Organization meeting on just this subject, the question of testing in the work place.

**CHAIRMAN WATKINS:** When will that be, Dr. Johnson?

**DR. JOHNSON:** In March it is planned for now. So I think much of this data will be coming out very shortly.

**DR. CONWAY-WELCH:** Where will that be?

**CHAIRMAN WATKINS:** Where will that be held?

**DR. JOHNSON:** In Geneva.

**CHAIRMAN WATKINS:** The Chairman of our International Health group here may want to have a representative there.

**DR. WALSH:** Which one is that?

**DR. JOHNSON:** It is planned to be at WHO in Geneva.

**DR. WALSH:** Oh, in Geneva, yes. We get invited to them all, but it is hard to determine which one is valuable to go to.

**CHAIRMAN WATKINS:** Dr. Johnson, Johns Hopkins has, as I understand it, over $40 million in AIDS research grants, probably the largest of any academic institution in the country. You talked about the need for additional research in the area of our discussion here, and I am just wondering, of that $42 million now, about what is put into the area of research on the brain damage and these kinds of things that you talked about?

**DR. JOHNSON:** There is $110,000 in the prospectus study of gay men, there is about $100,000 per year in a study of peripheral nerve disease and we are putting in for extension of more at the present time because at the present time, it is not a great deal. That money is divided between an AIDS treatment unit, between the large prospective studies done in school public health. It is done on studies of teenage sexuality and activities, it is done monitoring the entire sexual transmitted disease clinic. The university has done a great deal, both the school of public health at the hospital and at the medical school and now at the nursing school in terms of programs.

**CHAIRMAN WATKINS:** It sounds like a very small amount for the emphasis that was placed by this panel this morning on this issue. I just wonder if you feel that you are just barely moving it in the direction you feel it has to go.

**DR. JOHNSON:** We have an application pending.

**CHAIRMAN WATKINS:** Well, I know we have been impressed by this new institute, Johns Hopkins AIDS Institute which has been established. If you send us a letter on this other issue, then we would like to have any more information of about where that institution might be going and perhaps others like it in the nation, and what your intentions are there.

**DR. JOHNSON:** I would be happy to.

**CHAIRMAN WATKINS:** Mr. Grey, I think you probably have given us some of the most useful testimony we have yet to hear from a person with AIDS, and we are very appreciative of your willingness to come before this Committee and give the kind of forthright testimony. It has been extremely useful. Earlier today, we had a presentation by an administrator of the Health Resources Services Administration of the government. They were quite proud of the fact that they were able to move the dollars for AZT funding, some $30 million appropriated by the Congress, rapidly into the states. I asked the question, about the rate at which it was delivered to the individual. For every dollar of AZT support given to the state, how much of that dollar has now reached the individual and in what time frame? He is going to supply that to me, but I would think with your comment earlier today, it would be very useful, I do not know if you have access to the information in Iowa, but if you could trace the time of receipt of the dollars to the state and then give me some feel for how the persons with AIDS have been able to access those dollars for AZT support, I think it would be useful as supplemental information to Dr. Sundwall's submission to the panel.

**MR. GREY:** I would be happy to follow up in writing on that.

**CHAIRMAN WATKINS:** I have to say, from my point of view, because we are dealing with a psychosocial issue, that this has been one of the most talented and informative panels, and I think the Commission will share my view, that we have had come before this Commission. We have been impressed by your testimony. It has been crisp and sharp. It seems to make sense from a visceral point of view that many of us who are not schooled in these areas have to face. Many of us here are like the nation at large. We also have to be educated, and I think we all learn a great deal from these presentations but this one has been, I think, somewhat unique today. You have given us insights in a range of things that affect this entire infectious disease and how we are going to deal with it because we are going to have to come to grips with some of the tougher issues later on that we touched on today, and you are right in the middle of it with your comments on confidentiality and discrimination. We know that.

We know what laws can do in some areas and what laws cannot do. Attitudes need to be changed. The education process has got to be real, and I think that Dr. Johnson's presentation earlier on the neurological impact is extremely helpful to calm or to bring some order out of the otherwise confusion that comes from perhaps biased reporting, not wittingly but unwittingly. It comes out and then gets fanned out as national policy.

So, I thank you for coming before us. We are going to have to terminate now and adjourn until after lunch, and we hope that you will continue to dialogue with us. We have asked you for some specific things. We do not want to cut any of you off. In the afterthought, you might come up with some ideas you think will be useful for the Commission to make recommendations on to the President, and you should feel free to do that. Hearings for you, witnesses here today, are wide open, until we close on the 24th of June. Thank you very much.

(Whereupon, at 11:33 a.m., a recess was taken until 12:30 p.m., the same day.)

## AFTERNOON SESSION

**DR. CONWAY-WELCH:** I am pleased to open the afternoon session of the Presidential Commission on the HIV Epidemic. This afternoon we are focusing attention on issues of care that surround special populations, broadly defined.

We are pleased to welcome our panel this afternoon and I would like to clarify how we will conduct ourselves for this presentation. Each of you have been asked to present approximately five minutes of testimony, or summary of recommendations to the Commissioners.

After all of you have presented that, the Commissioners then will be able to ask question and we are very anxious to have adequate time for questions and answers, which is why we have to impose the limitation of the brief testimony.

We will start with the first round of questions with Miss Pullen, who is on my far right, and each Commissioner will ask one question. If we have time, we will then repeat ourselves, starting with Mr. Creedon on my left and each Commissioner will ask one question.

We are very anxious to learn as much as we possibly can from you and we appreciate your time and effort being here today.

First of all, I would like to introduce Dr. Edward Barrett. Dr. Barrett is President of the Academy of General

Dentistry and is at the University of Detroit. Dr. Barrett, good afternoon.

**DR. BARRETT:** Good afternoon. Since you have already given my name, I will not repeat it. I will start right in.

On behalf of the University of Detroit, at which institution I am the Director of Continuing Education, and the Academy of General Dentistry, I thank you for the opportunity to share my views on access to dental care.

The growing need for dental care among HIV-antibody-positive people is challenging our knowledge and our ability to treat this special population. For people with AIDS, dental care can be an urgent need. Because these people suffer immune deficiencies, a seemingly minor oral infection can trigger a life-threatening systemic illness.

The vast majority of dentists nationwide have responded to the AIDS epidemic by adopting infection control measures recommended by the Centers for Disease Control and the American Dental Association to protect their patients, staffs, families and themselves. An October 1986 survey of 2,181 U.S. dentists conducted by the American Dental Association showed that only 23 percent of dentists always wore gloves when treating patients. But in less than a year, these figures have changed dramatically.

In August 1987, the Academy surveyed its membership -- all of whom are members of the American Dental Association-- find that 78.3 percent of Academy members always wear gloves with patients. It is important to note that this survey was conducted after the June 1987 announcement that a dentist had developed the HIV infection, apparently through his practice, but before the OSHA began enforcing regulations on personal protective equipment for health care workers. In this case, dentists have responded to the AIDS crisis independent of government intervention.

Perhaps the most important issue here is the availability of providers and sites to care for AIDS patients. In some areas, professional organizations at the local and state level have taken action to provide care for HIV-infected people, people with AIDS and ARC and indigent people at varying stages of infection.

This has occurred in Los Angeles. It has occurred here in Washington and also in Chicago, where the Chicago Dental Society has developed a referral system to send patients to private dentists, to city, county and private clinics and to area hospitals and dental schools. Judging from the success of this and similar programs, the development of such referral systems throughout the nation should dramatically improve access to dental care. Some observers have criticized dentists in private practice for failing to treat HIV-infected people. Some dentists, out of ignorance and/or fear, have simply refused to treat HIV-infected patients. In other cases, outside forces are at work; for example, at least one dental malpractice insurer has excluded from coverage any claim arising from HIV-related dental treatment.

Many dentists are treating HIV-infected patients, knowingly or unknowingly. Some patients are afraid to tell their dentist about their HIV status. Other high-risk people simply do not get tested and do not know their HIV status. Without infection control techniques, the risks of this behavior are potentially enormous, from the standpoints of liability, the health of the patient, the safety of the staff and other patients.

But I believe that these problems are becoming less common as dentists and the public learn more about HIV. There is another problem, too. State confidentiality laws shouldn't prevent a physician or an HIV test site from informing a dentist of a patient's HIV status.

Encouraging more dentists and dental facilities to treat HIV-infected people must be done through education and information, to both the profession and the public. The profession needs to continue to learn how to provide the proper care; the public must learn, through a massive educational effort, that going to the dentist does not put their health at risk. The government should take a much more active in providing funds for this educational effort in coordinating it with the private sector.

Encouraging more dentists to treat HIV-infected people would take some pressure off of public and private hospitals, which are now providing a great deal of dental care, but some of these hospitals are providing dental care only to those AIDS patient, who are receiving medical treatment there.

Despite this load on the hospitals, I must caution against attempts by the legislatures and courts to force a dentist to provide care in his or her office to HIV-infected people. A dentist who provides care to an AIDS patient in an improper setting could do the patient harm. This isn't an excuse to deny a patient care. A dentist is ethically bound to provide care for his HIV-infected patients or to make an appropriate referral. That is a message we are trying to get out to the whole profession.

At the same time, we need to learn a great deal more about the proper setting for treating of HIV-infected people. We do not know, for example, whether it is more efficient and cost effective to provide this care through HIV-dedicated facilities, through hospitals, through public or private clinics or through individual dentists. I would encourage the Federal Government to fund research and demonstration projects to get the answers to these questions.

To summarize my recommendations: Together with the private sector, the Federal Government should fund and coordinate a national education program to inform the public about HIV in general and about the safety of health care services, such as dental care.

Number two: In cooperation with professional organizations, the government should help to educate dental personnel in caring for HIV infected patients and to reinforce the infection control message with practical information on its implementation. This will encourage dentists to treat HIV infected patients without fear.

Number three: States should use federal AIDS prevention funds to survey dentists on their knowledge, attitudes and practices concerning AIDS and infection control. Such surveys would help determine what type of education is needed by the dental profession.

Number four: The Federal Government should fund demonstration projects to determine the cost-effectiveness and efficiency of caring for HIV-infected people through AIDS-dedicated facilities, hospitals, public or private clinics or through individual dentists.

Number five: All comprehensive AIDS treatment units should include dental care. A dentist should be a member of every HIV health care team and should be fully integrated into AIDS prevention and treatment programs. The Federal Government should dramatically improve its planning and coordination of AIDS prevention and education activities among federal agencies, state and local governments and the private sector. Thank you.

**DR. CONWAY-WELCH:** Thank you very much, Dr. Barrett.

Dr. Barrett, I wondered if you might be able to comment on an article that was in USA Today today and that article had to do with a survey that was done of about 1,200 dentists, who attended a dental meeting and were tested and none of them positive. At the same time, four out of five dentists reported that they would not treat AIDS patients, contrary to the group's professional standards to treat all patients. The reasons cited were fear of catching AIDS and the fear of losing other patients. Could you comment on the potential discrepancy in those two numbers?

**DR. BARRETT:** Well, I think that there is very little risk -- there is risk, but very little risk involved in treating these patients, as long as you use infection control methods. I think that is proven.

I think the second point I have already addressed is fear. It is lack of understanding and I do think that the statistics I showed do demonstrate that there is a very good improvement in the number of dentists that have adopted infection control methods, but, you know, it is early in the ball game.

**DR. CONWAY-WELCH:** Those numbers suggest that given the amount of time, the time lag that occurs between becoming infected with the virus and developing antibodies, which the tests respond to, that, in fact, it is very unlikely that there is a big risk to dentists, who are caring for HIV-positive patients because they only really started using gloves and so forth in the last 12 to 18 months as a broad group.

The American Dental Association has come out with a policy statement that dentists may refuse to treat HIV-positive patients and should refer them to other sources of dental care. Could you comment on that?

**DR. BARRETT:** I am not sure I quite understand what you mean. That they are free to refuse to -- would you repeat, please?

**DR. CONWAY-WELCH:** My understanding is that the recent American Dental Association policy statement suggests that dentists may refuse care to HIV-positive patients and suggest other sources of care that they should seek. Is that interpretation correct?

**DR. BARRETT:** I am not sure that is correct. I don't recall ever seeing anything like that.

**DR. CONWAY-WELCH:** I would like to perhaps ask Dr. Rogers if he might comment on those areas, either now or after you present your comments.

**DR. ROGERS:** I can comment now. No, that is, I think, a misinterpretation of the ADA principles and codes of ethics. The principles allude to the fact that dentists should be free to choose patients that they would like to care for, but not to abandon a patient merely because they are HIV-infected.

I think those codes allude to the fact of freedom of choice of patients, just as there would be a corollary that patients would have freedom of choice of practitioner.

**DR. CONWAY-WELCH:** Do you see a discrepancy in that versus the fact that four out of five dentists surveyed -- of 1,200 dentists, four out of five have said that they would not want to treat an HIV-positive patient?

**DR. ROGERS:** There is a discrepancy, I think -- and I would agree with Dr. Barrett in the sense that it is a matter of education and allaying what I think are -- or not think, but feel, are irrational apprehensions. And I would allude to that in my presentation.

**DR. CONWAY-WELCH:** Dr. Barrett.

**DR. BARRETT:** I would like to make a comment.

The attitudes that you are referring to aren't really totally related to dentists. In the medical world, they have a situation in which a specialty cares for these people. If these same people presented to a physician's office, they would be referred to an infection specialist. And, so, there is a natural flow for these patients to be provided care. Unfortunately, in dentistry, we don't have a specialty that manages this sort of thing and, unfortunately, there are those who have had no training in infection control -- and, please, understand that that wasn't taught in our dental schools until the last three or four years, with rare exception.

So, the dentist has had to take this on on his own. He has had to learn infection control. Secondly, dentistry is changing and working with people that are compromised certainly was not taught 20, 25 years ago in a dental school. They do address those things today. So that a dentist that has been trained 25 or 30 years is confronted with things that he does not know how to manage. He has had no training.

So, that is the problem that we have. And now we are trying, with continuing education, to get these things brought to the forefront.

**DR. CONWAY-WELCH:** I think that probably we will have an opportunity to ask some more questions regarding this and I appreciate your willingness to help clarify this because I think it is a topic that is of great concern to the American people, as well as to dentists certainly. I would like to introduce Dr. Vincent Rogers --

**MR. CREEDON:** Madame Chairman, may I follow up on the question.

**DR. CONWAY-WELCH:** Certainly.

**MR. CREEDON:** Just reading in your paper, Dr. Barrett, a dentist is ethically bound to provide care for an HIV-infected patient or to make an appropriate referral. That seems to suggest that he has the alternative of not providing care, as long as he provides an appropriate referral and I thought that was what the chairman was trying to get at. Is that the ethical standard or not?

**DR. BARRETT:** If he feels that he is not capable of providing care, then I think it is intelligent for him to make a referral.

**MR. CREEDON:** But is it only if he feels that he is not capable or does he have the option as a professional to say, well, I am not going to provide the care, but I am going to refer it to somebody else. I guess what we are looking for is what is the professional standard?

**DR. BARRETT:** What is the profession's what?

**MR. CREEDON:** Standard. What is the ethical standard?

**DR. BARRETT:** I think it is important that care be provided, but there are people that just have no background in this area --

**MR. CREEDON:** Well, if there is no background, I think it is a different problem, but it seems to me the Surgeon-General has come out and said that the providers of medical care, including dentistry, as I understood it, were obligated as a professional matter to provide service to people who need it.

**DR. BARRETT:** I would agree with that provided they have the training and background to provide that service.

**MR. CREEDON:** Okay. So, it is only if they don't have the background, then they refer?

**DR. BARRETT:** Yes.

**MR. CREEDON:** This doesn't say that. Your statement, it seems to me, does not say that. It seems to me the statement begs the question and suggests that you can get out of the problem by referring it and if that is what four out of five dentists are doing, it sounds like they are not performing the ethical standard that you are articulating.

**DR. BARRETT:** Well, that certainly wasn't my intent when I made the statement.

**MR. CREEDON:** I think the four out of five number is a number that we have to be concerned about. I mean, here we have a profession, well-educated people, to whom we should be able to communicate the facts about how the disease is transmitted or is not transmitted and what standards can be taken to protect them. And if we can't penetrate a profession, how do we get the message out to the American people.

**DR. BARRETT:** The profession is part of the American people. There is a great deal of anxiety and fear involved in this whole question and that is what we are trying to break down.

**DR. CONWAY-WELCH:** Mr. Chairman.

**CHAIRMAN WATKINS:** I think we need to wring this one to the ground. I don't see a point in moving on to other statements right now. I think it is a very significant issue and if we heard words like "because some dentists are not technically qualified to deal with infectious disease and the American Dental Association within the next year has set up a very stringent training effort and demanded that those that were going to remain in the American Dental Association must get themselves through this so that then the ethical standard set would be identical to that set by the American Medical Association to see a balance in there," I think we would feel more comfortable with a technical argument.

Maybe that is underway and maybe there is a very hard regimen being imposed for those that are now in dental schools and if we could hear those kinds of words, I think we would feel a little bit better. I am very confused as to what the policy is.

**DR. BARRETT:** Well, I think you have to be fair. I think that you may be coming down a little hard on the dental profession. I have seen articles, I have seen statistics where the same thing occurs in the medical field. The difference is that they have a specialty which takes care of these people. I have seen statements where 25 percent of the internists in this country refuse to see these folks.

**DR. CONWAY-WELCH:** I am a little confused of referring to the "specialists". My understanding is that AIDS patients are being treated by a whole variety of physicians with different types of medical backgrounds, as well as nurse practitioners, social workers, a variety of other health care providers.

I am not clear that your statement about having a specialist group to whom the medical physicians refer patients is clear.

**DR. BARRETT:** Well, in my part of the country there are infectious disease specialists, which is a subgroup of internal medicine, that function in that area in all the hospitals and that is where AIDS patients are sent.

**DR. CONWAY-WELCH:** I think we are seeing on a broader focus, though, that health care workers with a variety of backgrounds are interacting with AIDS patients on a day-to-day, hands-on basis and certainly infectious disease specialists are part of that.

Should we -- I would like to now introduce Dr. Rogers and, hopefully, you might be able to help us come to grips with this issue. Dr. Rogers is Chairman of the Department of Community Dentistry at Georgetown University School of Dentistry here in Washington, D.C.

**DR. ROGERS:** Madame Chairman and distinguished members of the Commission, I am Dr. Vincent Rogers, Chairman of the Department of Community Dentistry at Georgetown University here in Washington, D.C. Formerly, I was Assistant Commissioner for Clinical Services with the Baltimore City Health Department in Baltimore Maryland.

I am here today, however, to represent the American Dental Association and thank the Commission for the opportunity and privilege to address one of the most challenging public health concerns of the 20th Century, although, hopefully, not of the 21st.

The catastrophic illness known as AIDS is commanding, unabated, the attention of health care providers and the population-at-large. Those of us in the health professions are all too familiar with the monthly adjustments upward by the Centers for Disease Control of mortality and morbidity figures for individuals with AIDS and the projections for those seropositive for the human immunodeficiency virus.

At present, as you are aware, the CDC reports, as of December 1987, 28,000 deaths from AIDS, with 20,000 new diagnoses in this same year. The current projections estimate almost 270,000 cases to occur by the year 1991.

Studies by the National Institutes of Health and the University of California at San Francisco reveal that intraoral lesions are among the first opportunistic infections that appear during and after the prodromal period of HIV infection. In fact, 33 percent or one-third of patients evidence oral lesions as the primary or initial manifestation of infection.

Ninety-five percent of patients show some level of lymphadenopathy or swelling in the head and neck regions. A study by Greenspan and others at the University of California has demonstrated that 100 percent of patients diagnosed with one form of opportunistic infection, namely, hairy leukoplakia of the tongue, eventually develop full-blown AIDS within an average of 30 months.

Further, for individuals with AIDS, the frequent complications of common oral infections leading to general discomfort and systemic opportunistic disease make access to dental care critical to their stabilization and well-being.

Clearly, therefore, dentists and dental professions have major roles to play in the early diagnosis, treatment, counseling and referral of the HIV-infected person, as well as prevention in high-risk populations.

Research also indicates that the AIDS virus can be isolated in saliva, in addition to blood and other body fluids.. Since few dental procedures can be rendered without contact with saliva, blood and aerosol contamination during the course of treatment, dentists are concerned about their level of risk of exposure in treating patients with HIV infection.

Many dentists have begun to question their obligations, ethically and legally, to continue or initiate dental care to persons in any of the high risk categories or with any stage of HIV infection, maintaining that risk of exposure may jeopardize continuing ability to practice, the health of auxiliary office personnel and the health of other patients.

Some members of the profession recommend that referral of HIV infected individuals to special or dedicated facilities or to hospital-based programs is more appropriate because of perceived inability to maintain infection control in the private or traditional dental office setting.

These apprehensions and fears persist despite the preponderance of scientific and epidemiologic research out of CDC and NIH that risk is minimal when recommended infection control procedures are followed, protecting both practitioners and patients. Of 1,200 dentists -- and this refers to the article today -- tested anonymously for the AIDS virus at the 1987 annual session of the American Dental Association, no dentist tested positive for the presence of the AIDS virus.

As the focus of today's session is upon access and treatment, it is important for the American Dental Association to clarify for the Commission and the dental profession as well, its position on dental care for HIV infected persons in order to assist in the formulation of rational national policies, appropriate recommendations and effective strategic responses for the country to address this crisis.

The American Dental Association wishes to stress the commitment of the profession to fulfill its obligations to care for all patients. The Association maintains that HIV infected persons may be safely treated in private dental office settings, with minimal risk to transmission of the virus to other patients and dental personnel when established, effective, infection control guidelines are followed.

Unless a patient's physical, medical or mental condition compromises the ability of the dentist to care for the patient or treatment requirements jeopardize the patient's best interests in the private office setting, referral to other sources of care should not be necessary. The patient's best interests are served when he or she is allowed to continue the relationship with his or her attending dentist. Such is the policy inherent in the ADA's Principles of Ethics and Code of Professional Conduct for all patients.

Inability to maintain proper infection control, however, is not a valid justification for referral. Dentists should not abrogate their professional, ethical and legal obligations under the pretext of behavioral deficiencies in proven and established protocols for barrier techniques, sterilization and prevention of cross-contamination in the dental office.

The Association further supports initiatives to develop a national policy on HIV infection, which can become a basis for coordinated efforts by the public and private sectors to educate the general public about the prevention of HIV infection in all segments of the population. The oral health aspects of HIV infection and issues related to the practice of dentistry should be included in any national policy and strategy to reduce and prevent transmission.

There should be no question that HIV infected individuals should be treated with compassion and dignity. At stake in the challenge of the AIDS epidemic is the status of dentistry as a healing profession.. For the dental profession to respond in such a manner that obligations to self-interest override obligations to patients would be the beginning of the erosion of the professional ethics and the trust that society has placed in the health professions.

This trust is given legal sanction through the conferring of licenses to practice dentistry and moral sanction through the conferring of elevated status, which dental and medical professionals enjoy in the community by reason of their special knowledge, skills and expertise.

The dental profession has responded in the past to challenges of care for the handicapped, the elderly and the economically disadvantaged, but the gravity and magnitude of the challenge posed by HIV infection is mandating an examination that goes beyond professional codes and ethical analysis.

Rather, the health professions must recommit themselves to a moral philosophy of care and carrying for persons in need of our knowledge, our skills, expertise and, indeed, our compassion. The American Dental Association believes it has the responsibility and obligation to serve the needs of all patients, based upon current and emergent scientific knowledge and accepted legal, moral and ethical imperatives.

The Association's present policy is a dynamic one and is not static. It will be shaped in the future by scientific research and information that will bring new enlightenment to this public health challenge. In this way, the best interest of patients and the profession's ability to respond will be best served. I have several recommendations and will go on to those.

To the extent that the U.S. has a tradition of appeal to the President for executive intervention and guidance during times of national emergency, that the Commission call upon the President of the United States to address the American Medical Association, the American Dental Association, the American Public Health Association and other health care organizations to coordinate their professional expertise and ethical obligations to address the challenge of AIDS for the country, drawing upon the American traditions of ingenuity, resourcefulness and compassion for fellow citizens.

To the extent that health education and information is essential for effective professional and lay response to the AIDS epidemic, the ADA would encourage a national initiative to coordinate federal, state and local efforts to educate both the professions and the public to allay irrational fears concerning risk of exposure for patients and practitioners in dental settings.

To the extent that single males comprise the majority of the group at-risk to HIV infection but receive low priority in the determination of medical indigency in state Medicaid programs and eligibility guidelines, that the Federal Government advocate waivers at the state level to broaden eligibility for and scope of dental services to foster early diagnosis of oral manifestations of HIV infection, treatment and prevention in this affected population.

To the extent that the black and Hispanic populations in this country are disproportionately at-risk to HIV infection and least likely to have adequate health insurance and access to care, particularly dental care, that the Federal Government support waivers in the 51 state and District of Columbia

Medicaid programs to broaden eligibility for and scope of dental services under guidelines of the respective jurisdictions. Such expansion of eligibility and services would foster access to dental care for early diagnosis, again, treatment of oral manifestations of HIV infection and, of course, prevention within the affected populations.

Finally, to the extent that dental care services are frequently precluded from third party insurance programs for services rendered in outpatient and inpatient settings, as a consequence of complications and medical interventions, the ADA would recommend inclusion of dental services as part of appropriate medical management of HIV-infected individuals, who have private insurance coverage. Such a recommendation would enhance access to care and diminish provider disincentives to render needed dental care services. I would like to thank the Commission for the opportunity to address this issue today.

**DR. CONWAY-WELCH:** Thank you, Dr. Rogers. That was very helpful. May I clarify one point?

**DR. ROGERS:** Yes.

**DR. CONWAY-WELCH:** The issue of the incorporation of principles of infection control in dental school curricula, could you clarify whether that is currently part of the curricula and whether it has historically been part of the curricula or not?

**DR. ROGERS:** Yes. At Georgetown, we have instituted curriculum stages to include this and at a number of other dental schools this is already in force. And the American Association of Dental Schools has called a task force and will be meeting regionally throughout the country to institute curriculum guidelines in infection control in schools of dentistry.

**DR. CONWAY-WELCH:** Have they not been part of the traditional dental curriculum?

**DR. ROGERS:** Yes, indeed, they have, but to amplify and perhaps clarify what Dr. Barrett has said, I think the risk of exposure and transmission of communicable diseases has not achieved the weight and gravity that it has to this -- with the AIDS epidemic.

**DR. CONWAY-WELCH:** Thank you very, very much.

I would like to move on to Dr. John Bartlett. Dr.Bartlett is Director of AIDS Care at the Johns Hopkins Hospital in Baltimore and he has been asked today to speak briefly on the care of general common illnesses in HIV-infected people. I know you have been kind enough to come to respond to questions and answers from the panel about those issues. I wondered if you had any presentation that you wanted to make prior to that?

**DR. BARTLETT:** I would like to make a brief presentation if I could. I don't have a prepared talk however.

My message to this Commission -- first of all, I would like to thank the Commission for the opportunity to appear. My message to the Commission is that I think that there are several models of care that you have heard about. Some will work for one system and one will work for another. I would like to briefly mention a system that we work with and suggest that perhaps we don't need more money to take care of AIDS patients, but could do much more if there was reallocation of the resources that are currently available.

I think there are many models to take care of AIDS patients and I think this panel has probably heard many of them. There is the San Francisco model with extensive use of outpatient facilities. There is the case management system that has been the fetish of the Robert Wood Johnson Foundation. There are a number of different plans that various groups are trying.

The system that we set up at Hopkins is largely comprised of four components and those are the four components that need help in various areas. There is an inpatient unit. There is a chronic care facility, home care facility and an outpatient component.

Our group is a multidisciplinary group. There are 62 people who participate in the care of AIDS patients. This includes a number of medical specialists, nutritionists, home care therapists, nurses, psychiatrists, counselors. It is a variety of services and I think you could probably envision what they are. They are actually built very much on the oncology model with the notion that AIDS is sort of like cancer in that it is a disease where patients have a common problem and they require many specialized services that extend well beyond the usual resources found in the medical center.

So, we have approached this disease somewhat like cancer and used the oncology model. I think that it turns out to provide a patient compassionate, comprehensive and cost effective care and certainly the data so far generated by that group would testify to that summary.

In terms of cost effectiveness, which I think is something that the Commission is probably quite concerned with, I think that -- I don't have the final numbers, but I do know that our average length of stay is 13 days and our average cost of hospitalization is $10,400.00 and that our total cost of care from the time of the first AIDS defining diagnosis until death is going to come in in the neighborhood of probably 35 or 40 thousand dollars. It is going to be on the low side compared to many other studies or many other surveys. It may be a bit higher than it really needs to be.

The reason I think it can be somewhat better than it might be under other circumstances is that, quite frankly, if you have a member of that group taking care of AIDS patients, they have the legacy of having taken care of 400 before them and, therefore, when that patient gets a headache, they know precisely what to do and are unlikely to order a lot of unwarranted tests or suggest a lot of ill-advised therapy and so forth. I do think there is a case for specialized care of the AIDS patient. I am not sure that is practical around the country. I am not sure that our model is going to work in many other cities, but I think for us it has worked and it has worked well.

This is really specialized services with what we might call the equivalent of AIDS doctors, who are from the ranks of infectious disease, as was mentioned before. Now, we do have a number of problems and when I started, I mentioned that I think that we could do much better if we could reallocate the monies that are already available for the care of AIDS patients. There is an inpatient component, a chronic care facility, home care program and an outpatient component.

Now, in the inpatient unit, we have a designated inpatient unit that is comprised of ten beds, but we have to move to twenty because we have an average daily census of twenty. Most of the care providers that I mentioned and most of the AIDS care team of the 62 people that I mentioned are in the hospital or hospital-based and that is where the services are.

There is in the State of Maryland a single hospital, Seton Hill Manor, that will provide a chronic care facility that will accept an AIDS patient. I find as I go around the country that our problem is not dissimilar to many others. Chronic care facilities simply do not accept AIDS patients for a variety of reasons. Well, I can tell you this: If we take one of our patients in our hospital where the average cost of care is perhaps six to eight hundred dollars a day and try to move them to a bed that costs a hundred or a hundred and fifty dollars a day, the group that will pay the $600.00 will not pay the $150.00. If you can understand that, you are better than I am. That is kind of rule of thumb.

In addition to that, most of the chronic care facilities are simply unwilling to accept those patients. If you look at the outpatient care -- we run a big outpatient clinic; we see about 60 patients a week and we are following over 800 patients in our clinic now. I just went over the figures this morning because I thought they might be appropriate for this panel. Our care is provided by 12 health care professionals, physicians and physician assistants, that do it on a volunteer basis. They are all volunteers.

We have one paid employee for the clinic and that is the nurse coordinator. Our clinic loses $25,000.00 a year. If you can understand that, I wish you would let me know. We can't get paid. Many of our patients are on medical assistance. We don't even send a bill for medical assistance patients who are seen in the outpatient clinic. Every time we see one we lose money. It is not break even. It is losing money.

When those patients are in the hospital, the average or the standardized first day evaluation, which is comprehensive evaluation by the physician of record, our bill is $165.00. Medical assistance will pay $27.50. There are not very many professionals of any sort that are willing to accept 20 percent of their charges. So, we have accepted a fair total in professional fees, substantial losses in areas where I think it is unnecessary. I am not trying to say that we ought to pay the care providers more. What I am saying is that if we had the money that is currently allocated for inpatient care and had the liberty to use an effective system, cost effective system, to move patients to other levels of care, I think we could provide even better service at a lower cost.

Specifically, many of our patients come in the hospital and they need several days of acute, comprehensive care, but then they could easily be moved to a step-down unit, which is lesser care but more care than is provided in the nursing facility, but it has a smaller staff or a staff that is less per patient and, therefore, is less expensive.

From that facility they might move to skilled nursing care or chronic nursing care and from that they might move to home care. We have little control over any part of the system outside of the inpatient unit. We can't control the chronic care package. We can't control the home care package. There are 40 suppliers of home care in the Baltimore area. I imagine most areas in the country have something similar, but it is out of our control and the outpatient facility is, as I mentioned, a financial disaster. So, I think if we took the money -- quite frankly, if I see a patient that has got pneumocystis pneumonia, I might be able to treat him as an outpatient -- we would lose a lot of money, but would be able to at least treat him as an outpatient -- or I could put him in the hospital and I can tell you any third party payer would be pleased to pay six or eight hundred dollars a day. There is something wrong with that system.

**DR. CONWAY-WELCH:** Thank you, Dr. Bartlett.

One of our concerns and interests is in models that work and finding out what doesn't work and I think you have been very eloquent in your concerns and I am sure there will be questions as we move into the questions and answers.

Continuing in our focus on special issues affecting AIDS patients, I would like to introduce Dr. Robert Janco from Vanderbilt University Medical Center and he is going to be addressing the special care issues surrounding folks with hemophilia. Dr. Janco.

**DR. JANCO:** Mr. Chairman, members of the Commission and ladies and gentlemen.

You have heard my name. I am an Assistant Professor of pediatrics and hematology oncology at Vanderbilt, where I am the director of a comprehensive hemophilia clinic. It is basically a health care team serving close to 150 families with hemophilia or other coagulation disorders. I sincerely welcome the opportunity to speak with you, answer some questions and offer you my written testimony. If I could have someone turn on the first slide, please.

Serologic surveys performed in the hemophilia treatment centers using the ELISA antibody test and Western Blot confirmation show that 80 to 90 percent of men with hemophilia were exposed to HIV from contaminated clotting factor concentrates, mostly during 1981 and '82. Seroconversion rates are highest for men with hemophilia A and are less for children and for men with hemophilia B.

This means that among an estimated 14,000 severe hemophiliacs in the United States, as many as 11,000 may be seropositive. If Commission members have difficulty reading that, it is summarized on page 2 of the written document.

From the Centers for Disease Control, we also know that 524 AIDS cases have been reported in hemophiliacs in this country. In fact, Figure 1 on page 21 of the written testimony for the Commission members shows that the number of cases reported per quarter has been relatively stable for the last seven to eight quarters, giving a fairly constant incidence of AIDS in hemophiliacs of 1 to 2 percent a year.

However a recent CDC survey of six hemophilia treatment centers suggests a prevalence rate of 15 percent and other surveys suggest an actuarial incidence of 22 percent. From these data one could project from 1,200 to 2,400 additional hemophiliacs developing AIDS.

Moreover, surveys show that 5 to 20 percent of spouses of HIV-positive hemophiliacs have been infected by their husbands through sexual transmission. Now, despite these grim figures, newer heat-treated factor concentrates appear to be free of HIV, so that newly-diagnosed hemophiliacs are essentially free of HIV risk. Next slide, please.

For the hemophiliac who has spent his life treating painful joint bleeds and putting up with various complications, the sudden news about HIV exposure has been psychologically devastating. Indeed, it is a cruel irony that these factor concentrates, which promised freedom from constant medical care turned out to be contaminated with HIV.

The family of the hemophiliac has also been devastated. Most hemophiliacs, after all, are sexually active

young men and many have wives and young children. Now, the hemophiliac must face the thought that he may have infected his wife and she must face her own fears of dying. She must face her ambivalent feelings towards her husband, who has infected her and still she must help him deal with his own guilt feelings.

And what about siblings of hemophiliacs? They have special fears, guilt and concerns. What about the adolescent hemophiliac, who is HIV-positive? He faces serious psychological impediments to ever achieving normal relationships with young women.

Last, what about the mother of an HIV-positive hemophiliac? She may have brothers, uncles, a father and several other sons, who are also HIV-positive.

So, to these psychological stresses are added worries about exclusion from school, discrimination in the workplace, social ostracism or even segregation. For these families, confidentiality of HIV testing and anti-discrimination protection is not a bill before Congress or a legal concept. It is a matter of daily worry.

So, to these stresses, we add the medical care costs of hemophilia, even without the issue of AIDS. Estimates have shown that basic hemophilia care costs close to $10,000.00 annually. Add to this the cost for HIV-related illness and you can begin to see the financial burden to the fully-insured and employed hemophilia family. Next slide, please.

Special medical care problems, of course, add to the cost of HIV-related illness in the hemophiliac, who must receive expensive clotting factor should he need a biopsy or surgery to diagnose or treat an HIV-related problem. Hospital stays may be longer to insure adequate healing. Many have liver disease that makes surgery and anesthesia more risky and about 12 percent have an inhibitor, an antibody, that makes factor ineffective and adds great risks to surgery.

Yet, most hemophiliacs are reasonably healthy and currently receive highly sophisticated, comprehensive preventive health care services through an existing network of federal or state funded hemophilia clinics. Now in their 11th year, these clinics serve the majority of hemophiliacs in the United States. Next slide, please.

The hemophilia treatment centers have saved hundreds of millions of dollars in health care costs by decreasing hospitalizations and emergency room visits, by increasing employment and third party coverage and by improving the general health of most hemophiliacs. In fact, a year ago, the National Hemophilia Foundation presented a symbolic check for $1.9 billion, representing money saved to the Federal Government, for an investment of $3 million annually in comprehensive hemophiliac care.

Moreover, these clinics are highly experienced in the conduct of clinical research and serve as an excellent model for research in the prevention, care and, hopefully, cure of AIDS. May I have the slide off, please.

In my experience and based on discussions with many other health care providers and other clinic directors around the country, I make the following recommendations, based on rough calculations from figures available to me.

First, the Social Security Act should be amended to allow the AIDS patient to receive disability income as soon as one month, rather than six months after diagnosis. Once disabled, the hemophiliac may not have any income or cash with which to pay health care premiums and basic living care costs. I calculate these additional five months of social security disability for 160 hemophilia patients at $390,000.00 a year.

Second, we must enhance existing hemophilia treatment centers to aid them in clinical research in prevention, care and, hopefully, cure of the problem. These clinic personnel have abundant expertise in such research and represent a valuable national resource, not only for research, but also for the provision of the highest quality of care in the most cost effective manner.

As such, they serve as a model for both hospital and clinic-based health care delivery for HIV-positive individuals.

Enhancing these treatment centers would cost 3.6 million in salaries and services, in effect, doubling the current budgets.

At the same time, basic tests of the immune system are helpful in caring for HIV-positive individuals. At present, most hemophilia programs do not cover such tests and hemophiliacs are reluctant to use insurance reimbursement, fearing loss of insurance, should their insurance company find out. Very basic tests of immune function might be accomplished in this population for less than $1 million.

Third, complex psychological issues and needs of the HIV-positive hemophiliac family requires financial, legal and psychological support services. They could also be implemented through existing clinics by additional hiring of experienced counselors.

I should point out these counselors could also function as educators within the community, working closely with employers, schools and other interested groups. Salaries for these counselors would total 5.5 millions.

Fourth, we must insure that HIV-positive hemophiliacs have equal and speedy access to experimental drug trials and other clinical research and therapy of AIDS. Already, innovative, collaborative efforts between hemophilia clinics, the National Foundation, NIAID and the AIDS Treatment Evaluation Units are underway for an AZT trial. However, we must expand such trials by providing start-up funds. I would estimate $600,000.00 now.

Fifth, even more highly purified factor concentrates may affect the immune system of the hemophiliac less, offering some hope of immune restoration. Now, while such data from these newer concentrates are very, very preliminary, these products would be used in all hemophiliacs if they were not prohibitively expensive. I suggest, therefore, that an independent nationally convened panel of experts make initial and periodic recommendations on the use of these newer, more expensive products, such that third party insurers would reimburse the hemophiliac for such increased cost when these products are indicated.

In fact, such a panel met in Atlanta on Monday of this week to discuss this exact issue. The impact of widespread adoption of these newer, more expensive products on the third party insurers would be significant and, thus, deserves a thorough cost benefit analysis; yet, it strikes me that the hemophiliac, who was, after all, exposed to HIV through contaminated concentrate, deserves to receive the benefits of more highly-purified factor.

Lastly, I would like to make a philosophical statement of personal opinion that requires no cost analysis.

I note that Admiral Watkins is a graduate of the Naval Academy and a former Chief of Naval Operations. He, thus, epitomizes the qualities of leadership and service to his country. These same qualities must be exercised by the President now. He is, after all, the captain of our ship of state and steers the course for our society to achieve a consensus in dealing with this national tragedy.

I urge you to emphasize in your report the vital role of the President in developing and executing a national strategy, in resolving controversy by setting an example, in supporting more basic and clinical research dollars, in directing widespread educational programs and in facilitating alternative approaches to care. Thank you.

**DR. CONWAY-WELCH:** Thank you very much, Dr. Janco, and thank you for the numbers as well. That will be very helpful.

I would like to now introduce Dr. Bill Mitchell, professor of medicine at Vanderbilt University. Because we hear so much about the pros and cons of alternative and non-traditional therapies, Dr. Mitchell has been asked to speak briefly about the natural history of the HIV infection and how that relates to the impact of healthy lifestyles, good nutrition, et cetera, on the growth and development of the virus.

**DR. MITCHELL:** Madame Chairman of the Care Hearings, Mr. Chairman of the Commission, ladies and gentlemen of the Commission, I have been asked to make specific recommendations to you concerning ways and means of improving health care from the prospective of the natural history of HIV infection and possible means of retarding the natural progression of pathogenesis induced by HIV.

Exposure to infectious HIV can result in a variety of clinical sequelae, as illustrated in Slide 1. There may be no evidence of infection following exposure; yet, some patients demonstrate explosive development of AIDS and death within a few months of probable initial exposure. More commonly, there is a progression of symptomatology from Lymphadenopathy Associated Syndrome through AIDS Related Complex to frank AIDS and death with or without an associated AIDS Dementia Complex.

The factors which may influence HIV-induced disease progression include the immune status of the individual at the time of exposure, the number of infectious virus particles gaining access to target cells at the time of exposure -- that is, the dose -- route of exposure, co-factors, such as other infectious viruses present at the time of exposure or acquired subsequent to exposure and the specific genomic sequence of the highly mutable HIV to which the individual is exposed or subsequently exposed with a resultant diversity of HIV genetic forms.

If we can see Slide 2, this is a little easier to see -- after virus gains entry into cells, establishing an initial infection, it obviously will infect CD-4 (T-4) helper cells. Also primary targets are macrophages or monocytes, probably Langerhans' cells of the epithelium; and probably various glia cells of the central nervous system.

Now, I have listed some co-factors that you can see on the illustration such as Epstein Barr virus, cytomegalovirus, et cetera, which may activate the integrated virus. One of the things you need to consider is that the virus can enter and stay in a latent state and not cause disease, but can be activated by various cofactors with a virulent virus replication and progression of disease. Slide off, please.

Massive efforts are being made by both the Federal Government and the ethical pharmaceutical industry to find effective methods of HIV intervention. The highly mutable nature of HIV and the recent discovery of an HIV-infection enhancing antibody in about half of HIV seropositive patients will make vaccine development the most formidable task ever faced by vaccine developers.

A brighter note can be found, however, in the development of anti-viral chemotherapeutic agents. A single FDA approved chemotherapeutic agent has emerged; that is, AZT or Zidovudine, which lowers mortality but at high cost in morbidity due to its inherent toxicity to the bone marrow.

Although there are other promising drugs with significantly less toxicity than AZT currently in clinical testing which may prove efficacious singly and/or in combination with sub-toxic levels of AZT, they remain unavailable at this time to the individual infected with HIV.

Nevertheless, there are prudent, common sense recommendations that can be made to individuals who have antibody evidence of HIV infection. These include the obvious disengagement of high risk activities, avoidance of unnecessary exposure to non-HIV infectious agents, the maintenance of good nutrition and the establishment of a good rapport with a primary care physician in order to facilitate a rapid response at the first signs of infectious disease of any type.

My first recommendation to you is to be highly cautious of endorsing folklore medicine or practice that is not verified by research or is generally accepted as good health practice. As a corollary to this recommendation, I would suggest that you consider whether model legislation is needed for enactment by the individual states to strengthen their current statutes dealing with the sale of worthless nostrums.

My second recommendation to you concerns health care workers and laboratory workers at risk of disease through accidental exposure to HIV. To my knowledge, no health care institution has established guidelines designed to respond immediately to an accidental exposure. Yet, we know that probably intervention initially may, at least theoretically, abort infection.

I would urge the development of model guidelines, which would be reviewed on a continuing basis by the Public Health Service, so that any advances in anti-HIV research can be timely incorporated. I would welcome questions on that later if you would care to ask me.

I would like to turn your attention to a different but related issue. In any other infectious disease process, all individuals at risk would desire to know whether they had been exposed. Nevertheless, because of the public hysteria and social stigma attached to AIDS there is a reluctance, especially by some members of high risk groups, to undergo AIDS-antibody testing and a frontal assault on the concept of routine testing due to the fears of the societal response to those found to harbor the virus.

These fears, unfortunately, are well-founded and I would like to emphasize that. All physicians who routinely care for AIDS patients know examples of loss of employment, housing and insurance by individuals infected with the virus. Some insurance companies may deny insurance on the basis of suspected inlusion in high risk groups, an unconfirmed HIV ELISA assay or even a negative assay under the guise, "where there is smoke, there is fire."

Conversely, surgeons, for instance, correctly claim that they have the right to know who is HIV-positive and who is not and that to treat everyone as HIV-positive with resultant safety precautions increases the risk of surgery to non-infected patients by increasing time on the operating table and decreasing the manual dexterity resultant from double-gloving, eye goggles, face shields, et cetera.

Both sides of the debate are correct. There is, however, a solution which I urge you to recommend to the President and this forms my third recommendation to you. Adopt model legislation -- and I know there is some pending at the federal level and is held up, but, nevertheless, adopt model legislation at the federal level, which protects the rights of all citizens, regardless of their AIDS-antibody status. I would suggest that the following elements be included -- and I don't mean this to be all inclusive.

One: The willful breaking of patient HIV status confidentiality by an institution or individual be subject to a meaningful monetary fine and liable in tort action.

Two: Discrimination in employment and housing be expressly forbidden.

Three: HIV-antibody status in medical records be restricted from the insurance industry, regardless of an applicant's signed or verbal agreement to record access.

The insurance industry should be required to perform confirmatory Western Blots or any other equally confirmatory test on any ELISA positive screens it elects to conduct on applicants. The industry should be expressly forbidden from the denial of insurance based on an assumption of membership in a high risk group due to area of residence or employment. Thank you for your consideration of my recommendations.

## Discussion

**DR. CONWAY-WELCH:** Thank you very much, Dr. Mitchell. I would like to open the panel now for questions from the Commissioners and we will begin on my right with Miss Pullen.

**MS. PULLEN:** Unfortunately, I didn't mark where I wanted to ask you about something, but I do want to ask you to expand a bit on the co-factor element in terms of the function of a secondary infection activating a latent HIV infection.

**DR. MITCHELL:** There is the general concept among pathogenesis investigators that the virus can remain latent and that various things may activate and serve as co-factors in stimulating replication of the virus. A good example of this, I believe, is given by HTLV-I and HTLV-II retroviruses. HTLV-I is the etiologic agent in adult T-cell lymphoma. It is indigenous in southern Japan, it is seen particularly in southern blacks in this country and in the Caribbean. Another virus, HTLV-II, may well be the etiologic agent in a rare disease known as hairy cell leukemia. If one uses HTLV-I or HTLV-II infected cells, for instance, as targets for HIV infection versus non-infected cells, (i.e., lymphocytes not infected with the virus) one can speed up productive viral infection by many days. For instance, peripheral blood mononuclear cells usually take about two weeks to get a good productive infection. Some cell lines infected with HTLV-I take only two and a half to three days to set up a productive infection in vitro.

Similar types of mechanisms could be operating in vivo. For instance, in the homosexual community, individuals are frequently infected with cytomegalovirus, Epstein Barr virus, hepatitis virus, et cetera, and it is generally thought, without proof, that these viruses may be co-factors which similarly stimulate replication of the virus.

It may well be that this is one reason this group has had such an explosive development of HIV induced disease and have borne the brunt of the AIDS epidemic in the United States to date. Certainly, in Africa, it is a heterosexual disease. There are other co-factors that are thought, perhaps, to be operative. There are genomic sequences that are the same in the AIDS virus and certain control elements, regulating immunoglobulin synthesis, such that stimulation of immunoglobulin synthesis may -- at least it happens in vitro -- may stimulate a latent virus to replicate.

**DR. CONWAY-WELCH:** What would be some examples of that stimulation?

**DR. MITCHELL:** Well, one example of that may -- at least in an in vivo situation could be, for instance, various vaccine administration to an HIV infected individual. This is somewhat at variance, I understand, with what is a joint commission of pediatrics and internal medicine vaccine group, but in my mind, I would be very hesitant at any type of vaccination of individuals that are seropositive and are in a state of wellness and have not progressed into the various syndromes and associated of sequelae of the infection.

**DR. PRIMM:** Would an example of that, Dr. Mitchell, be inoculation, secondary to intravenous drug use, the continuous using of the needle?

**DR. MITCHELL:** Well, the intravenous drug users, they use unsterilized syringes and, of course, they can, similarly -- while they are infecting themselves with HIV, can similarly infect themselves with other viruses.

**DR. PRIMM:** My point, Dr. Mitchell, was self-inoculation with the same needle, their own needle over and over again without proper cleansing of that needle, could that act as a stimulus, as an inoculant.

**DR. MITCHELL:** No, unless there was a growth of an infectious agent in materials left in the needle, and I really doubt that, so that one was increasing the cofactor dose, I seriously doubt that that would occur.

If the needle was limited to that single person, that should not be a co-factor.

**DR. CONWAY-WELCH:** Thank you. Dr. Lilly.

**DR. LILLY:** Actually, I would like to carry this same discussion just another step further and perhaps you can help me with a problem that I encounter fairly frequently.

In the history of most infectious diseases, there has been a continued variance about the causative agent. While the very large majority of knowledgeable people accept HIV as the causative agent of the disease AIDS, there are a few voices that persistently doubt this.

I would simply like to have your opinion about how certain are we that HIV is, indeed, the causative agent of AIDS.

**DR. MITCHELL:** As certain as anyone can possibly be. It is similar to parents of school children wanting to know that there is absolutely no chance that -- this disease can be transmitted to their child. We all know that it can't, but you can never make an absolute statement. There is nothing absolute in this world, but as far as I am concerned, I am as absolutely certain about that as anything HIV being the etiological agent that I know.

**DR. CONWAY-WELCH:** Ms. Gebbie.

**MS. GEBBIE:** A question for Dr. Bartlett. I don't know whether I missed something you said or confused something you said. You were talking about ways that the same amount of money now being spent could be spent better if there were more control of it and you started giving examples of different parts of the system.

When you were talking about home care and made reference again to control, I wasn't clear whether you saw problems simply in not being able to control moving the money to home care when you wanted it or whether there were problems in the provision of home care where some reshaping of the care itself or some different authority over the care was needed.

Could you clarify that?

**DR. BARTLETT:** Well, it is a good question.

I think I had in mind both actually. What I would like to see is, at least for our model, a capitated system, where we would be able to provide all four elements, including home care. I don't think we really have quality control of the home -- the hospital has very good quality control for what transpires in the hospital and I don't see that level of quality control in the home care programs and I don't see that the physician is really in charge of the case. I think we have lost control over that element of health care.

**MS. GEBBIE:** Although in most home care situations which I know, there is a prescribing physician, who is, in fact, working with the nurses to set up the care.

**DR. BARTLETT:** Oh, there is very definitely a prescribing physician and there is a physician who is medically, legally responsible and the physician of record, but at least most systems that I know of, the physician, when pressed -- doesn't like to say this, but, in fact, doesn't really have a good command of what is going on.

**MS. GEBBIE:** Would you provide us, and you will get this in written form, with a financial description of how you see the money divided up now, but how you would finance that capitated system, how you would spread the money if you could create the system?

**DR. BARTLETT:** Yes.

**MS. GEBBIE:** Thank you.

**DR. CONWAY-WELCH:** Dr. Walsh.

**DR. WALSH:** Dr. Bartlett, I am an advocate of home care. Just a brief comment before I get to my question is the problem with home health care, as you know, is the reluctance to allocate funding appropriately. It has never been established that home health care in the end really turns out to be more economical than other types of health care, primarily because of fear of abuse and that sort of thing and of more frequent use. In other words, the resources, encourage multiple home care visits and so the costs build up. That is why I think it is very important that you have come in with not only your suggestions but with some type of explanation that would support the economy, as well as the quality of the home health care.

I am concerned, Dr. Mitchell, about your statement because of a couple of things.

**DR. MITCHELL:** I welcome critique.

**DR. WALSH:** You are urging that this Commission make compelling legislative suggestions. I notice that among those suggestions you make are penalties for the physician, restrictions on the insurance company, regardless of the risk and regardless of the fact that if there are shenanigans on the part of the purchaser of insurance, that the rest of us will all pay, but nowhere in your statement do I see you express any concern for the rights of the uninfected.

You suggest no penalty whatsoever for the known seropositive or infectious individual, who willfully distributes by his habits that infection. I think one of the great problems that we have is that -- if you want to, you know, make it as broad as possible -- the civil rights of everyone is a question, not just civil rights of the infected or of the seropositive individual.

My own feeling is that we should go very slow on legislation of any kind until we really have this whole thing in balance. Would you tell me why you have no concern for the uninfected?

**DR. MITCHELL:** Well, the difficulty that we have and the argument that we have is whether people should have HIV

ELISA antibody screens and then confirmatory tests. If the civil rights of individuals that are HIV-positive are vigorously maintained and guarded, I don't think the civil rights of the vast bulk of the citizens of the United States are at risk. It is the people that are at risk that are having their civil rights violated and have had them violated are the individuals that are HIV-positive and this is the reason there is such reluctance among various groups for the various screens that can help in the maintenance of health care.

Now, at the same time, I would agree wholeheartedly with you. Anyone that knows that they are HIV-positive, knows that they are at risk of spreading the disease and willfully spreads the disease is as guilty of homicide as someone that walks into a grocery store and shoots the grocer in the head.

**DR. WALSH:** Well, if you feel that definitively, would you add that to your recommendations?

**DR. MITCHELL:** Yes, you may add it as such.

**DR. WALSH:** You seem to be pretty definitive about that and I noticed it is so glaring. Your determination on the other side is so great that I felt that you must have a similar feeling.

**DR. MITCHELL:** Well, since I am an arch conservative usually, I am very liberal about this particular disease. I think it represents the greatest threat that mankind has had in an awfully long time.

**DR. WALSH:** Well, that is why I think we ought to protect the uninfected as well.

**DR. MITCHELL:** Again -- and I don't think there is really any data on it -- it is my perception, though, that if we look and weigh these two things, the individuals that willfully infect other people gain a lot of notoriety and that is newsworthy. However, the people losing their housing or their jobs, but who may be relatively well, but have an HIV antibody positive test, that is not very newsworthy.

**DR. WALSH:** Oh, yes, but there is no argument on this Commission about protecting those people at all, none whatsoever.

**DR. MITCHELL:** I believe that the President has taken the position that this should be at the level of the states, this legislation. This disease is so complex, I don't believe individual states can come together with meaningful legislation that is based on medical and scientific fact that will protect their citizens, unless they have model legislation and they can make their own legislation tougher than the federal.

**DR. WALSH:** I appreciate that you will at least add that anyway. May I ask Dr. Janco one question, so you won't have to come back to me.

**DR. CONWAY-WELCH:** No, I don't think so. Mr. DeVos.

**MR. DE VOS:** I commend the Chairlady for standing up to Bill over there.

I want to get back to Dr. Barrett, if I might. The panel here, at least the Commissioners, know that I am the guy who is always working on the cost thing and I have a little problem with everybody saying what the Federal Government should do when a lot of these things can and must be achieved closer at home.

I like Dr. Bartlett's comment on "We don't need more money; we just have to spend it more intelligently" and I guess that sort of applies when I look down your list of recommendations, Dr. Barrett. I pencilled in about on all of them and they sort of read -- and I am sure that it is not only from you but from your associates and your industry -- it says the state should use federal funds, the state should do this and the Federal Government should do that. Most of it all says the Federal Government should do something.

Yet, when I looked at your second one, which refers to training of doctors, I just wonder at what point does the industry become accountable for the training or when the training institutions take some of this accountability instead of just assuming that federal funding should come to do this. It seems to me the industry, the institutions, the universities should be training their people or your own industry should maybe doing that. Are there some ways that you could re-work these recommendations in terms of what everybody who is faced with this can do in their own town, in their industry, in their school to help this problem?

You don't necessarily have to answer me. Maybe you would be willing to go back and just take a hard look at some of those because we aren't going to be able to do everything everybody wants at the federal level. Dr. Rogers, you, too, even though in some of your recommendations you differ with his because you are at least talking about what the industry can do.

**DR. ROGERS:** Dr. Barrett sort of deferred to me and I do want to say that I agree with you and would like to say that the American Dental Association, for instance, which represents organized dentistry in this country, has developed and will be implementing, beginning in February, a training program that will go out to all dentists in this country, which will instruct them in infection control guidelines and how to manage the problem in their offices.

This program will include video tapes, audio tapes and will show them how to manage this from the standpoint of organized dentistry.

And as I said earlier in my statement, that the universities are, indeed, responding to this by including infection control guidelines in their curricula. Right here in Washington, D.C., with Georgetown University as an example, I understand that the Whitman Walker Clinic was here yesterday and in our Department of Community Dentistry we will have an elective clinical rotation in which our senior students will be caring for HIV-infected patients. In that regard we will be training future practitioners in how to manage the problem.

**MR. DE VOS:** I appreciate so many recommendations we receive but so many of them just quickly say "federal money." I don't know whether they have thought through the dollars in some cases. Maybe we can ask them to. I am assuming, that is an oversight, but in order to drive some of those costs down, the voluntary organization, the industry, and the hospital, is where we really got to start to attack some of this stuff.

So, I appreciate your input and I am sure Dr. Barrett wants to do that as well as we do. We have been meeting here for days and everybody just comes and says, well, I will take a million here, just a billion there and a couple hundred million for this and it is just a parade of them. That is why we are trying to say, hey, let's think of what we can do and that is the message we all got to begin to do on this whole problem. Thank you very much.

**DR. CONWAY-WELCH:** Thank you, Dr. Rogers. Thank you, Dr. Barrett. Dr. SerVaas.

**DR. SERVAAS:** My question is to Vanderbilt University here and I didn't get your specialty, Dr. Janco.

**DR. JANCO:** I am a pediatric hematologist oncologist, which means basically that all of my patients are immunosuppressed, either because they are on chemotherapy or because they have HIV exposure.

**DR. SERVAAS:** Then I will address my question to either of the two Vanderbilt gentlemen. I have a concern that if we have a million and a half or a million to a million and a half AIDS-positive individuals, the hemophiliacs mostly know they are AIDS-positive. So that I guess that my biggest concern is more with the AIDS-positive individuals who aren't suspecting that they are AIDS positive. The hemophiliacs who used Factor 8 before the heat treatment began on Factor 8. Of course, the new hemophiliacs wouldn't have -- newly-diagnosed ones would not be vulnerable, as vulnerable.

My question is this: What if -- we have all these things that we shouldn't do for an AIDS-positive person. Just like a pregnant woman, we shouldn't have them clean the cat litter because they might get toxoplasmosis or the bird cage because of histoplasmosis.

We shouldn't give them live polio virus vaccine in measles and mumps or we shouldn't have it in the home with a pregnant woman. If they are AIDS-positive, they shouldn't be vaccinated for mumps or rubella vaccine. All of the other things, the salmonella infections and there is a whole litany of things that we shouldn't be letting them do. You mentioned some of them, Dr. Mitchell.

But how can we keep our AIDS-positive people, who don't know they are AIDS-positive from going on and getting toxoplasmosis or any of the other infections, salmonella, which they shouldn't have gotten because they were vaccinated? Are we going to see some polio cases because we vaccinated some kids for polio and they didn't know they were AIDS-positive? That is what I don't understand.

And then I guess my other question is: What good studies do we have of experiments going on to keep people -- this large group of hemophiliacs would be a good group to study, but to keep them from becoming ARC or AIDS after they have been AIDS-positive for awhile? Are we experimenting with a lot of different things to see what we can do to find the answer, to keep them from progressing?

**DR. JANCO:** I think the essence of your question, Doctor, is what can we do for the majority of individuals who are HIV seropositive to halt or impede the progression to full-blown AIDS. Is that correct? Okay.

I think that is an excellent question and I think the hemophilia population represents an ideal population in which to study that notion. Going back to the issue of co-factors, one of the things that we in the hemophilia treatment community are concerned about is the relative impurity of factor concentrates. Most of you probably don't realize and I didn't really learn this myself until many years ago that the clotting factor concentrates are basically freeze dried plasma. We know, obviously, that they contained AIDS virus. We knew that they had hepatitis virus. We now know they have non-A, non-B cytomegalovirus and other things.

Moreover, they are 95 percent junk protein that a hemophiliac doesn't need; only about 5 percent is the missing factor concentrate. So, the hemophiliac, who infuses himself on the average of about every week or every other week is infusing mostly foreign junk protein and probably some residual viruses. Now, what is the effect on that anti-genic stimulation of the immune system, either by the protein, the degraded proteins, or contaminating viruses on the immune system of the HIV seropositive hemophiliac, who is otherwise healthy? Okay.

I think that is of some concern to us. So, I think basically purity is a goal to which we should all aspire with respect to factor concentrates and I think that we need more ongoing research into the co-factor issue relevant to hemophiliacs. They are a captive population. They are compliant. They come back to their physicians on the average every six months or sometimes more often than that.

They are used to participating in clinical and research trials. They are an excellent group, I think, with which to study questions and design experiments.

**DR. SERVAAS:** I just would really like to hear an answer to how can we justify not giving vaccines that shouldn't be given to AIDS-positive individuals, by saying we can't test them but we want to go right ahead and do all these dangerous things for them and then they will be coming in with infections much earlier than they would have if they had known about their condition.

**DR. MITCHELL:** But certainly most of the HIV-positive individuals are not going to be in the pediatric age range, where you are initially vaccinating.

**DR. SERVAAS:** But the mothers would be.

**DR. MITCHELL:** The mothers would be, yes. But, for instance, if I were HIV-positive and I perhaps needed tetanus toxoid, I would weigh the risk, theoretical, of receiving a booster of tetanus toxoid (I presumably would have been vaccinated in my youth) of getting a booster of tetanus toxoid versus the very, very small risk of actually getting tetanus. But the vast majority of individuals are already going to be vaccinated against most of the things we are vaccinated against.

**DR. SERVAAS:** But I was asking about bisexual fathers, for instance. If you give a polio vaccine in the home, aren't you endangering that man's life?

**DR. MITCHELL:** You may be. I don't have an absolute answer to that.

**DR. CONWAY-WELCH:** Thank you, Dr. Mitchell. Dr. Primm.

**DR. PRIMM:** Dr. Mitchell and Dr. Bartlett, in New York State and Nassau County, people who are found to be HIV antibody positive, a physician can notify that individual's significant other or spouse about the seropositivity of the individual to safeguard the innocent people that Dr. Walsh was talking about.

Both of you -- one of you is an infectious disease person and the other a pathologist dealing with contagious diseases all the time. What would be your recommendation besides the one, number one, that you recommended, Dr. Mitchell, the willful breaking of patient HIV status confidentiality by an institution or individual should be subject to a meaningful monetary fine and a liable in tort action. We are talking about protecting the innocent now and I imagine you would fine any physician or hospital or institution that would notify a significant other or a spouse.

**DR. MITCHELL:** I would obviously remove that. Informing the spouse informing the surgeon that is about to do surgery,is justified. I would remove that discourse from the disclosure. At the same time, though, what I am really getting at is the hall gossip, the spreading of information on HIV-positivity more by word of mouth that serves no purpose, other than to identify someone as a pariah.

**DR. PRIMM:** How would you suggest, Dr. Bartlett, that we protect those individuals who are subject to infection by significant others in that situation?

**DR. BARTLETT:** I think the most important thing is to get the rules clarified. I think most physicians simply don't know what to do. They feel an obligation to notify other people who are at risk. On the other hand, we have all felt that that was a breach of patient confidentiality and I think most of us feel that we are walking on very thin ice in this whole issue. I think most of us do not understand our obligation.

In addition to that, I would say that most physicians probably don't really know how to go about finding or identifying all the sexual partners of many of the patients that we treat. It is awkward; it is uncomfortable; it is something that we have never done in the past.

So, I think the issues are tough and I don't think they are very clear to the medical community. I know that in our own health department, the health department is now notifying the patients that they are going to notify the sexual partners. How they get a reliable list and so forth is something I don't know.

**DR. CONWAY-WELCH:** Mr. Creedon.

**MR. CREEDON:** I have a series of questions, really, for Dr. Bartlett, but I think they are all one question really.

DR. CONWAY-WELCH: A, B, C and D. Dr. Walsh will be after you.

**MR. CREEDON:** Did I understand, Dr. Bartlett, that you have about 800 patients that you are treating?

**DR. BARTLETT:** No. We have, well, over a thousand patients that are seropositive, but about 400 who have had AIDS or have AIDS.

**MR. CREEDON:** Four hundred. So, that is a really significant percentage of the total number of cases that we think are out there.

**DR. BARTLETT:** In our area, yes.

**MR. CREEDON:** There is what, 6,000 or something like that. So, it is not an insignificant number.

Yesterday we had testimony from a number of other doctors, who were from hospitals and one of the complaints that they had was that under the DRG system that they were not getting enough money from the Federal Government on, you know, Medicaid cases. Are many of your cases Medicaid?

**DR. BARTLETT:** Our patient payer breakdown shows that about 35 to 40 percent are Medicaid.

**MR. CREEDON:** Do you get enough money from the Federal Government to.

**DR. BARTLETT:** I can't tell you about the hospital side. The professional fee side, we do very poorly. We get about 20 percent of the charges for inpatients and we get nothing for outpatients. I think it is a problem. It is one of the reasons I thought a capitated system was a better system.

**MR. CREEDON:** Is there a feasible way of moving to a capitated system, as you see it? You know, you say, well, the present system is wrong. Enough money is being generated here to take care of a patient, but it is not being generated in the right cubbyholes.

Is there a feasible way of having a capitated system, which would extend over the period of time that the person is ill and until death? I guess what I am saying, is that there is something wrong and I think we agree there is something wrong, but how do we right it. What do you recommend for the Commission to deal with this issue, it seems to me, which is a very important issue?

**DR. BARTLETT:** What I would suggest is that this be one model that might be examined. What I would propose if I was given the opportunity is that I would be able to approach third party payers, whoever they may be, for a capitated system, in which we would assume the role of care providers for a person who is newly diagnosed with HIV infection and we would take care of that patient through the entire course of the disease. We would do it with a fixed amount of money.

**MR. CREEDON:** Now, do you think with the present system that the Federal Government has, the DRG system, that that could be made to work?

**DR. BARTLETT:** I don't know how it would translate into the current health care system in detail. I can't tell you that. To me, it is an attractive approach. The problem that I have had, quite frankly, is that we have struggled with every element that I mentioned. The inpatient unit is one that is well in hand and it is the one part of this package that we control and it is the one that is smooth.

The chronic care facility, we have been talking about it for two years. I am on so many committees that deal with chronic care and the state has provided incentives for chronic care facilities to become receptive for patients with AIDS and so forth, but we are quite frankly right back to square one. If this meeting was a month ago, I would have said there are three chronic care facilities that will now accept patients. We are back to one and no progress. We are right where we were two years ago. I think we are going to talk about it until we all die.

I feel the same way a little bit about some of the other components of the system. I don't think we are making any headway. It is too complicated. There are too many people involved. I would really rather have the third party payers simply provide a capitated fare and then have us provide the care with all four elements and let us run the four elements and let that dedicated team participate in all four components of it, something we don't do now.

**MR. CREEDON:** Could there be a model along those lines? In other words, could we recommend to somebody that the government provide the financing for that type of model? You know, you mentioned the Robert Wood Johnson model and the San Francisco model and we heard about those this morning, as a matter of fact. And one of the questions is, well, how do you evaluate objectively these different models because the people who are involved in them obviously will think of them as being great, but who objectively evaluates them and decides -- I mean, you don't want one model for the whole country, as you mentioned because certain amount of pluralism is probably healthy and good, but how do we determine whether a model is good and should be tried and the government should finance some of it?

**DR. BARTLETT:** Two or three ways to do that. One is cost effectiveness, which is obvious. The second is somebody is going to have to monitor client satisfaction. The third is that whoever is the judge of this ought to be outside of the system that is being evaluated. So, it may be that what you would wind up recommending is that one group that is independent of the case management system and the San Francisco model and all of the other models, perhaps, assess all of them for comparative purposes, but it has to be somebody outside. We can't ask a surgeon to judge the outcome of his surgery. I agree with you.

**MR. CREEDON:** I would request that if you have any further thoughts about this, I would certainly welcome receiving them. If you have some further thoughts on just how this could be done in our present framework and method. Maybe it can't be done. Maybe we have to recommend significant changes, but I agree that we need to find a way of dealing with the case from beginning to end and in a way that provides quality care and in a cost effective way. Now you just have so many pieces to it that it is hard to do that.

**DR. BARTLETT:** It is impossible to have flow. You know, if we do get a patient into a chronic care facility, then movement back becomes most awkward because that is a shot that is being called by another person and similarly with other components of the system. That is why I think one system managing all four components would be much more effective. You could manage the flow through the system.

**MR. CREEDON:** Would Johns Hopkins be prepared to do that as an institution?

**DR. BARTLETT:** Well, I can't speak for the institution, but I expect that they would. I have discussed it with the people there and I think they are quite ready to move in that direction.

**MR. CREEDON:** Thank you very much.

**DR. CONWAY-WELCH:** Thank you, Mr. Creedon.

I would like to clarify a couple of points and then I would like to turn it over to the Chairman and then if there is time, I would like to ask the other Commissioners if there are any other questions, beginning with Dr. Walsh.

**DR. WALSH:** Do you want to go first?

**DR. CONWAY-WELCH:** Let me go first. I had two points directed to Dr. Mitchell.

What harm can come from endorsing or supporting harmless nostrums? By that, I presume you mean a good diet or exercise or that sort of thing.

**DR. MITCHELL:** As part of my duties at Vanderbilt, I am also medical director of a clinical reference laboratory of specialized assays and this is one example, I believe.

Several weeks ago, the head of the Microbiology Section got a phone call from one of the, I believe, state of California attorneys, asking us if we could identify bovine colostrum. Now, why in the world would they care whether we could identify bovine colostrum?

**DR. CONWAY-WELCH:** That is cow's milk.

**DR. MITCHELL:** Well, the first --

**DR. CONWAY-WELCH:** Prelude to milk.

**DR. MITCHELL:** Yes. Which is high in antibodies. One of the recently recognized viruses in cows happens to be bovine immunodeficiency virus, in which antibodies against that virus have cross reactions with the human immunodeficiency virus. So, on the basis of that, unscrupulous operators or -- I think they are unscrupulous -- in California, began to bottle this as a douche of various types with the idea that it would protect against casual sexual practices. This is a far-out example, but anything that relieves the responsibilities that individuals have in terms of -- and this goes back to Dr. Walsh's comments to me

-- that relieves them of their responsibilities of not spreading the disease by thinking by some worthless nostrum that they are being responsible, I think, is adding fuel to the fire.

Certainly, anything that comes out of a prestigious presidential commission carries a lot of weight. So, I would be just very careful and research folk remedies very carefully before endorsement. There probably will be multiple efforts to get the Commission to endorse a variety of things. You can endorse what you wish, but I would be careful in doing it.

**DR. CONWAY-WELCH:** Thank you, Dr. Mitchell. Dr. Bartlett, I would like to ask you a quick question on what happens when an AIDS patient comes to you for general medical support? He has a cold or he has cut his finger or has a broken leg or whatever. How does that care differ, if at all, because the patient is HIV-positive?

**DR. BARTLETT:** I don't think it really makes any difference. If they require a specialist, then they will get referred to a specialist. I think there are probably some medical care providers that are reluctant to provide care to AIDS patients. I think we heard a lot more about it years ago than we do now. I really don't think patients with AIDS or HIV infection have difficulty getting access to the health care system, getting hospitalized in acute care facilities. I think the other parts of it are difficult, but that part of it is not, in my own perception.

I think we are going to occasionally encounter it. For the simple problems, the same people that provide care for AIDS as practitioners of medicine can take care of cuts and sore throats and those sorts of things. If they break their leg, I am not going to take care of it, but we will refer them to an appropriate source and then they would, in all probability, take care of that element of the disease in concert with us. I don't think there is probably going to be much of a problem in there.

I do think that there is a problem in the provision of dental care. I appreciate what Dr. Rogers said at the end, that the American Dental Association has endorsed all these good things. But I can tell you that when I talk to patients, their perception of the availability of dental care is meager.

**DR. CONWAY-WELCH:** Thank you. Mr. Chairman.

**CHAIRMAN WATKINS:** That brings me back to the same issue. We have an opportunity with this Commission -- I think it is emerging as we mature -- with the competent witnesses that are coming before this Commission to take advantage of the good services of the television, radio and written media industry, to help educate the American people ourselves in the process, but certainly everyone else because the dialogue is continuing. It is not edited out. We had public television going for four hours yesterday. I think it is very beneficial for the American people, so I think when we have a controversial issue come before us, it is very good to air it and to give the best minds in the nation an opportunity to explain the position to the American people.

For example, we had Dr. Richard Johnson, who is an internationally-recognized expert on the effects of HIV on the brain and the nervous system this morning. And he and the colleagues present as panelists were able to put in perspective an article that appeared in the written media that moved around the country very rapidly and on which some decision-maker had actually made moves that were probably unnecessary and premature. It had to do with early identification of neurological damage, cognitive damage to individuals as possibly being the first sign that you could find in the HIV-positive but asymptomatic situation.

So, I think we have responsibility that when an issue -- and certainly I have been -- I have been in this town a long time and I have been the subject of a lot of vilification and a lot of partial truths and I understand all that, but I think when an article comes out that states that an ADA survey released last November -- and I will address this to Dr. Rogers since his colleague has departed -- that almost four out of five dentists would not treat AIDS patients, contrary to the group's professional standards to treat all patients and the reasons cited were fear of catching AIDS and fear of losing other patients.

One, is that accurate? And, two, if it is accurate, is it ethical? I think, Dr. Rogers, you answer that, at least in part, that it was not ethical in itself, but also Dr. Barrett indicated, as opposed to this article, that perhaps there were other detractors from making it mandatory as a policy, that the particular dentist treat the patient with AIDS, by stating that many of these dentists have not been through whatever is the necessary training program to permit them to be comfortable working with infectious disease patients.

So, I think it would be very helpful to kind of walk through this thing once again because I think you began to clarify it but I am not sure in my own mind, I am not yet convinced that the solid ethical front end of your statement, then modified by the "or referral," without further caveat along the lines you talked about in your training efforts that are going underway. You are trying to get a handle on this. You are getting ready for it. So, I assume that at some point in time, the "or referral" will drop off the policy. Am I understanding this correctly?

**DR. ROGERS:** Well, my comment on that, yes, it would be my opinion and I think would be the considered opinion of the American Dental Association that it would be unethical for a dentist not to carry through with his or her obligations. But I think once we have the experience with the history of information and technological transfer and this gets disseminated among the practitioners throughout this country, I would hope and I would have faith in the profession as being one of a scientific profession and one of the healing professions, that we would gradually see an erosion of this apprehension and fear.

I think if we look at the provision of dental services historically, dentists and dentistry has not necessarily seen itself as struggling, perhaps, with life and death situations, historically and traditionally. I think that the AIDS epidemic is changing that and I think we are going to have to address this challenge and, yes, just as we adopt and put into utilization other technological advances into practice as much as medicine does or any other profession, I think this is one instance in which putting into effect infection control guidelines, which exist, we will have to come up to muster in this regard.

In terms of four out of five dentists in that survey and, hopefully, it is a valid survey, would prefer not to treat patients, I would hope that that would be a gut and visceral response on their part.

In referring to Dr. Bartlett's remark about his experience in Baltimore, I do know there are collaborative efforts that are beginning in Baltimore for this with the health department in Baltimore and its new commissioner, Dr. Collier, and the Bureau of Dental Care under Dr. Jennings in Baltimore.

I do know that certain of their public health clinics see patients who are HIV-infected and the local dental society as a local part of the American Dental Association is beginning to have very frequently scheduled training and continuing education courses for its practitioners.

So, I am hoping what we are seeing now is an initial lag, but the profession will gain a responsive momentum in this regard.

**CHAIRMAN WATKINS:** It just seems to me that the CDC has published, I think, last fall some very clear and concise guidelines. Even to a lay person like myself, they did not seem complex in just a first reading and I am naive in this area, but it talked about goggles and gloves and masks and I have certainly been to dentists that use those things. It didn't seem complex.

It seemed as though it is the kind of thing that in the Navy we would have had a two week training program and gotten all our doctors squared away on the proper procedures and we would have moved right in to the new policy which said it is in synchronism with the American Medical Association because we need the courage of our people to continue carrying out the Hippocratic Oath and they had to reaffirm that. And they have the same fear in the emergency rooms and so forth.

We have people on our own staff, who are clinicians, who work at Johns Hopkins University in the emergency room up there and they have the same fears. The nurses have the same fears and, yet, the policy is clear. And, so, I am just saying -- I recognize that we are going to go through this transitional mode, but it just seems to me that there ought to be a caveat on the policy that says we have to overcome certain technical issues, but by policy we are not going to accept the failure of the traditional role that we have in delivering medicine, that we are going to be courageous enough during this period to say by policy we are going to treat them all. We are not going to refer, if "refer" allows some other kind of a cop-out on the part of the individual.

I am just trying to air this now so you have a chance to make it clear because we may not have many opportunities like this to discuss this issue until our report goes in and I think it is important that certainly we open the door not only to this discussion but any follow-on discussions you might have with us, so that we are not confused on this either/or ethical policy.

**DR. ROGERS:** There is always a problem with generalizations or a specific example, but if I could use my practice as an example. When I practiced at one time in Baltimore County, when the problem became evident in the early eighties, my associate and I at the time considered these very fears and apprehensions. I think my public health background, of course, facilitated what we did, in fact, put into practice in this one particular office and that was enter into a dialogue with the staff, with one another and, I think, equally as important, with our patients. If our patients asked us about this, we told them exactly what we are doing, not only to protect ourselves, but what I feel is more important, any problems with transmission to another patient or cross contamination.

There was some resistance or questions initially on the part of our patients of record, but within a very, very short time we no longer had those questions or when they saw certain practices change within the office itself, the apprehension among the patients changed. Also one of the concerns of the profession is about the cost of instituting certain of these infection control guidelines. The health care supply industry, so far as dentistry is concerned, is beginning to respond to that. I think, looking at any of the professional journals, the numbers of articles and advertisements on disposable articles in dental practice has increased 100 fold.

So, once dentists see this, that products and supplies are available in which there would be disposable items to care for patients, instruments, prophyangles, this sort of thing, I think information and technology will be incorporated into the behavior of the practitioner.

**CHAIRMAN WATKINS:** But doesn't the "or referral" modification of the policy tend to take some of the incentive out of your training and education effort. Doesn't it tend to allow that to move at a slower pace.

**DR. ROGERS:** I would agree, CHAIRMAN Watkins, that that escape or escape interpretation is there, but the Association, the American Dental Association will be stressing to its constituents that referrals should only be if the patient's condition is such that he or she can't be treated in that office setting or the dentist's expertise for a particular procedure that that person may need cannot be rendered in that setting.

I think it is --

**CHAIRMAN WATKINS:** Has that been defined sufficiently to say that that would be in a very unusual set of circumstances at this point?

**DR. ROGERS:** If it hasn't been clarified in the past, certainly the Association is taking steps to see that this is going to be carried out in the future. As I said, the educational packages which will be coming out next month will directly address this.

**CHAIRMAN WATKINS:** It is a very important issue and Dr. Bartlett's observations are the same observations that we have had in our trips to the field and, so, the perception is there that it is more difficult to get dental work done than to get medical work done for an AIDS patient.

So, I am just raising that because I think it is good to air it and I don't know if any other Commissioners have any other observations they would like to make on this particular issue, but I do think it is important that we have this dialogue and allow many others here in the room today and those who want to watch this dialogue take place begin to understand some of the background behind this.

**MR. CREEDON:** Admiral, I just have one question. Dr. Barrett, who has left, I notice is the president of the Academy of General Dentistry. Does that have a different position than the American Dental Association on the professional responsibility in this area?

**DR. ROGERS:** No, I would say not. I would think that the Academy of General Dentistry would be consanguineness with the American Dental Association.

**MR. CREEDON:** Because his statement was quite different from your statement. I mean, the written material is different from yours.

**DR. ROGERS:** I think that is just reflective of our different professional backgrounds; my coming from public health and ten years, was with the Baltimore City Health Department before coming to Washington. I think they are just two different perspectives.

**MR. CREEDON:** Thank you.

**DR. ROGERS:** But I think that it points to the fact that I think throughout all of the speakers today, that we all feel that we are talking about a coordinated effort, that it is just not one group or it is not merely the Federal Government or state or local. It is all organizations and also a need to incorporate the lay population.

**DR. CONWAY-WELCH:** Are there other questions relative to the dental issue?

**DR. WALSH:** Yes. I would hope, Dr. Rogers, that you would not want to leave this assemblage or the television audience with the idea that dentists learn nothing about infectious disease, particularly as to systemic manifestations in the mouth, when they were in school, whether it be 40 years ago or today. Talk about cop-outs. That is the greatest cop-out of all. What you are talking about is a decision that many physicians make out of ignorance about AIDS, that there is a great fear of AIDS, but you learn in school systemic lesions of the mouth probably better than most physicians do and systemic manifestations of disease and continuing education availability when a new disease arises, like AIDS, certainly is available, as you suggested you are doing at Georgetown now as an elective thing.

I would not want everybody here to be afraid to go to the dentist for fear that you don't know what you are looking at when you open your mouth. I know better and I know you know better, but I think that should be emphasized because I think we have been partly misled by the statement of Dr. Barrett, unintentionally perhaps, but I found years ago when I was practicing medicine and I saw lesions in the mouth, it was not unusual for me to seek a dental consult rather than a medical consult because there were some lesions that I felt you may recognize better than others. That is the real cop-out. For fear of not being recognized, I am going to keep going.

**DR. CONWAY-WELCH:** Oh, no, I promise you I will recognize you. Ms. Gebbie has a comment on this issue.

**MS. GEBBIE:** All of the discussion around the training programs you plan to have focus on relation to AIDS itself or HIV infection itself and appropriate infection control procedures.

In a fair number of discussions of this subject, people believe that -- not just for dentists but for a number of other health care providers, who decline to care for AIDS patients, the reference to "I don't know what to do for the procedures" or "I don't understand the infection" is a cop-out for biases and prejudices of the groups of people who are most infected with this particular virus; fears or disrespect for those who are gay; the same kind of attitude toward drug abusers or minority groups.

With that regard, most people doing training programs have found a need to include that kind of social issue, along with the technological. If you have not considered that -- this is more a comment than a question -- would you please look at that because you may find everybody passing the technical test and still patients not getting in the door because of those social attitudes.

**DR. ROGERS:** Well, I would just comment on that.

In the number of presentations that I have done before various professional groups here locally and in other states, I more than make sure that we talk to the sociological and behavioral aspects of this, both in terms of for the patients and changes in behavior on the part of the practitioner.

**DR. CONWAY-WELCH:** I would like to extend the discussion for ten minutes until quarter of. So, Dr. Walsh, do you have a different question and then the other Commissioners --

**DR. WALSH:** I have a comment and a question -- the question is based on ignorance. That is why I need your help. Is your knowledge of the case management situation in San Francisco equally thorough because we have heard such a variety of costs that come with case management and I wonder, how all of these costs are arrived at. You say 30-40,000. Someone else will say 12,000 or 9,000. This gets into the whole long term care situation, not just for AIDS and I am a great believer in the fact that we are only going to get what you want with AIDS if we address the entire long term care question because we are not going to get legislation for just or one illness when there is so much need for other long term concern. You might want to giv that some consideration in what you propose to us. The questio I really wanted to ask you, Dr. Janco, was this and it comes out of ignorance. I have read both in the media and other areas of the literature that the progress of AIDS in hemophiliacs is different than the progress of AIDS infection from seropositivity to infection in other infected groups and I don't know if it is true. Secondly, if it is true, I have no concept of why and I wondered if you could help my ignorance on that.

**DR. JANCO:** I am not sure I have the answer to your question, but I think what you are driving at is that early during the AIDS epidemic, it seemed that the number of cases being reported to the CDC in hemophiliacs was leveling off, as I pointed out in that figure in my written testimony, at about 40 patients per quarter. So, we were beginning to have, I think, perhaps, a slightly smug attitude that, yes, indeed, the natural history from progression of seropositivity to full-blown AIDS would be different in our population for some reason. Unfortunately, newer data now suggest actuarial incidence rates around 22 to 30 percent, suggesting prevalence rates around 30 to 35 percent, that would tend to suggest that the overall progression is the same.

But I don't think we really know. There may still be some differences in terms of the time or the types of illnesses that are seen. I think we need to learn a lot.

**DR. WALSH:** Is there data from the time of recognized seropositivity to the time of either ARC or AIDS, is it longer?

**DR. JANCO:** Yes, sir. There are some data. I think progression from the time of known seropositivity to full-blown AIDS, has been within five to six years from information available from serum banks and the proportion progressing is as high as 30 percent plus; slightly less in children under the age of 13.

**DR. WALSH:** But you don't understand why there is a difference?

**DR. JANCO:** I don't think we do. We are concerned about the issue of co-factors, though.

**DR. WALSH:** Yes, but I just wanted to be sure because I had heard that but I didn't know for sure.

**DR. CONWAY-WELCH:** May I ask, are there any other questions. Ms. Pullen.

**MS. PULLEN:** Dr. Mitchell, you mentioned the need for developing guidelines for immediate intervention in accidental exposure. Could you expand on that a little bit, please, not only in terms of what you would recommend for guidelines, but also in terms of telling us what means can be taken to -- I think you used the term "abort" infection.

**DR. MITCHELL:** Well, I not infrequently get phone calls from other places that request advice on needlesticks days after the occurrence. I think one needs to segregate various needle stick risks. They probably should be related in terms of risk of how much blood is actually placed in a needle stick and the severity of the injury. As surgeons particularly become more and more involved in the care of HIV-positive individuals, where they are immersed in blood and where there is the possibility of non-integrity of their gloves or actual injury; for instance, an injury on a bone spicule were to give them a cut in their hand, I think that there needs to be, and I don't know of any institution that has guidelines that actually looks at the risk or what one would guess the risk would be or what one should do immediately.

It strikes me that with a known injury or accidental infection and you know it at the time, certainly that wound should be very adequately debrided immediately. There probably should be the institution of various antiseptic agents. For instance, 75 and 90 percent ethanol inactivates the virus. Betadine, in a very recent article, we know very rapidly inactivates the virus and there are a number of antiseptic agents that probably would not be hazardous.

Thirdly, and this is one -- the reason I was not more direct, if one had an injury in which one could make an educated guess there was a high risk of HIV infection, should one be immediately be put on AZT, knowing what the risk of serious bone marrow depression or even, I would guess, that AZT is going to have some rate of aplastic anemia. These things need to be, I think, evaluated and I can't tell you exactly how to approach that, but I think that each institution should have guidelines so that these things are not worried about over 24, 36, 48, 72 hours, but that there are effective practices in effect when an accident occurs in which there is a high risk of infection. Institutions need to have on board what their mode of action will be with any given accident.

**DR. CONWAY-WELCH:** Thank you. Are there other questions on this area?

**MS. GEBBIE:** A follow-up to that, a comment and then a question.

In the answer you just gave, it sounded to me like you were mixing some potential research protocols on interventions with guidelines based on current well thought-out understanding of the disease. Is that accurate?

**DR. MITCHELL:** Yes. One of the problems, obviously, is that AZT is not without its hazards. In fact, the way this really -- we were discussing this in my laboratory recently, where we handle infectious HIV daily and we were discussing what do we do in the case of accidental exposure and we have had -- people in my laboratory said I don't care what my risk is, I don't want to take AZT. Others would say "yes," I would.

**MS. GEBBIE:** Is your comment about the lack of procedures to follow after an injury based on any kind of a survey of institutions, adopted policies or just the phone calls you happened to have gotten?

**DR. MITCHELL:** Just the phone calls from everywhere, including my own institution. It would be interesting if Dr. Bartlett's institution has a policy.

**DR. BARTLETT:** Well, we have a policy that will take care of -- through the medical adviser -- that will take care of the definition of an exposure versus non-exposure, take care of the serology according to CDC guidelines and take care of management of the wound. We do not have a policy dealing with AZT and I think that is because there is no right or wrong answer. There is no information.

I do think the point that was made is a very important point and I hope the Commission will address that issue. We have to be aware that people that work in the health care industry at the present time take a risk and we who are part of that effort want to make that as risk-free as we can. I think it may be very difficult to recruit people to do this work in the future.

**MS. GEBBIE:** There has certainly been some discussion of that at a number of sites.

**DR. BARTLETT:** And we really need to be able to provide better assurance that it is safe and I would put that at a very high priority. Making the workplace safe ought to be a very high priority. If AZT will do it, then we ought to find out as quickly as possible.

**MS. GEBBIE:** The reason I asked the question is that it has been too easy for a public hearing to have a discussion such as we have been having here and to not clearly make the difference between what is a perfectly valid and appropriate research question that ought to be tested under controlled circumstances, from what is a clearly understood policy that ought to be implemented everywhere. The intent of my question was to separate those, not necessarily for you but for those who might be listening to our discussion. Thank you.

**DR. CONWAY-WELCH:** Thank you, Dr. Bartlett. Is there a short question from this group.

**DR. SERVAAS:** I have a short question for Dr. Bartlett.

I have encountered a number of patients, who before they knew they were AIDS-positive had gone from doctor to doctor. I wondered if in your practice there, you have encountered that and the other part of my question is if you are sure that the hemophiliacs are doing better than the general population of AIDS patients, might it be that our AIDS-positive people or our AIDS patients then later got AIDS because they were given corticosteroids or antibiotics that they shouldn't have had or other things that weren't in their best interests before they knew they were AIDS-positive and that the medical profession then waited until they came down with AIDS or ARC to know that they were doing the wrong thing for these patients?

**DR. BARTLETT:** I agree that a lot of patients are treated by physicians that are relatively naive to the early stages. I think that the early phases of the infection, the asymptomatic patient who has abnormal laboratory tests, the patient who presents with constitutional symptoms and the very rare, but occasional patient that presents with neurologic findings is the one that is going to miss detection.

I think there is an easy explanation for that. They are usually vague complaints, the kinds that physicians encounter in their office on a regular basis and the great majority of doctors got all of their training before 1982, so they never saw this during their training period and it just emphasizes what you have already said and that is that we really need a vigorous education program.

Now, I expect that hemophiliacs are usually plugged into a system of care and that the care providers are very adept at being able to detect any evidence of HIV infection and that may be why they are a bit different. IV drug abusers don't have IV drug abuse doctors -- at least I don't know of any -- and the same would be said of the great majority of gay patients, who are usually unknown in terms of sexual preference and go to a variety of practitioners, who are not necessarily aware of their lifestyle nor of AIDS.

So, I think there is a rational reason for your observation. I am not happy with it, but I think it is reasonable.

**DR. CONWAY-WELCH:** Thank you, Dr. Bartlett. Thank you, Dr. Servass. I think we need to ask the Chairman if there are any comments.

I would like to thank all of you for your time and effort and particularly since you were notified around the holidays and I am sure spent some time over the holidays working on your suggestions and presentations. We are very grateful to you and we appreciate the time. We would like to commence with the next panel immediately. We would like to continue our panel addressing special issues of AIDS patients and I would like to begin with Dr. Minkoff. Welcome. You have shared information with us before. I would like to again state we would like very much to have your recommendations as close to five minutes as possible so that we do have time for questions and answers. You have seen how interested and how chock full of questions everyone is and we will begin questioning this time on my left with Mr. Creedon. I would like to introduce Dr. Howard Minkoff, Associate Professor, Director of Obstetrics and Maternal-Fetal Medicine at the State University of New York Health Sciences Center in Brooklyn. Dr. Minkoff.

**DR. MINKOFF:** Thank you very much. I would like to take this opportunity to discuss the resources required to care for HIV-infected women. The HIV epidemic affects women in at least two unique ways. First, CDC testing policies currently focus on women so they may be identified as infected long before symptoms develop. Thus, a special set of resources is needed to care for women identified before or during pregnancy as being asymptomatic carriers of HIV.

Second, caring for infected women involves caring for infected families. Resources are needed to stabilize and support those families. I would like to use my few minutes this afternoon to outline the implications that these two differences have on care requirements and to development the thesis that regional comprehensive AIDS family care programs, which can provide services and can liaison with community agencies, would best serve the needs of infected families.

When the CDC's recommended testing programs are fully implemented, thousands of women will be found to be asymptomatically infected with HIV. We must not be deluded into thinking that an absence of symptoms connotes an absence of needs. Quite conversely, if we expect testing to lead to a reduction of viral transmission, then a multitude of resources must be provided so that women will be willing to accept the testing and to practice recommended risk reduction behaviors. Women who test positive will need detailed, compassionate, time-consuming counseling about reproductive and life choices.

Unfortunately, since the demographics of HIV infection reflect the demographics of intravenous drug abuse, the initial confluence of disease will occur among poor minority women in disenfranchised communities where hospitals and clinics may not be able to afford counselors. Thus, the first resource needed is funding to provide counseling to infected women.

The counseling itself involves a presentation of options. If a patient chooses to avoid the risks of pregnancy, she will need abortion services. Access to those services is sometimes hampered by financial and geographic barriers. The constraints of the Hyde Amendment should not apply to HIV infected women.

Further if Title X funding is denied when abortion is discussed, then some women may not even receive information about alternatives to a potentially life-threatening pregnancy. Patients who choose to continue a pregnancy, as do most seropositive women, need ongoing psychosocial and medical support. Support groups for infected women must be developed to allow these women to continue to function as mothers.

When the child is born, the needs of the family unit expand. Respite care, day care and housekeeping assistance for the mother, pediatric care for her child and foster care for children whose mothers cannot provide care are needs which are not currently met. As HIV spreads to women and becomes a family disease, however, these resources will be required to stabilize and support infected families since they can maximize the biologic mother's ability to maintain her family in the face of compromised physical and emotional reserves.

Since foster care houses those children whose nuclear family dissolves, foster parents should have access to the same services as biologic parents. All these efforts should be coordinated by a regional comprehensive AIDS family care program that can triage an individual's needs and then either provide services, such as medical care or psychosocial support, or access services through a liaison with community agencies. These programs would in effect serve as ombudsman for the infected family, helping them to interface effectively with social agencies and to remain intact as long as possible.

The care program could also assist agencies to recruit foster mothers and family day care workers from the communities. Those community agencies providing services would receive educational programs for their employees. The educational components of a comprehensive care program should be developed with the understanding that the most cost effective care is that directed towards uninfected, but at risk women. As noted, once a woman is infected, her family is infected and the cost of caring for an infected family is overwhelming.

Resources for educating at risk women and for educating clinicians, who routinely see these women, around issues of sexual and reproductive health must be provided.

In sum, in order to institute testing, provide options to infected mothers, maintain infected families intact and provide better placement for homeless children, the following resources will be needed:

First, counselors to allow implementation of testing programs.

Second, funding to assure that all options, including abortion, are available to infected pregnant women, independent of financial status.

Third, day care, respite care, housekeeping and social support services to help maintain intact the infected family and to assist mothers who choose not to abort.

Fourth, medical care for asymptomatic and symptomatic mothers and children.

Fifth, care for children without parents. As the pediatric AIDS crisis expands and puts greater stresses on systems of child placement, the flaws in those systems come into sharper focus. Hearings dealing specifically with foster care might help to restructure a system being asked to address problems never imagined at the time the system was created.

All these resources can most efficiently be instituted via a comprehensive AIDS family care program that would incorporate the resources of the community, as well as those of regional medical centers. This proposal recognizes that HIV infected asymptomatic families can best be cared for within their communities if education, medical expertise and consultation are provided to community agencies and also that specialized medical center-based services must be available for those members of the family who develop disease.

A comprehensive AIDS family care program is the approach most likely to provide all these services in a coordinated, cost efficient manner, which respects the integrity of the family, as well as the needs of its individual members. Thank you.

**DR. CONWAY-WELCH:** Thank you very much, Dr. Minkoff.

I would like to introduce Ms. Jackson. Virginia Jackson is a registered nurse and a certified nurse midwife and she is employed at the North Central Bronx Hospital.

**MS. JACKSON:** Good afternoon, ladies and gentlemen. I would like to thank the Commission for this opportunity.

I am a certified nurse-midwife on the staff of North Central Bronx Hospital in New York City, where the entire obstetrical service is operated by midwifes. North Central Bronx is a city hospital. Most of our patients are poor or working class. We manage 5,000 deliveries a year, while maintaining the lowest maternal and child morbidity and mortality rates of any city hospital and a cesarean section rate of only 12 percent.

We do not know how many of our clients would be found positive for HIV. We do know that approximately half of our clients had the potential for exposure to the virus through IV drug use, sexual activity or blood transfusion. In accordance with CDC recommendations of August 1987, all clients stating possibility of exposure are counseled regarding testing, possible effects on the fetus and preventive activities.

I offer the following recommendations for care of HIV seropositive women with the understanding that I must consider all the women for whom I care HIV positive.

The first recommendation is to reduce the cesarean section rate. The rate of operative delivery in the United States is embarrassingly high. One in five births is a cesarean, with many hospitals reporting as many as one in three. A cesarean delivery exposes the woman to a greatly increased risk of infection, as high as 80 percent of all cesarean deliveries result in significant maternal morbidity.

In a woman who is already immunosuppressed, such an infection would also carry the risk of mortality. Moreover, an operative delivery also increases the risk of maternal hemorrhage by as much as 30 percent greater than with normal delivery. A large hemorrhage may necessitate the administration of blood or blood products. Current screening does not guarantee the freedom of blood products from HIV. Every effort should be made to prevent the spread of this virus, including protecting the woman from excessive blood loss.

It is important to recognize that the greatest single factor contributing to the high rate of cesarean sections is the repeat cesarean. Prenatally, women should be encouraged to prepare for a vaginal birth after cesarean. Providers of prenatal care should have accurate information and a positive attitude about such preparation. Special VBAC classes have shown great success. In hospitals, efforts should be directed toward development of greater skill in management of labor to avoid unnecessary primary and repeat cesarean sections, with institutional review of all operative deliveries with assessment of need. Providers should be held accountable for their clinical judgments.

The cost of such an effort in providing staff with information and counseling skills would be more than offset by the reduction in cost of fewer operations. Less material, personnel, time in hospital and medications are involved. For the fetus, there are fewer admissions to the neonatal intensive care unit for iatrogenic prematurity.

Secondly, stop the use of routine prophylactic episiotomy. The incision of the perineal body at the time of delivery is the most frequently performed surgery on women under the age of 40. Again, such surgery increases the risk of infection in the immunocompromised woman. Episiotomy has no proven benefits. On the contrary, there is considerable evidence of its adverse effect.

An additional benefit of decreased use of episiotomy is the removal of one source of potential infection of the provider. During repair of the incision, the provider may inadvertently stick herself with the suturing needle. Studies have shown the infrequency of the need for suturing in the absence of episiotomy.

Again, the cost of training providers in techniques to prevent tearing of the perineal tissue balance the savings incurred with less use of material and medications.

Thirdly, to reevaluate the recommendation to advise against breastfeeding. The benefits of breastfeeding are well-known. Special efforts and programs, government and private, have been developed during the past five years to encourage the practice of breastfeeding among women in this particular population. If we are to follow the CDC recommendations at North Central Bronx, we would find ourselves unable to counsel any of our clients to breast feed their infants.

I am very concerned about the basis for this recommendation. AIDS transmission via breast milk seemed to be assumed possible because HIV has been found in some samples of breast milk from HIV-positive mothers. Support for the opposite contention comes from the Caribbean where a large population of seropositive mothers breast feed their seronegative infants. This practice did not result in an increase in seropositive children. The three cases of infants, who apparently became infected via breast milk, were from mothers who had become infected from blood transfusion.

I feel that extensive further study and testing are needed before such a recommendation can be made, the recommendation to advise against breastfeeding. It is unusual to balance unknown risk with known benefits and decide in favor of the unknown. We should also consider the implications for those countries for which there are no readily available, safe alternatives to breastfeeding. A study examining the benefits of breastfeeding seropositive infants may yield, possibly, findings supporting the protective nature of breast milk, even in this situation. Historically, the recommendation to avoid breastfeeding in the case of hepatitis B, for instance, was eventually reversed.

The cost of such a study or studies would be several hundred thousand dollars. A study population would be quite difficult to gather. Informed consent, confidentiality and long term follow-up represent the obvious problems in such an undertaking.

Fourthly, the testing for the presence of HIV makes sense only in the context of prenatal care. One-third of mothers now get insufficient pregnancy care. Annually, 662,000 women do not begin care until the second trimester of pregnancy; 207,000 do not start until the third trimester or get no care at all. Furthermore, let us look at who is not receiving adequate care. The percentage getting insufficient care is highest among the unmarried, teenagers, the least educated, black women, Hispanic women and the poor. You will note the crossover between those at risk for HIV positive status and those receiving less than sufficient prenatal care. Outreach programs are very much needed, with a greater emphasis on community-based centers.

This is not a totally new approach to care provision; however, the funding of new centers would be costly. Indeed, a commitment to continuity of care, so valuable in decreasing adverse outcomes and increasing opportunities for counseling, would require the hiring of more personnel and I would say particularly midwives. Midwives have a record of excellence in the provision of care to all of the risk groups noted above.

Overall savings in decreased neonatal intensive care costs, maternal high risk care costs have, however, been demonstrated in many pilot projects.

Fifth and finally, counseling of women will remain inadequate, as long as the providers of care are not able to deal professionally and compassionately with the issue of AIDS. Extensive work is still needed to prepare staff on all levels for caring for HIV infected women. Information is needed, for instance, on the safety of Rhogam, prepared from blood products.

Counseling efforts should be made to prepare parents for the care of HIV infected infants before they are born. Every hospital employee should have assistance in locating information about HIV. The staff should be provided with the opportunity to acquire the informational and behavioral skills for coping with their role in the provision of care.

**DR. CONWAY-WELCH:** Thank you very much, Ms. Jackson. I next would like to introduce Dr. Arye Rubinstein -- did I say that correctly -- from Albert Einstein College of Medicine and he is speaking to the problems of care of HIV infected children. Thank you, Dr. Rubinstein.

**DR. RUBINSTEIN:** I serve as a director of the Pediatric AIDS Clinic at the Albert Einstein College of Medicine; at the same also as director of the AIDS Comprehensive Family Care Center.

This is probably one of the first pediatric AIDS centers in the United States and to date, the largest one. We have cared for more than 300 children with HIV infection since 1979. We have recently also established a pediatric cooperative study group, which includes practically all the hospitals in the Bronx and some hospitals in upper Manhattan and Westchester. This cooperative study group currently cares for about 500 HIV infected children.

My recommendations, therefore, are representing not only my own views but those of the whole cooperative study group.

It is estimated that today there are around three to five thousand HIV infected children in the United States and that this number will increase rapidly. It will probably reach ten to twenty thousand in 1991. These estimates may, however, be conservative. In some urban areas, including ours, the number or the percentage of HIV-positive pregnant women is currently above 2 percent. We, therefore, estimate that in the Bronx alone in 1988, 500 HIV infected children will be born.

The problem of pediatric AIDS does not reside only in the infected child, but almost uniformly is preceded by infection of an adult family member, especially of the mother. We have recently also noted, the risk factors are multigenerational. They are traced not only in parents but also in other family members, such as grandparents.

These families are unstable, unable to care for themselves and for their sick children and many children are abandoned or orphaned. Moreover, almost 90 percent of our HIV infected pediatric population is neurodevelopmentally handicapped, needing additional specialized psychosocial, rehabilitational and special educational services. As a result of these circumstances, the treatment of pediatric AIDS is more complex, requiring major commitments.

It is impossible for me to address all the issues in five minutes. I have recently completed a comprehensive document dealing with recommendations for pediatric AIDS and for a comprehensive AIDS family care centers. This is a 300 page document, which I will deliver to the committee, if requested. The major problems related to pediatric AIDS and the AIDS family are in our view as follows:

There is inadequate medical care for the HIV infected child, for the symptomatic as well as for the asymptomatically infected child. There is also inappropriate care for the uninfected other children in the family.

There is an absolute necessity of co-treatment of adult family members. Therefore, we have successfully implemented the concept of an AIDS comprehensive family care center, as has been mentioned previously by Dr. Minkoff.

There is an urgent need for an aggressive outreach to the patients' communities. A need specific to pediatric AIDS is the establishment of day care centers, respite and residential care facilities and rehabilitation services, including special education.

Our estimates for the medical care expenses for a child with moderately symptomatic child run currently at 35 to 40 thousand yearly. Expenses for a child in day care, based on our experience in an abbreviated 9:00 to 3:00 day care program that we developed at Einstein are estimated at 50 to 75 thousand dollars per child per year. These expenses, of course, are much lower than having a child hospitalized for the year.

In our view, it is preferential to focus on outpatient care delivery. Our present expenses of the comprehensive AIDS family care center are ranging around $3 million yearly. By the end of 1988, these expenses will probably increase to four or five million. At least ten such centers are necessary to accommodate all pediatric patients in the United States.

The burden of care for these children and for their families is immense. Burnout in health care personnel is accelerating and sources of funding are limited and inaccessible.

Recently, a $20 million bill has been presented to Congress cited as the Abandoned Infants Assistance Act of 1987. We are extremely pleased with this bill, which is a small step in the right direction. There is, however, an urgent need not only for allocation of more funds for pediatric AIDS and for AIDS families, but also to make these funds easily accessible, avoiding often insurmountable bureaucracy. Thank you.

**DR. CONWAY-WELCH:** Thank you very much, Dr. Rubinstein. I am sure I speak for everyone when we request that you share your model with us.

I would now like to introduce Dr. James Oleske. Is that correct? Dr. Oleske is at the University of Medicine and Dentistry of New Jersey and is also speaking to the issue of care of HIV infected children.

**DR. OLESKE:** Members of the Presidential Commission, I am a pediatrician specializing in immunology and direct the Division of Allergy, Immunology and Infectious Disease at the University of Medicine in Newark, New Jersey and serve as the medical director of The Children's Hospital AIDS Program in Newark, New Jersey.

As of January 1988, there have been 49,342 cases of AIDS defined by the CDC; 736 in children under 13 years of age. Estimates by our CDC suggest that by 1991 there may be as many as 13 million Americans infected with this virus.

Based on the experience in Newark, New Jersey, I feat that by 1991, the number of HIV infected children in the United States may be as high as 20,000 with symptoms. There are currently over 130 active pediatric cases for at our Children's Hospital AIDS program. Since 1981, we have cared for 95 children who have died with this tragic disease.

As of January 1988, one in twenty-five babies born in Newark, New Jersey are infected with the AIDS virus. Most infants and children are infected with HIV by perinatal exposure. Their mothers become infected either through intravenous drug use (60 percent) or because their sexual partners are HIV infected (40 percent).

Over half of the mothers infected by sexual exposure did not know of the risk behavior in their sexual partner and first became aware of their infection only after AIDS was diagnosed in their infants.

Fifteen percent of HIV infected children were exposed via transfusion with contaminated blood products or blood. The cohort of infants between 1978 and 1985, who received blood transfusions in nurseries or our hemophiliac population are at risk of developing HIV infection and need to be followed closely for the next 10 to 20 years.

The present screening of blood products and treatment of coagulation factors fortunately will prevent future cases of blood acquired pediatric AIDS. All infants born to HIV infected mothers, perinatal exposure, will demonstrate antibody to the AIDS virus but only half will be truly infected. Almost all perinatally infected infants will become symptomatic and die.

Symptoms, which include failure to thrive, lymphadenopathy, swollen liver and spleen, inflammation of the brain, pneumonia, recurrent bacterial infections, recurrent diarrhea, kidney and heart failure appear usually by six months to two years of age. Once with symptoms of HIV infection, children rarely live more than two years.

It has been our experience in Newark, New Jersey that infants and children infected with HIV have two to three hospitalizations per year, each lasting ten to twelve days. The average per hospital yearly cost for each child is $50,000.00. Based on current estimates, by 1991, one in every ten pediatric hospital bed will be occupied by a child dying of HIV infection. There are over 40,000 pediatric beds in the United States.

The hospital cost alone for pediatric cases of AIDS by 1991 will almost reach a billion dollars. At the present time, hospital costs for pediatric HIV infected children is predominantly covered by Medicaid. This program, at best, covers for only half of real hospital costs.

The outpatient care requirements of HIV infected children are extensive. Care of such chronically ill children often require skills that are sometimes beyond the capabilities of the mother, who herself is often very sick. Provision of care to be effective must not only provide medical services to the infected child, but also provide the child's mother and family with a wide range of psychosocial support services.

Over 30 percent of pediatric AIDS cases are in foster care. It has been our experience in Newark that each HIV infected child requires two to three outpatient visits per month. The cost of each visit is often high because of the intensity of the medical services requires; approximately $600.00 per month per child. Only a part of outpatient services are covered by Medicaid. For these outpatients, physician reimbursements are abysmally low. The extensive services required and present reimbursement schedules will discourage private patient care and further burden hospital facilities at great additional cost. Projected outpatient costs for pediatric AIDS by 1991 will exceed a hundred million dollars. The burden of providing health services to pediatric AIDS patients has heavily fallen on already resources of urban hospitals. Pediatric AIDS to date has been an illness that has occurred in economically depressed minority populations.

Continued spread of the AIDS virus among IV drug abusers and by heterosexual contact will ensure the tragic increase of cases expected not only in our urban poverty centers but eventually through the United States. The wolf is at everyone's door. The major burden of pediatric AIDS, however, for the next decade will still fall on the already taxed inner city hospital public health care system.

Based on six years of experience in clinical care and research of pediatric AIDS, I would off the following recommendations to the Presidential Commission:

I. The designation and support of centers to provide comprehensive medical and psychosocial services to HIV infected children and their mothers. Pediatric AIDS should be considered a maternal-child health problem. Medical services should be available and coordinated for both the mother and the child infected with HIV. At the present time HIV infected women can only receive competent HIV-related health services at centers which are predominantly directed at provision of health care services to IV drug using males or gay men.

The HIV infected mother is frequently unable or unwilling to spend the time required for her own health care, in addition to that of her child's. Existing pediatric AIDS treatment programs could be expanded by addition of physicians, nurses and social service staff support with expertise in maternal health issues.

Supplemental support to an existing pediatric AIDS program could provide maternal services with approximately $350.000 to $450,000 in increased yearly personnel cost. It would require one and a half to two million dollars to establish new maternal-child AIDS treatment programs.

II. The establishment of pediatric AIDS day care and respite care centers. Such centers will need to be linked to either established pediatric AIDS programs or ideally to the maternal-child AIDS program centers already suggested above. These "day care" centers would be able to serve the multiple care requirements of HIV infected children and the children including a site for early intervention programs for those children with neurological handicaps. Over 60 percent of HIV infected children will develop CNS disease.

It would also provide the provision of respite care for the caretakers of these children. Such centers would ideally serve as a resource for the educational and psychosocial service needs of the families of HIV infected children.

Siblings of HIV infected infants, themselves not infected, frequently require social, psychosocial and medical supportive services that could be provided at these respite care centers. The cost estimates for personnel for such pediatric AIDS respite care centers would be $250,000 to $350,000 per year.

III. Establishment of community-based transitional foster care homes to provide services to children, who would otherwise become "boarder babies." A model of this type of home has been presented previously yesterday by Ms. Mary Boland. The St. Clair's Home in Elizabeth, New Jersey, presently cares for five children at a time and has been in operation since May of 1987, with a yearly budget of approximately $300,000 per year.

IV. Reconstruction of entitlement programs, Medicaid and Medicare, to extend and increase benefits for outpatient services. New Jersey has recently established a Medicaid Waiver for more realistic support of our outpatient services available to AIDS patients. Our Children's Hospital AIDS Program in Newark, New Jersey emphasizes the importance of avoiding hospitalization through provision of extensive outpatient services. This not only increases the quality of life but decreases the health care costs.

V. Continued and, as necessary, expansion of the recently established AIDS cooperative treatment groups, ATAU's and CSG's. These NIH-supported study groups need to provide the research and investigational drug therapy studies that will eventually lead to the treatment and prevention of HIV infection. As areas in the United States are identified with increasing numbers of pediatric AIDS cases, pediatric cooperative treatment groups will need to be added to those already established. The personnel cost for a pediatric AIDS treatment group is approximately $500,000 per year.

These cooperative treatment study groups should focus on research and investigational drug studies. They should be linked to clinical care centers providing health services to HIV infected patients.

VI. Finally, and possibly most importantly, the recognition on the highest government level of the immense problem HIV infection poses for the foreseeable future. There needs to be a commitment not only of necessary funds to provide disease surveillance, biomedical research and clinical care of HIV infected individuals -- perhaps $12 billion by 1991 -- but also a commitment to coordinate leadership of the complex and diverse agencies responding to this most tragic of epidemics. This leadership must be educated, unbiased and compassionate.

Mr. Chairman, I appreciate the opportunity to make these recommendations and wish you godspeed in your deliberations.

**DR. CONWAY-WELCH:** Thank you very much, Dr. Oleske.

I would like to introduce Dorothy Ward-Wimmer. She is a registered nurse and a clinical nurse specialist at the Children's Hospital Medical Center in Washington, D.C. and I understand she is a hug therapist, as well.

**MS. WARD-WIMMER:** Good afternoon. Thank you very much for this opportunity to speak on behalf of the children. The statistics have already been thoroughly reviewed. What they do not reflect, however, is the complexity of the needs of these children and their families, all of whom require medical management, advocacy and social services.

The typical child, for example, may need oxygen, oral medications, gamma globulin injections, strengthening exercises, maintenance of a special diet and regular visits to the clinic for examinations and blood tests. Goals may range from treatment of life-threatening infection to such normal growth and development tasks as potty training. All of this care involves the coordinated effort of the physician, clinical specialist, social worker, physical therapist, nutritionist, home care nurses and probably most importantly, the parents, be they natural or foster parents.

May I make the following recommendations, please, for your consideration:

One. Infants born to HIV-positive mothers must first have available routine well baby care. Regulations must be changed so that once identified, the HIV infected child becomes eligible for entitlement programs. Currently, he or she must wait until a diagnosis of AIDS is documented. Also, infected children who are symptomatic should not receive live immunizations. For such children the killed polio virus vaccine, not easily accessible, must be made available inexpensively to private practitioners.

Two. HIV-positive mothers need similar routine care and screening. To eliminate the need for twice as many visits, care should be available under one roof. It seems practical, therefore, to establish mother/child clinics staffed by adult as well as pediatric practitioners. By better maintaining the parents' health, we will extend their ability to care for their own child.

Three. Care must be assumed by all providers. Personnel must be available to care for these children in hospitals and extended care facilities. Discrimination in health care based on diagnosis must be seen as part of a generic definition of "discrimination." Additionally, foster care agencies need to be willing to consider some non-traditional populations as potential caregivers. These might include the handicapped or HIV infected persons.

Fourth. Children die from this disease at the same rate as adults. Experimental drugs, therefore, must be made equally available to the children. The standard practice of using conventional treatments until new ones are approved is unfair to the children because there are no conventional treatments for HIV infection to offer them.

Five. Home care is the most humane and cost effective way of caring for most patients. Standard models of home care delivery, however, cannot effectively address the needs of ill groups; that is, the whole family. This is usually due to fiscal constraints. Existing services must be thoughtfully expanded to reflect real needs.

For example, standard support considers a night nurse at home a luxury. However, if providing assistance at night so a mother can get sufficient sleep to maintain her already weakened condition, enables both the mother and the child to remain at home, then this assistance is a logical alternative, not a luxury.

Another option might be extending foster care to an entire family. This would include underwriting the cost of home care for a parent and a child being cared for by a grandparent or other relative.

Six. Many children live with parents who are still active drug users. Standards for child protection must be scrutinized and services expanded to eliminate the long wait for investigative action. Models for cooperative arrangements with local police departments need to be established as a way of providing protective support to home care staff, who must spend much time in high crime rate areas and these models must include regular checking in on the in-home personnel, not just providing taxi service.

Seven. Existing services are not, in fact, being fully utilized because parents are unable to make in-person applications. Entitlement programs, such as Medicaid, WIC, SSI, need to increase their staffing at local levels to include sufficient outreach workers to meet this need. An alternative might be the authorization of other caregivers, family members or volunteers to provide that required documentation.

Ladies and gentlemen, this disease is preventable through behavior change. It is spread almost exclusively through specific human behaviors and can, therefore, be effectively stopped by changing these behaviors. Drug treatment and anti-poverty programs need enhancement. A 50/50 chance of having a healthy baby versus having one infected with AIDS looks like good odds to a woman who perceives her future as otherwise hopeless because of her drug addiction or social status.

The adolescents of today will be the parents of infected children tomorrow. Information, confidential testing and detailed counseling must be made widely available, hopefully with, but even without parental consent. Education is essential but telling the facts is not enough. Teenagers compass tests about AIDS in the classroom, yet, translate none of that knowledge into behavior change. Nearly all of the mothers of the children with whom we work at Children's knew the facts about HIV transmission, but what they hadn't learned was how or why to change their behaviors.

Lack of information is life-threatening. Blaming another person is not the answer. The good news about AIDS is that we don't have to catch it. Each of us has the responsibility not to become infected with HIV. Parents must realize that just as we explain the right way to cross the street long before we give a youngster permission to do so, we must teach our children how to protect themselves from disease all disease. Materials which guide parents on how to talk about these sensitive issues must be made available to them.

The incidence of pediatric HIV infection is rising. We hold in our hands right now the future of literally thousands of children. We must confront their issues directly. We must not allow them to become prisoners in a war of isolation, stigmatization and mistreatment.

I urge you to recommend immediate support for creative and preventive education, interventions aimed at primary problems of drug use and programs of innovative and compassionate care. Thank you.

## Discussion

**DR. CONWAY-WELCH:** Thank you very much. We would like now to open the panelists for questions from the Commissioners and we will begin with Mr. Creedon. One question each, please.

**MR. CREEDON:** The pediatric problem seems to be one of the most heart-rending phases of this terrible disease. I thought I understood from Dr. Oleske's paper that 90 percent of the HIV infected children are covered by Medicaid and I don't know whether that is a much higher percentage than the AIDS cases generally.

We have had testimony from other hospital representatives that where an AIDS patient is covered by Medicaid the hospital does not collect its real costs in caring for the patient. On the immediately preceding panel, there was a Dr. Bartlett, who is from Johns Hopkins, and he was saying there were four phases of treatment, not for a child who has the virus, but of someone who has AIDS and on inpatient, the chronic care, the home care and the outpatient care. It was his view that there was enough money in the system to take care of all four of those, but it just wasn't allocated the right way. He was urging that consideration be given to having a system that involved capitation. In other words, a certain amount would be available for payment to take care of a patient through all four of these required categories of treatment.

I wonder whether you have, Dr. Oleske and Ms. Ward-Wimmer, in particular, given that idea any thought; the possibility of a capitation approach. Maybe it is being done in some situations. I don't know -- what the problems would be and whether it is something that we as a Commission could or should recommend, especially for children.

**DR. OLESKE:** First of all, the disclaimer is that I try to be a good physician and care for my patients. It is difficult for me to also function on a level of a cost analysis expert. I spent a lot of time going through charts at our hospital trying to get this data ready for you of what the cost is to care for our patients.

New Jersey does not have yet a DRG designation so that you are right. Ninety percent of the patients we take care of fall under benefits for Medicaid. The hospital does not get reimbursed for full cost, in fact; only partial costs for those hospitalizations.

**MR. CREEDON:** Do you have any idea of the percentage that you would get reimbursed?

**DR. OLESKE:** It is less than half. It depends on how aggressive the physicians and medical records are in documenting the various other illnesses besides AIDS that would boost up the reimbursement schedule, but it is never going to be greater than probably 60 percent because of the fail safe mechanisms written in the Medicaid law. So, the hospital is always going to be at a disadvantage.

I have no objection to a per capita system if that is the way the entitlement programs could best allocate resources and services to HIV infected patients. I question whether, in fact, there is enough monies allocated and out there and that we are just not smart enough in knowing how to tap into that resource. I would question that, in fact, there is not enough resources allocated for this disease.

I agree with you, though, that sometimes monies are allocated that we don't know how to tap into.

My last recommendation, which is basically very strong leadership that would coordinate these activities of these diverse agencies, is correct. I would challenge how many American citizens know the name of the director of Health and Human Services versus how many Americans know that the former director of the Defense Department was Caspar Weinberger. I would guess that less than one in a thousand Americans know the name of the leader of Health and Human Services.

**MR. CREEDON:** When you are talking about leadership, are you talking at the federal level?

**DR. OLESKE:** Well, I think that I had some, if I may, angry response to the last panel. Mr. DeVos asked the question of shouldn't you look locally and statewide for support and not just go to the Federal Government. My comment to that is that we have not received any support for our pediatric AIDS program until 1987 and we now gratefully have some federal support. Prior to that time, it was all local effort. We have exhausted the local and state resources available. We now have to turn to the Federal Government because we have no one else to turn to.

I think that in fairness to those of us who have worked with the clinical problems of pediatric AIDS patients is that, in fact, we have looked for local resources. We have exhausted local resources and probably state resources and now I think we are left with and ask for support from the Federal Government.

I would argue with you that, in fact -- and, Admiral, you may comment on this -- that if our intelligence agency found out that a hostile power had a viral warfare agent that was going to kill 13 million Americans by 1991, that there wouldn't be in the Defense Department a large cry and probably some action in getting funding to prevent one of those infections or deaths. Yet, we have an enemy, this virus, which, in fact, we are not responding in that same kind.

I think, in fact, that we should take a war effort against this virus. In fact, in one way I am happy to see an Admiral chairing this committee.

**CHAIRMAN WATKINS:** You are the first one, Dr. Oleske. Thank you very much.

**DR. OLESKE:** I almost would like to make the suggestion, although it is hazardous being a Humphrey Democrat, is that Health and Human Services probably would be better off if it moved into the Department of Defense. They would probably get more money.

**CHAIRMAN WATKINS:** We will make that recommendation to Dr. Bowen.

**DR. CONWAY-WELCH:** Dr. Primm.

**DR. PRIMM:** My question was for Ms. Jackson.

You seem to intimate in your thesis that the Caribbean experience in relationship to breastfeeding allowed you to now be a proponent of breastfeeding for HIV mothers, despite the fact that there were three cases reported where there was transmission of the virus through breast milk.

I am concerned about it because it seems as if there haven't been enough studies and if we advocated breastfeeding by mothers who are HIV-positive, that unquestionably we might have some problem in that area.

Also, what is the difference between being infected through a blood transfusion and being infected through use of the intravenous needle? I would think that transmission of the virus is the same whether it be through sexual intercourse or a needle that is infected with the virus or through a blood transfusion.

Perhaps the effectiveness of transmission would be different but once one is infected, one would be the same. So, what kind of influence would that have on whether the baby would be infected through the transmission of breast milk? I wondered about that.

**MS. JACKSON:** Once one is infected, one is infected, but there is a greater amount of virus actually transmitted through a blood transfusion than through needle sticks or sharing needles. The only thing I was suggesting in that statement is that it does call for further study as to what actually happens with breastfeeding.

I think that you are absolutely right; it is a very, very difficult area, but I am concerned that the CDC recommendation came so quickly and on so little data. This is an unusual thing to have happen when so much effort has been made to encourage breastfeeding and for excellent reasons. I think that there is a population already breastfeeding that could be looked at. That is what I am suggesting where we direct some study effort into finding out.

**DR. PRIMM:** I would like Dr. Rubinstein or Dr. Minkoff, to respond to that, if you would.

**DR. MINKOFF:** First of all, I agree that breastfeeding in general is something that should be encouraged; however, I don't fault the CDC for jumping as aggressively as they did. And they did distinguish between countries where there is an option to alternatives to breast milk and countries where there is not.

I think that we have always assumed that any secretion that has been shown to contain virus should be treated with extreme respect and since the virus has been found in breast milk, I think it is appropriate that we advise people not to feed their children with this secretion that may have virus in it. I think the onus should be on those who wish to take away the proscription.

**DR. RUBINSTEIN:** Well, I believe that there are numerous studies looking at breast milk, showing that breast milk contains the infectious virus. What the infectivity of this virus is indeterminate. We have been looking at transmission of the virus during pregnancy to fetuses and children. We found in fetuses aborted in the second trimester a transmission rate, which is identical to that found in women who go on with the pregnancy, deliver a baby and sometimes breast feed. That gave us an indication that practically all the transmission of the virus from mother to the child occurs during pregnancy. The Caribbean study also does not exclude breast milk as a source of HIV transmission.

**DR. CONWAY-WELCH:** Dr. Servaas.

**DR. SERVAAS:** My question is to Dr. Oleske and Ms. Ward-Wimmer. Ms. Ward-Wimmer mentioned creative, preventive education. I was told at the CDC that there is some pretty good evidence that the immune compromised HIV antibody positive woman can hurt her health by becoming pregnant. Would your education and prevention programs tell these women that they not only have the 50/50 chance of an infected baby, but that they have the chance of bringing on full-blown AIDS in herself and possibly dying from AIDS when she might not have had she not become pregnant?

If we could find some good studies or do some studies and we could get the word out to women, then might they not avoid pregnancy when they know their AIDS antibody virus status.

**MS. WARD-WIMMER:** Theoretically, that is a very valid and good statement. The difficulty is the fact that we are dealing with women who are primarily poor, already disenfranchised from usual health care and by the time they become pregnant, they want that baby. It is too late. It is a good point and it is something that does need to be brought out more and more as we educate our women.

The real thrust of my notion of preventive education was the education that is geared to little children, who are growing up in America today, learning how not to become infected, learning about not using drugs, learning about not having unprotected sex, learning about taking care of themselves, taking care of their own health, learning how not to be afraid. All of us have a right not to live in fear. That includes people who are HIV infected and those of us who are living in the world with others who are HIV infected. We have to learn that we don't have to be afraid of it. We can take care of ourselves and we don't have to catch it.

**DR. SERVAAS:** Dr. Oleske, do you have any ideas on how to shut off the faucet and prevent all these tragic deaths in these AIDS children?

**DR. OLESKE:** I used to naively think that if I could just talk to some of the patients I have seen and say to them you don't want to have another baby like that we just watched die for the last two years and also damage at your own health. You are losing weight; you are getting sicker -- that that would be enough on face value to convince that woman not to get pregnant again.

I think Dr. Rubinstein, Dr. Scott in Miami, all of us have seen just the opposite; that, in fact, women have had second and third children while still very sick and have other children with this disease, sometimes having normal children.

The thing I have learned over the last several years was that there are so many complexing psychosocial issues related to culture and poverty that I never appreciated before. I remember one time trying to convince an Hispanic woman to tell her sex partner, who we knew was positive, to use condoms. She came back a week later beat up, when she made that suggestion. And I was naive enough not to appreciate that was going to happen.

What I would suggest is that we should develop family oriented maternal and child health programs, where we could provide close attention, especially with nurses and nurse midwives because I do think women relate to women better than men to women in this issue. If education regarding the risk of AIDS is one to one and it is intense and it is related to their culture, we may be able to change high risk behavior.

But I think at the same time, from a global point of view -- and I know the Commission can't do this alone -- we also have to look at AIDS as it relates to plain old poverty and drug use. If we don't do anything about poverty and drug use and self-esteem, then it is still all "band-aid" response. Now, I am not saying that we shouldn't try to do band-aid response because we are facing a wolf that is going to kill our children and I think we can maybe change behavior by intensive educational purposes, but it is not going to be as easy as a television telling a woman don't get pregnant.

**DR. CONWAY-WELCH:** Thank you very much. Mr. DeVos.

**MR. DEVOS:** I appreciate the work you do and I look at some of you and I feel like I am seeing the first people I have seen that are really burned out. You are so distressed by the challenges you are living with everyday and you can't understand why the rest of us don't catch up with you.

I understand that frustration. I think maybe we represent the rest of the nation that hasn't caught up with you and we certainly represent most of the states which have not caught up with you. When talk about how we are going to finance these costs, you are going to have to spread them. Indeed, we, and you, and somebody, including this Commission is going to have to communicate to the rest of the states that they have got to get on board because some day it is going to catch them and bite them bad. They are not and so when we speak of it around here, we are trying to figure how to communicate this message. How do we get the other states and cities to come on board when they think they are not going to be affected? I don't care whether you are talking about Wyoming or you are talking about any one of 40 other low-incidence states, who think they are just going to get by.

So, it is a huge communication job and I want to commend you for as forthright and as heart-rending a presentation as I think I have heard. We have all got band-aid solutions. There have been a lot of agencies in this government that have tried, for instance, a war on drugs. We have tried war on poverty, going back as far as my whole history and I don't know where those fixes are. I sure wish I did.

I have a simple speech I give. It says actions have responsibility, but the people you are talking to and that are involved in the middle of this epidemic just can't seem to get their hands around that. I don't know where the problem is. I salute you. This Commission is not going to solve all of it. Maybe we can be an example. Maybe we can set a pattern that might give some hope to those problems.

My comments are to thank you for the great job you do. I salute you.

**DR. CONWAY-WELCH:** Thank you. Dr. Walsh.

**DR. WALSH:** I want to go back to the breast milk issue because there have been other cases in the Caribbean. Admittedly, the cases reported that came out of Africa were very skimpy data. But the thing that concerns me is that Dr. Rubinstein is correct about most transmission being in utero before the child is born. Yet, we go through what Dr. Oleske points out, that you still will have intermittent normal pregnancies in which a normal child is born.

I don't think there is anyone who doubts that you can isolate the virus in breast milk just as you can in saliva, but I mean saliva doesn't transmit it. I don't think that there has been adequate study or proof that breast milk transmits it, even if the virus is isolated, but it occurs to me that the precaution where other sources of nourishment are available may still be worthwhile because we have been told, for example, that in the hemophiliac population even if both parents are already seropositive, that they urge the use of condoms or if one or the other is seropositive, they urge the use of condoms because repeated exposure may aggravate and hasten the development of the illness.

I think that the same thing is what CDC is talking about concerning breast milk. But I was most impressed when, of all people, Steve Josephs told this committee -- and he was the champion of breast milk -- that we should be re-thinking breast milk. Now, in view of the enormity of the problem that you have all been exposed to, can anyone of you tell me why there is not or is there any substantive research going on in this area?

I have been exposed a great deal internationally and I am in Geneva as often as I am here and I am not aware of any in-depth studies going on. I don't know how complex or complicated it would be if they were or how expensive they would be, but is there any value in encouraging in-depth studies?

Anybody can answer this. And do you think that the use of breast milk does possibly give the infected mother repeated exposure to the child and, if so, is that destructive exposure or is it not?

**DR. RUBINSTEIN:** I think that I was misunderstood. We do not recommend breastfeeding. I criticized the Caribbean study but we do not recommend breastfeeding by a mother who is HIV infected. There are three cases in whom it is quite clearcut that a baby has been infected through breast milk. In these cases the mother was not HIV infected during pregnancy. She was infected at delivery by a blood transfusion and subsequently breast fed her baby who was then infected. These are unquestionable cases of transmission via breast milk.

One cannot presently conduct a study to determine if breast feeding transmits the disease to a baby. I believe that it is unethical and cannot be done and will not be done.

I am aware of studies done in Africa and the story there is totally different. Breastfeeding in Africa has dramatically reduced mortality of the baby population and I would not stop breastfeeding there. There are ongoing studies there that evaluate whether the transmission rate from mother to baby is higher in Africa than, for example, in the United States.

**DR. WALSH:** The other part of the same question is also part of the problem, I understand that in some of these instances where the mother has been seronegative and we think that she was infected postpartum, she may well have been carrying the AIDS virus and still infected that baby in utero. Have you got any more data on that?

**DR. MINKOFF:** Theoretically, it is possible but if you look at the case descriptions, I think the sexual partner of the woman was negative. So, her source would be unknown, other than the blood.

**DR. OLESKE:** There is limited data that CMV acquired infection from breast milk is associated with less severe disease, than non-breast milk acquired CMV. So, my colleague, she may be right, that, in fact, we are wrong in recommending not breastfeeding in the already infected infant and I don't think we know.

As Dr. Rubinstein states, I guess it is going to take studies in countries where there is a large amount of breastfeeding going on, such as Africa, to prove the point. Certainly, I think, we should clearly recommend that breastfeeding continues in countries, who do not have access to sterile water and formulas.

The other problem -- and my OB/GYN colleague at the end of the table may want to comment on this and I hope he doesn't get made at me, but you asked why studies aren't done on breast milk. Well, as it turns out, except for concentrated urban areas, especially in New York City, obstetrical research in AIDS and gynecological research in AIDS has been limited because OB/GYN, like all of us medical professions, have been slow to want to get involved with the AIDS problem. So that the people who have ready access to breast milk, in general, are not always those who are most interested in doing the basic research that is required, the virological cultures and the studies that need to be done.

**DR. WALSH:** Should we be encouraging more research in this area?

**DR. OLESKE:** I think that you are right, that encouragement of research, which includes research on the infectivity or non-infectivity of breast milk is important.

**DR. MINKOFF:** I think there is no denying that obstetricians have not been rapidly into the fray, but I think it is understandable. It has not been recognized as, quote, unquote, our disease. It was a disease first of gay males and then it was a disease of drug using males and it is only recently that people became aware that this was a problem involving women. A lot of my colleagues who are interested in infectious diseases are in communities where the virus has not reached.

**DR. CONWAY-WELCH:** Thank you. Ms. Gebbie.

**MS. GEBBIE:** I think Ms. Jackson had a comment.

**MS. JACKSON:** I think there is research that can be done. I agree with Dr. Rubinstein that prospective research would be unethical. However, given that, there is a population that is at high risk for seropositivity. Those women have been breastfeeding their babies, some of them, and we can, perhaps, do retrospective studies. The unfortunate thing is that, you know, we don't know what their HIV status was during their pregnancies. We do not know what their HIV status was immediately after.

You are sort of picking up, you know, in the middle of something happening, but there is nothing going on right now, nothing, in this country and it is very difficult for me to tell all 5,000 women, who deliver annually, that they should not breastfeed and that is what I am doing now.

**DR. WALSH:** That is why I raised the question.

**DR. RUBINSTEIN:** I would like to add one point, which I think was misunderstood.

Principally, what Dr. Oleske said is correct. If you have a child that is already HIV infected, why shouldn't the mother breastfeed that child? We all know that breast milk contains many protective factors. However, it is almost impossible to identify in the newborn, born to an HIV-positive mother, if this newborn is actively infected or only passively acquired the antibodies from the mother. There are situations where it takes up to 21 months to identify an active HIV infection in a child. So, you can't -- in practice, divide the babies into the two groups, infected and uninfected.

**DR. WALSH:** Thank you.

**DR. CONWAY-WELCH:** Thank you. Ms. Gebbie.

**MS. GEBBIE:** I almost hate to change the subject because this has been really interesting but I want to go back to some of the money, the financing issues. Since Rich has left, I will take on his job.

I suspect part of the problem is that all of the solutions you have proposed or the shifts you have proposed appear to be more people-intensive than technological and those are almost always harder to sell in our system, but they are also harder to understand. What you have presented is just x dollars per year for a program, without identifying the components of that program and the number of patients that would be served for the increment of money you identify, which we need to see in order to translate it into a nationwide proposal or a systemwide proposal.

I don't expect an answer right here, but I would really appreciate it if each of you, but particularly the three physicians because of the kinds of programs they outline, would give us a comprehensive annual budget, based on a specific number of patients, so we can see all the components of it and what the whole thing put together would cost, not just the nice increments you added on. That would enable us to compare your proposals with some of the others we have seen and to put it into perspective with some of the other things we are looking at.

**DR. OLESKE:** Without appearing to be fresh, while I am doing that, who are you going to send up to take care of the patients in Newark, New Jersey?

That is the dilemma we are in every time Dr. Rubinstein or Dr. Quentin Scott or myself or those involved in AIDS clinical care are asked to testify, we are asked the same thing. Prepare this; prepare that. We don't have the personnel support in the centers where there are large numbers of patients to do all those things that you request.

Now, I spent a lot of time just to get those numbers I presented. Maybe they are very naive, the numbers I gave you, but they were based on reviewing charts of hospitalized patients and patients in outpatient. It is a little bit unrealistic for you to ask, for example, for me to go up and write a detailed budget for a program that probably will never get funded when I have at least 200 priorities ahead of that.

**MS. GEBBIE:** Let me comment a minute. I understand that process but I also understand that it is rather naive on your part to think you can say I need $300,000.00 to do something wonderful but I can't give you the back-up. I mean, it is a two-way process.

I believe that there are the systems in which you work, hospitals, health departments, universities, a good number of fiscal experts, who, in fact, work with this kind of thing a good deal of the time and for whom it is a relatively simple task to round out some of the numbers.

I would really request that you look at providing us a more complete statement of what it takes to care for a hundred children or last year's number of children; something that enables us to put it in perspective with some of the other competing requests for dollars and some of the other descriptions of programs that we are having to struggle with.

Otherwise, what it sounds like is you want a nice Cadillac for your patients that would make life better for them, but it does not fit together as part of a program.

**DR. OLESKE:** Let me expand. I am naive and I will plead guilty to that, but the problem is my university doesn't want to be designated an AIDS center. The people there, the experts that could help me are told not to encourage the development of such programs provide these services.

So that we have a major crisis of leadership at the medical universities that are in cities where there are a lot of AIDS patients, concerns about whether or not medical students will stay; will residents stay; and their response to that, I feel, is misguided and unethical, it states, "no, we shouldn't respond. We don't want to develop programs. We don't want to generate the numbers because we don't want the money."

Now, those are the responses of people who run the programs on a much higher level than those of us who run the programs, which take care of the patients. I am telling you that goes on. So that when you say to me, Dr. Oleske, just go back to the University of Medicine and there are a whole bunch of people that will help you generate the numbers, I am telling you that that is not really the reality.

Now, how you change that, I agree with you, is not just listening to me and giving $500,000.00. That cost estimate -- was based on our budget to the NIH for a CSG and it was legitimately what the personnel costs were. I went through how many nurses we have per patient. I will try to break that down more for you.

**MS. GEBBIE:** Perhaps you could just send us a copy of the grant, which would have some of the patient numbers in it and that would answer a good deal of my

question.

**DR. OLESKE:** Okay. All of that information is available at the NIH through the ATEU and the CSG systems that have already established budgets.

I guess part of my frustrations, is I have testified now three times before -- well, you are not Congress, but before --

**MS. GEBBIE:** Thank you. I appreciate that clarification.

**DR. OLESKE:** -- before Congress and before a prestigious group like this and it is always interesting to me that the one testimony people didn't know about the other testimony people. The left hand doesn't know what the right hand is doing. We have to say it over and over again and it sometimes does get frustrating, but, in fact, the NIH, the CSG and ATEU's, based on numbers of patients, drugs available and programs that could be developed to provide for these patients already have approved, peer reviewed budgets that are available.

I will try to do it again for you because I realize how important this Commission is. I am just saying that sometimes it is very frustrating when you see and have to answer the same questions over and over again because the problem doesn't change and, in fact, it is just getting worse.

**DR. WALSH:** There was a fellow 1,988 years ago that did that for 33 years. He preached the gospel. He had a lot to say.

**DR. CONWAY-WELCH:** Dr. Lilly.

**DR. LILLY:** I would like to ask Arye Rubinstein a question. I would simply like a little fuller description of the day care program. What are its advantages or what does it consist of? What is it replacing that would be less effective and more expensive?

**DR. RUBINSTEIN:** The development of the day care program was initiated as a result of the assessment of costs that we were asked about before and as a result of the assessment of the care for children's HIV infection in the families.

In addition to that, there was an assessment of the other alternatives of day care of HIV infected children. Are they being admitted into regular day care centers? With all due respect to the recommendation of the CDC that these kids could enter regular day care centers and regular schools, these children especially in the young age group, are not easily admitted to regular programs. HIV infected children are developmentally handicapped. In our study, 90 percent of the kids who are HIV infected are also developmentally handicapped. In those instances, these kids can not be admitted to the regular day care centers. They also had limited access to special educational programs. So, that there had to be found some kind of a respite program where these children can acquire their educational needs.

The second reason and probably the most important one for the development of the day care center was the difficulty of finding foster parents or adoptive parents. I remember, we once advertised for one child, trying to get a foster parent for this child and we got 600 responses. When we screened them, we ended with none.

One of the major reasons is the difficulty identifying foster mothers. Foster parents were ready to take these kids into their homes, but were not ready to give up their occupation. However, if you have a child whose mother died or whose mother is incapable of taking care of him or her, and if this child is placed in a day care program, it is much easier to find foster parents. In fact, after I successfully opened our day care program, within, a few months, we located 16 foster parents for HIV infected children for who we had previously no foster parents.

Unfortunately, later on, the city restricted the hours of operation of the day care center. Initially, we offered day care from 8:00 in the morning or even 7:00 in the morning until 7:00 in the evening. Hours were then restricted from 9:00 to 3:00 and that somehow handicapped the program. All-day day care centers are going to make a tremendous impact on pediatric AIDS.

In addition to that, the plan was to open another day care program which will combine educational programs with medical programs and preventive programs and educational programs for the families. It will undoubtedly have a major impact on the control of the epidemic and on the care of these children and their families.

If I may for one minute, Frank, resort to the question of cost, the cost analysis is extremely difficult. I share Jim Oleske's frustration. I can give you an example of what happened to me. I was asked to develop a cost analysis for a center for pediatric AIDS and for families with AIDS including pregnant women, who are HIV infected. It took me about six months to write this proposal. This proposal was never submitted for funding for the same reasons that Jim Oleske mentioned before.

With regard to the day care center, the costs that I mentioned before are based on the total cost of the operation of this day care center, divided by the number of children in the day care center.

**DR. CONWAY-WELCH:** Thank you. Ms. Pullen.

**DR. LILLY:** Could I just ask a very quick question?

What is the documented incidence of pediatric AIDS, that is, the transmission factor with sperm donation, by artificial insemination?

**DR. OLESKE:** Low enough that it is not a problem.

**DR. LILLY:** Are there documented cases.

**DR. OLESKE:** I think there are two.

**DR. MINKOFF:** Two. One in Australia. One donor caused several infections in children. It is very rare. There are now standards to protect sperm from being infected.

**DR. CONWAY-WELCH:** I would like to thank the panel. We are also sensitive to the patients that did not get seen today because you shared your time with us, but we hope that we will be able to respond in a helpful manner. Mr. Chairman.

**CHAIRMAN WATKINS:** Can we flesh out the suggestions that were made by a number of the members of the panel on the maternal-child health centers a little bit more? We don't have to do it all today, but maybe we can follow up with some work with you.

Where should they be? Should they be in the hospitals? Should they be in the community health centers? Should they be in drug rehabilitation centers; perhaps, one section devoted to women and children? What is the idea in more specific terms? Is it in all of the above to some degree or with some kind of network linkages? Could someone perhaps discuss that at this point in general terms and then maybe we can pin that particular volunteer down to come in with a more specific concept of what might be the optimum?

**DR. OLESKE:** I will just comment briefly.

I think that you always have to take advantage of what you already have in high risk areas.

In Newark, New Jersey, my recommendation would be to link a maternal component to our already fairly-active pediatric AIDS component. It might be in another area of the country that IV drug abuse clinics are, in fact, providing expanded services to women and it would make more sense to attach the pediatric component to that system.

I have no problem with different systems taking advantages of resources to expand their services to mothers and children. Obviously, I am a pediatrician so my bias is for strong pediatric programs, but I don't think it necessarily has to be a pediatric program that provides clinical care to women nor does it have to be necessarily a woman's program that then adds on providing care to children.

Either one of those systems would probably work. I do have some inherent problems with attaching it to drug using clinics only from the point of view is that the majority of IV drug abusing clinics that take care of AIDS patients -- are predominantly geared to male health issues. You have to remember, that half of the women haven't used drugs but were infected because their sexual contacts use drugs. Having someone who has never used drugs receive their health care at a clinic that is geared and oriented to drug use behavior would be the least acceptable option.

In general, I think, it is going to be the OB/GYN program that expands to pediatrics and the pediatrics programs that are established expanding to OB/GYN and women's issues.

**DR. MINKOFF:** I agree. I think the answers are going to be quite parochial. Every institution in every region has to look at their resources and develop their own program. I think there are advantages to having it in a hospital because the least mobile individuals are sometimes physicians. The center should be staffed by social workers, health educators, day care workers, and you can have an internist come regularly and a pediatrician come regularly, There has got to be a sense however, that this is a center from which people can be sent out to social services in the community and it can coordinate a variety of functions.

I personally think for the most part in-hospital centers probably will work best.

**MS. JACKSON:** From my point of view, I think community centers would work best, in part because of what I brought up about the lack of prenatal care that women are currently receiving and it is not because they don't know that they can't take a bus and go to the hospital and walk in and get prenatal care.

In our state, prenatal care is free. You have to go through a lot of forms; you have to go through a lot of interviews, but you can get prenatal care. Now, why aren't the women showing up? Why is it that a third of these women walk in and have their babies? I think that it may be that for whatever reason, of lifestyle or it could be many other factors that go into this whole problem in society, they are just not coming to the hospitals.

So, it may be that for a time we may have to go to them and that is my suggestion, that there is more community-based outreach programs and more actual care being delivered within the communities in smaller groups.

**DR. RUBINSTEIN:** I am probably biased. We have been funded by the Robert Wood Johnson Foundation to develop a model care program for children with AIDS and for their families. That experience taught me several lessons. Number one, you need a multidisciplinary team to address the issues. Number two, we were more successful in reducing costs in hospitalization and pain to these patients by developing a family approach. In our clinic, for example, we employ a core teams. When the family comes in, the pediatrician examines the child, the internist the adult and the obstetrician and gynecologist is on site and examines the mother.

By doing this, we improved compliance and the expenses per patient plummeted. Furthermore, we developed through this grant a community outreach program that I must admit is not completely effective. We even developed a tracking system. We went to the communities with methadone maintenance programs, looking at drug abusing women who were HIV infected or HIV uninfected. We followed these women between pregnancies. If they became pregnant, they had the monthly testing. They were then referred to a women's counseling service in the AIDS family care center.

The compliance of the population in this center initially was around 10 percent. With about 20 or 30 follow-up phone calls per patient, the compliance increased from around 10 percent to 20 percent. A tremendous effort is necessary to get these women in. When these contacts were made with the community, through the community outreach program, we could not improve compliance at all. Our success was very poor and, therefore, we redirected our efforts and planned to develop a multidisciplinary team in the medical center with all the specialists, and then place computer terminals in various community medical centers and various emergency rooms in the Bronx, so that each one of these families or patients in these families will have access to the medical center, whether they come to us directly or whether they request services in an adjacent medical center.

**MS. WARD-WIMMER:** I just wanted to add one point and that is the issue of getting to the medical center, wherever that might be. I mean, we could build an excellent mother/child clinic the mothers aren't going to want to take three buses to get there. They are already tired; already infected and now we ask them to carry a child, who is wiggling and squirmy and arrive by 9 o'clock in the morning. We have to be willing to look at being realistic in the way that we build our budgets and the way that we make our plans. We have to look at listening to specific communities and not just make an assumption that building a center is going to be the answer. We have to look at issues of access and compliance, as well. We may need to provide vans for the centers that have vans.

**CHAIRMAN WATKINS:** But it doesn't lessen the urgency on the general recommendation you are talking about.

**MS. WARD-WIMMER:** Absolutely not. I just don't want us to be --

**CHAIRMAN WATKINS:** It gives me a little bit better perspective on the variety of needs that have to be met. You might have to do it differently in a lot of different areas. So, there is no one model, obviously, that you are coming up with.

**MS. WARD-WIMMER:** I think if we all put our heads together, you would find that there are probably a half a dozen basic needs that would have to be met in any center.

**DR. OLESKE:** One of the things someone mentioned, that it is hard to fund personnel, but it is always easy to fund chrome and things; capital costs but not people. We have been very proud in our Children's Hospital AIDS program that we have about a 95 percent compliance rate of predominantly IV drug user women bringing their children in once a month for ongoing regular prospective care and it is not because we I have a lab that does cell sorting, but it is because we have received some Robert Wood Johnson money that allowed us to hire two social workers and those two individuals, by talking and showing the concern that sometimes physicians and nurses can't, I think, turned our whole program around so that, in fact, it is a very important issue that we need people that can address the needs of other people.

The programs have to be rich in personnel because that is what makes it work.

**CHAIRMAN WATKINS:** One of the things that is certainly coming out of this set of hearings is that if this nation lost the Robert Wood Johnson Foundation, we would go under. We applauded them earlier today but everything that we are hearing across the board in our presentations has been strongly endorsed by that forward-thinking foundation and an example of what they have done for the nation as a whole.

**DR. CONWAY-WELCH:** Thank you very much. Thank you for your time. We would like to commence with the next panel immediately.

We thank you for your time and your patience. We always have too much information in too short a time. I would like to welcome you here today and thank you for your time and continue our focus on special issues surrounding the care of special AIDS patients. We ask you to limit your information to five minutes because, obviously, the questions and answers period is where we get to the meat of the issues. Then we fall back on your testimony and documentation for additional information. I would like to start with Ms. Pullen, when she returns, on my left, for questions. I would like to introduce Barbara Blum. She is president of the Foundation for Child Development in New York City and is going to address the issue of boarder baby care. Ms. Blum.

**MS. BLUM:** Thank you very much. It is a pleasure to be here today. I am Barbara Blum, president of the Foundation for Child Development, an organization that supports research, policy and direct service programs for disadvantaged children. The Foundation's service programs are focused in New York City, which, as you know, has the very highest concentration of AIDS cases and the largest foster care caseload in the nation. In my previous position in the city and the state during the seventies and back into the sixties, I periodically dealt with a problem reminiscent of the situation facing our communities today -- upsurges in foster care caseloads that required rapid expansion of the child welfare system. One lesson that emerged from those experiences that may be useful to this Commission is that with careful planning and intensive recruitment, it is possible to significantly strengthen services for hard-to-place children.

Boarder babies are infants or children who are medically ready for discharge from a hospital but who have no family or faster caretakers prepared to take them in. In one month last summer, New York City had 30 children boarding in hospitals, who tested positive for the HIV virus. In the first five months of 1987, Harlem Hospital alone cared for 37 boarder babies with AIDS. Unless preventive steps are effective or unless research produces a cure, the growth in pediatric AIDS cases expected in the next three years is virtually certain to result in an increase in the number of children abandoned in hospitals.

To list the circumstances that lead to that abandonment -- the children's own health problems, poverty, homelessness, drug addiction, illness and death among their parents, the fear of contagion among potential caretakers -- is also to describe the magnitude of the challenge involved in offering these children appropriate care.

But however compelling, the number and complexity of the problems presented by these boarder babies has tended to obscure two other significant facts about their situation.

First, viewed as a national responsibility, the numbers of boarder babies with AIDS are currently small and can be manageable and if steps are taken now to develop workable systems for caring for them it is far less likely that the problem will exceed our capacity to solve it in the future.

Second, despite their special and tragic life circumstances, these children have no less need, and usually more, for the experiences that child development experts believe are important for all children; life in a homelike setting, appropriate stimulation of cognitive and language abilities, closeness and affection from consistent adult caretakers. These experiences should be available to the infants who initially test positive, but eventually test negative for the AIDS antibody and to children infected with the virus who are capable of surviving for some number of years.

In the case of AIDS children, we must bear in mind that predicted life expectancies are apt to change as more information on both the disease itself and its treatment become available. Moreover, society has a moral obligation to ensure that all children, however brief their life expectancies, have access to these very critical developmental experiences.

Future work to guide the development of a service system responsive to the needs of these children should be guided, I believe, by three broad principles.

First, while vigorous efforts must be carried out to remove AIDS boarder babies from hospital settings, those hospital environments themselves should be as homelike as possible. Hospital wards housing AIDS children need to be inviting and attractive. Children should receive consistent care from a small number of nurses. Parents and other family members, who may eventually be able to assume care for those children, should feel welcome.

Children should be stimulated by play and other activities appropriate to their age. Except for the special day care services to stimulate children, these hospital care practices can be carried out within the confines of an institution's regular routines and expenditure patterns. Capital costs for creating appropriate settings should be incorporated into a special Medicaid rate, as should the appropriate staffing costs.

It is crucial, however, to assign to the hospital ward at least one staff member, usually not available in a medical institution; a case manager/social worker person, responsible for coordinating all necessary services for boarder babies and their families and for acting as a liaison with the child welfare system to secure placement for the child.

The caseload for this manager, whose yearly salary would, I think, be in the range of $25,000.00, should not exceed ten AIDS babies at any one time. Assuming a three-week hospital stay for this child, this individual could handle an estimated 170 cases a year. In the end, the costs of such a position would likely be offset by shortened hospital stays and by transfers to more suitable and more economical settings.

In connection with the hospital services I have just discussed, I strongly recommend that large cities consider the feasibility of designating particular hospitals to care for AIDS boarder babies. Compared to a system in which all hospitals are expected to assume those responsibilities, targeting would result, I believe, in both cost savings and strong and more expert services.

My second point is that there is no reason to assume that it is necessary to create institutional foster care settings for boarder babies with AIDS. Efforts would be better devoted for to recruiting individual foster parents and to developing and supporting small group homes for these children.

You have heard, of course, how difficult it is to recruit foster parents, but it is possible. We need to build on the models that have begun. We need to refine our recruitment techniques and to be certain to provide adequate compensation. My best estimates at this period of time are that $40.00 to $75.00 a day is necessary in order to attract foster parents, who can care for children with different levels of disability.

In instances when foster home placements cannot be achieved, small group homes can also meet a child's developmental needs and are far preferable to institutional settings and certainly are less expensive. Intermediate care facilities designed to meet Title XIV standards are also needed for children, who have greater medical needs. These can be modeled on the ICF's developed over the last decade for children with developmental disabilities and they certainly could relieve much of the pressure created by reliance on hospitals for medical care.

The third point that I would like to stress is that in order to remove boarder babies from hospital wards, our society really must be prepared to offer natural parents, relatives and foster parents a wide range of support services, many of which you have heard about, but those services really are necessary to strengthen the emotional, economic and practical capacity of caretakers to nurture AIDS children.

Among the key services needed are respite care, day care, homemaker and home health aide assistants. These are really essential to caretakers, be they natural or foster parents, who are attempting to sustain children with AIDS. Health aides and homemakers provide needed relief. Day care provides a very normalizing influence and can stimulate the child's development.

Respite care allows families time to rebuild strength and resolve, which can be weakened otherwise by the strain imposed by the care that they are providing. To the extent that the exercise of developing appropriate care services for AIDS boarder babies acts as a catalyst, a grim epidemic may, at least, bring about an improvement in the way we care for vulnerable children.

Conversely, if the nation does nothing to stop growing momentum for consigning AIDS children to a contemporary version of the orphanage and if, moreover, these practices in treating AIDS children are allowed to spread to other groups in the foster care population, then the next generation may conclude that in responding to this tragedy, we have, indeed, compounded it. Thank you.

**DR. CONWAY-WELCH:** Thank you very much, Ms. Blum.

Dr. John Arradondo from the Oklahoma City/County Health Department is going to speak to the issue of minorities.

**DR. ARRADONDO** Thank you very much.

My remarks will be limited primarily to access, using the current modalities and mechanisms of service and I will recommend five pilot demonstration projects that I would implore you to consider seriously implementing at whatever level of expenditure you choose, so that they can instruct us for the near future in this epidemic.

In the matter of educating providers, I will defer to the remarks that Dr. Sam Matheny will make tomorrow since one of the references that he will use is a Physician's Aides Task Force Report on which I participated and am satisfied -- and which results I am satisfied with.

I also will not comment on research on AIDS and minorities, except to say that the disparity there is far greater than the disparity that I will refer to and mention concerning access.

By way of other preliminary remarks, I think it is important to recognize that access has as its major determinant economic status. There are a number of other minor determinants; physician distribution, provider distribution, both specialty service oriented and geographic, but those aren't nearly as great as the economic status. And social conditions are one of the most easily observed reflections of economic status.

I don't want to say much about poor nutrition or crowded housing when it is available or inadequate transportation. Someone has alluded to the difficulty of a person receiving health care when their major problem is getting across town to the clinic. And I won't say much about the scarce expensive medical care that serves many of the black and Hispanic minorities that is often delivered in a less than optimal environment.

I would be happy to comment about some of those, but many of these matters are accepted in the general parlance of the health service delivery system and I don't want to repeat them initially unless questions demand that.

The recommendations are not in order of priority. They do reflect some consultation with organizations and people around the country.

First, I recommend a simple project of reimbursing what I would like to believe is the most widely tested primary care physician, the family practitioner, board certified family practitioner at a special reimbursement rate for comprehensively serving patients, who have AIDS and who have HIV infection; a small project really to see just how well shifting care from tertiary orientation to primary care orientation can serve in this battle against AIDS.

It makes a lot of sense in both economic and quality of care terms. I can elaborate further if you wish.

A cost comment on that is that previous small studies along this line have indicated an overall decrease in the total cost of health if you factor outpatient, inpatient, acute care, chronic care.

A second pilot demonstration program, I would suggest using either Medicare or Medicaid, and there are pluses or minuses to each of these, but they exist, to pay for medical health charges for the care of any HIV infected person when that person brings in his or her significant other. I have inserted the words "sex partner" here, but it could be in the case of a child, a mother, or in the case of an IV drug abuse, "significant other," in the sense of function, as a therapeutic unit under the auspices, again, of what I think is the best primary care provider.

Bringing in the second person is a significant barrier. I recognize that right off, but full compensation for the cost of the service may well balance that. In any case, it has not been tested and I offer that for your consideration and purely for your consideration. I think careful consideration of it merits your attention and even inaugurating a demonstration program to see just what effect it would have may well surprise the medical care system.

The third recommendation, in populations where the proportion of physicians, who care for HIV infected persons is too low, and that can be determined through some arbitrary means or best of the literature based means -- I have inserted 20 percent here -- that we fund the provision of comprehensive personal health services through the local public health agency. It certainly would help address the uncompensated care burden that I am sure you have considered.

The fourth recommendation, using a set of primary care physicians, who would be amenable to networking among themselves, who may otherwise not be associated, to reimburse the care provided by all members of a designated multidisciplinary primary care team. Designated is important; multidisciplinary is mandatory. Primary care goes without saying. When the care is provided in the office and the home, in a hospice, in some other ambulatory care setting, in a nursing home, access to care in the office, home and the other places that I have mentioned for blacks and Hispanics has been accepted generally as less than desirable, significantly less than desirable, and that is related to maldistribution of appropriate providers, as I mentioned earlier, frequent areas of provider shortages and the decreased prevalence of adequate financing.

But the patients need this wide range of service. They need the health promotion. They need the disease prevention services. They need the diagnostic and the therapeutic services, even right up to and through the process of dying.

Caregivers need instruction. They need assistance. They need support; they need respite time. A designated multidisciplinary primary care health team may well be the best unit to coordinate that comprehensive array of health services delivery.

The last recommendation deals with something that has been discussed among the leaders of these particular organizations mentioned and that is I suggest you contract with some national grass roots membership organization to mount an education and service program in conjunction with some medical, dental care organizations in a selected number of cities for a specific amount. I labeled it $2 million. That is hardly enough to cover a piece of paper in the war against AIDS, but it is a significant amount when you relate it to the resources that have been aimed at ethnic minorities.

I realize you have had the information of the Secretary's report about the big six killers among blacks and ethnic minorities and I am sure you recognize all of the previous disparities in access service and outcome and I want you to know that these are known to these organizations that I have mentioned here and they are being addressed in one way or the other by these organizations. But the AIDS epidemic compounds all those previous needs and stresses the efforts that are being exerted to meet those needs.

So, a significant shift in resources is required here to get these organizations on the road to doing something about something that they really want to address.

In this instance, with the short survival of AIDS in general, not to mention the shorter survival of blacks and Hispanics who have AIDS, access demands prompt attention, since care temporarily delayed is equivalent to care permanently denied.

I guess, in other words, what we need in a sense is some kind of social earthquake. I won't repeat the nod to Admiral concerning the analogy of AIDS and war and the Defense Department and the Department of Health and Human Services. It has been said well, but a social earthquake to change the conditions that foster some of the things that complicate this epidemic.

We could start with the Commission, which has inadequate numbers of Hispanics and blacks on it, and go right through the health system and its halls of decision-making, where these people who constitute 50 percent of the perceived disease count and death count are included in less than their population numbers, far less than even their population numbers in the decision-making processes.

Needless to say, a social earthquake is needed to deal with drug abuse and to deal with the inappropriate sexual activity that certainly fosters the spread of this problem.

Lastly, I guess, almost by way of repetition, at the least we need a temporary rearrangement in the color, if you will, of the actors in this game or the soldiers in this war.

Madame Chairman, I will be happy to record -- I have recorded and I will be happy to transcribe the ad lib remarks to attach to the recommendations which you have in a copy.

**DR. CONWAY-WELCH:** Thank you. I think that would be very helpful. We would appreciate that. Now, we would like to go to Dr. Audrey Manley, who is director of the National Health Service Corps and she will be addressing issues about underserved regions. Dr. Manley.

**DR. MANLEY:** Thank you. I am Audrey Manley, director of the National Health Service Corps and I thank you for inviting me to speak to you today to discuss the role of the National Health Service Corps in providing primary care services to persons who have difficulty receiving care because they live in an area or are part of a population group for which adequate primary health care manpower resources are not generally available.

The primary mission of the National Health Service Corps from its inception in 1970 has been to provide primary care services to isolated or underserved areas and to population groups, who because of economic barriers, geographic, minority status, language, cultural or other constraints, are not able to obtain basic primary care services they need. At present, we estimate that 34 million Americans live in an area or are part of a group which have such shortages of primary care providers. Persons with AIDS may be considered among these "underserved populations."

As a result of the scholarships awarded under this program from the mid to late 1970s, this program has produced a large number of service-obligated providers, reaching a peak field strength of approximately 3,200 in 1986. The current field strength of 2,800 NHSC members has been used to meet the primary health care needs of various areas and populations through assignments to community health centers, the migrant health centers, the Indian Health Service, the Bureau of Prisons and through private practice arrangements.

After 1976, scholarship awards were allowed to decline in response to the increasing number of physicians being graduated from medical schools and locating in areas which formerly had few health care providers. As a result of the decline in scholarships awards since 1980, fewer than 100 obligated NHSC providers will be available for these assignments by the year 1994.

On December 1, 1987, the President signed Public Law 100-177, providing for the establishment of a new federal loan repayment program, a state loan repayment program and special repayment provisions for previous scholarship defaulters, who are in breach of their service obligations. Under these programs, we anticipate awarding 40 loans and returning to service a significant number of the present scholarship defaulters.

I would like at this point to turn my remarks towards how the NHSC program is presently involved in treating AIDS patients.

I have provided for you two handouts. My first handout shows a listing of the 30 standard metropolitan statistical areas, SMSAs, with the highest incidence of AIDS cases. The handout also indicates the number of designated health manpower shortage areas or HMSAs in these SMSAs and it indicates the number of NHSC health care providers, who are currently providing service in these areas.

The second handout indicates the number of CHCs and MHCs located in these areas and the current funding level for these programs.

AIDS patients require a wide array of medical, psychological, social and support services through the course of the disease. In addition to hospital care, virtually all experts agree that AIDS patients require community-based systems of services that include a continuum of care, which involves comprehensive AIDS-specific ambulatory care services provided by multidisciplinary teams of physicians, nurses and various specialists, who are familiar with AIDS and trained to manage AIDS patients.

This continuum of care also includes in-home medical care, supportive services, long term care, skilled nursing services, intermediate facility services, hospice services, case management services based at specialized ambulatory clinics or voluntary community organization, as well as emergency residential facilities for those patients, who can no longer afford housing. In many cities and counties, the full continuum of health care services required for AIDS patients are not available. Presently, the NHSC, in conjunction with other programs funded by the Bureau of Health Care Delivery and Assistance are addressing the needs of the primary care services for AIDS patients through the primary care centers located in these areas, where there is a high incidence of AIDS patients.

At these centers and through these other providers, AIDS patients are treated in the same system as other users. As the number of AIDS patients increase, finding adequate numbers of physicians, dentists and other primary care providers, who are trained and prepared to treat AIDS patients, may become a problem. Service delivery problems in the Indian Health Service and the Bureau of Prison sites could be even more acute.

Recommendations: The increasing need for appropriately trained providers, combined with the decreasing numbers of NHSC scholarship obligated providers suggests the need for some courses of action for providing proper care and improved access to services for AIDS patients that you may wish to consider.

Recommendation 1: Increased efforts should be made to inform AIDS patients about the availability of primary care services through existing federally-funded programs, such as CHCs and MHCs.

Recommendation 2: Steps should be taken to ensure that staffs of the CHCs and MHCs are properly trained and prepared to provide primary care to HIV infected patients and to develop and manage networks of community linkages to other forms of care for these patients.

Recommendation 3: We should consider allowing specialists physicians, that is, other than non-primary care providers, who are currently in default of their NHSC scholarship service obligation, to serve their obligation in a designated area or population group where there is a high incidence of AIDS. This is an option that could be made available under the special repayment provisions of Public Law 100-177.

And, finally, Recommendation 4: Continue to support the new federal and state loan repayment programs. These programs will allow for placement of additional NHSC primary care providers in HMSAs and for serving special population groups, such as HIV infected patients and AIDS patients.

This ends my testimony and I will respond to your questions.

## Discussion

**DR. CONWAY-WELCH:** Thank you very much, Dr. Manley.

We would like to open the panel for questions from the Commissioners and I will ask the Commissioners to each pose one question and then if we have time, we will circle back around for another set of questions.

I have forgotten where I am starting. I think Mr. Creedon -- no, Ms. Pullen.

**MS. PULLEN:** I don't have anything now. Thank you.

**DR. CONWAY-WELCH:** Dr. Lilly.

**DR. LILLY:** Dr. Arradondo, in looking over the recommendations that you submitted to us, particularly with respect to the issue of trying to encourage primary care, as opposed to sending people off to tertiary care institutions, and the way you have developed that in your oral presentation almost makes it sound like a case management system that you are proposing. I am not clear as to how an individual primary care provider is going to be able to supply all the services that we are told by everybody who comes before us is needed.

I am wondering, if you think that there are primary care providers who are capable of serving this sort of case management function?

**DR. ARRADONDO** One of the reasons that I chose to pick on, as it were, what I call the premiere modern trained primary care provider, the modern trained family practitioner, is because a very high proportion of these practitioners are trained to coordinate care, beyond that which they can provide, to monitor that care, to get the person receiving the care into and out of various portions of the health care system and maintain the continuity that is absolutely required in the normal course of events, not to mention in the case of AIDS.

What AIDS is doing, and if we ever are able to do a lot of HIV infected people before they are diagnosed as having AIDS, is accenting some of the weaknesses in the system. What I am suggesting is that some of the strengths of the system that have been recognized over the last decade or even two decades, be applied in a very purposeful manner. Yes, there are many family practitioners in this country, who know how to manage the care of patients, when they cannot themselves provide that care directly.

Perhaps more importantly, they know how to monitor it because not all care that is received is good care. Not all care that is received is specific enough or targeted enough and the physician assisting the patient and honing in on the need can help the need be met much more specifically than one or the other alone going out trying to get that need fulfilled.

**DR. LILLY:** Just one further --

**DR. ARRADONDO** By the way, case management in the way it is ordinarily thrown around is really adding another external person onto a system, a person who is somewhere in the middle of the milieu at best and asking them to manage a whole lot of people who are higher up in the hierarchy. Having that management done under the auspices of a member of the group, as it were, the primary care physician enhances the credibility of the management and certainly the initial entre of the management, even though the management itself often is delegated to the inner core of team members in that physician's office or practice.

**DR. LILLY:** That is encouraging to know because, in fact, one of the things that we have occasionally heard from the people who have testified before us is that the variety of services that people with AIDS need is enormous and that, in fact, it almost takes a specialist to know how to route people to all of these services that are needed.

Just one final point. In the written version of your first recommendation, you recommend that the service provider, the family practitioner, be allowed to recuperate 200 percent of the usual and customary fee for comprehensively serving patients with AIDS. How do you define 100 percent for that purpose?

**DR. ARRADONDO** Well, for starters, Medicare typically reimburses at the rate of about 80 percent of usual and customary. So, usual and customary is a well-defined factor within the health care -- the fiscal side of the health care system.

That figure is as much to get your attention as it is to invite thought. It is not a bad figure, though, when you look at the fact that economic incentives in our health service system have tremendous impact.

**DR. CONWAY-WELCH:** Ms. Gebbie.

**MS. GEBBIE:** I bet you can guess what my question is going to be. I am intrigued by your proposals and I think a good many family physicians would describe themselves as providing that coordination you have identified. I also think a good number of them have yet to see a patient with AIDS and might run the other way the first 25 that knocked on their door and said, "Hi. I am here for my comprehensive case management."

I have asked this of several other witnesses and it may not be something that you can sit down and do with a paper, but maybe you can help staff figure it out. In saying that you are paying a family practitioner 200 percent of usual and customary will overall drive the cost down is a fairly glib statement. I think we need to see that worked out for a typical sample of a hundred families that include an HIV-positive individual or some other combination of numbers that would let us see how this burden placed in the office practice will, in fact, cause costs to shift out of the hospital setting or out of specialist setting so that it all does hold together. So, if you could, either by comment now, but preferably by paper a little later on, help us see how that all holds together, it would be very helpful.

**DR. ARRADONDO** I wouldn't get stuck on the 200 percent, first of all.

**MS. GEBBIE:** I thought that might be where we would head, once we got started on this.

**DR. ARRADONDO** I think the capability of the modern trained family practitioner may be the best starting point. It is no accident that many organizations that purport to coordinate care and drive down the cost, namely, the health maintenance organizations, have focused upon the recruitment of family practitioners; modern trained family practitioners, mind you, as their primary providers, not a tandem of pediatrician and internist, although I don't want to get into any specialty argument here. I am just quoting the facts as I see them.

They are perhaps better analysts of fiscal costs than I could ever wish to be, but there are a number -- the literature has a few studies in it, at least, that point to smaller groupings of family physicians and various kinds of arrangements that through their coordination of care help to drive care down, primarily by decreasing hospitalization. I think that is the very clear notion there.

So, a comparison of ambulatory costs here and ambulatory costs there wouldn't be valid. It is the total overall cost. My comfort in making the statement of overall was based upon that aspect of the literature, not a hundred patients tested out. That is what I am suggesting you do.

**MS. GEBBIE:** But I think we need to see some of those other studies or some other analysis in order to move toward that, if we chose to. Thank you very much.

**DR. ARRADONDO** Well, personally, I would be happy to provide such data if the Commission were seriously interested in recommending such a pilot.

**DR. CONWAY-WELCH:** I don't know that we can say we are seriously interested in recommending a specific pilot, but we are seriously interested in looking at creative and alternative models for care. So, I would be interested in underlining that request that we would be able to work with you to get a snapshot of those figures. Dr. Walsh.

**DR. WALSH:** Dr. Manley, I am just curious about one thing primarily; the incidence of AIDS among the Native American population, the Indian. Is there much? We hear a great deal about minority incidence confined primarily to blacks and Hispanics, but I have seen nothing on the incidence in American Indians until you brought it up in your presentation. Do you have any information on that?

**DR. MANLEY:** I did make the inquiry about that and I do not have hard data. I have verbal input from the Indian Health Service, that the cases reported so far to date have been small. They supposedly have 40 cases. Now, that is 40 cases of full-blown AIDS. I cannot speak about the rate of infection beyond that.

**DR. WALSH:** Is that 40 cases from among the Indians that they care for, that they know about?

**DR. MANLEY:** Within the Indian Health Service.

**DR. WALSH:** How large is the Indian population that they are caring for?

**DR. MANLEY:** The Indian population that we care for is near one million, about 900,000.

**DR. WALSH:** Well, 40 percent that is a significant percentage. That is pretty damn high. Okay. Thank you.

**DR. CONWAY-WELCH:** Thank you, Dr. Walsh. Dr. Servaas.

Mr. Creedon.

I would like to ask a question of Dr. Manley. Am I correct in reflecting that at one point the National Health Service Corps did provide financial support for nurse training with the idea that nurses then also would go into underserved areas or have I dreamed that up somewhere?

**DR. MANLEY:** Yes, that is true. We provided scholarship support for nurse training through 1980. In the year '80-'81, the total number of scholarships being provided to nurses at that time was 147 out of the 1,700 that were awarded that year.

With the decline in scholarships across the board, nursing scholarships decreased significantly and we do not at this time support nurses in the scholarship program.

**DR. CONWAY-WELCH:** I obviously have some biases because as the dean of the School of Nursing, I am sitting at the moment on 17,000 inquiries from students, who are interested in going into nursing, the vast majority of which are women in their twenties and thirties and forties with adult responsibilities, who do need financial support of some kind. I, along with many other deans of schools of nursing, given this new interest from this new student population, are looking for creative ways of finding financing and it seems to me that one of the possibilities might be revisiting the support possible from the National Health Service Corps. Is there any discussion going on at the present time, considering the fact that we are confronting the biggest nursing shortage this country has ever seen?

**DR. MANLEY:** Well, we in the National Health Service Corps are implementing and mounting a major volunteer nurse recruitment effort, since we, too, are acutely aware of the nurse shortage problem today and anticipate for the future.

However, the loan repayment provision of Public Law 100-177 does provide for support of health manpower across the board. As we anticipate implementing that program in the future, even though we are only going to award 40 in FY '88, with expansion and increase, we would expect to include nurses and other health care providers.

**DR. CONWAY-WELCH:** I think I would like to talk with you later.

**DR. MANLEY:** I will be very happy to talk with you.

**DR. CONWAY-WELCH:** Mr. Chairman.

**CHAIRMAN WATKINS:** Dr. Manley, we have been very impressed by some of your people in the field in underserved areas. We were in Belleglade and had the privilege of seeing in action two of your National Health Service Corps people. Were they not there, no one would have been there.

**DR. MANLEY:** I didn't hear your question.

**CHAIRMAN WATKINS:** Without those two there, there would have been no doctors on site in Belleglade, dealing with the incredible problems that they face with the AIDS epidemic.

This illustrates the urgent need, it seems to me, to reinvigorate the National Health Service Corps and bring it back to life. You said you reached a peak a few years ago. Well, it is my understanding that the dollars were removed essentially from this kind of incentive programs, scholarship and so forth, in 1980.

**DR. MANLEY:** Correct.

**CHAIRMAN WATKINS:** It seems to me for a small expenditure and a tremendous payoff for people to put their service in the war zone of the underserved areas. They deserve this kind of incentive package like we used to have. I know it may be difficult for you inside a bureaucracy to recommend things that cost dollars, and by the way, I would like to applaud your uniform. I like its color and I like its symbol. So, if you could step out of your bureaucratic hat for a minute and give us your personal opinion. We are very concerned about some of the projections, despite what I would consider to be a very small program. Congress allows clean-up for a few things, and I have been in the recruiting business a lot, and it is tough out there.

Dr. Conway-Welch just said, the proclivity to come into the nursing profession in the nation is down 25 percent in the first few years of this decade from what it was. With a half a million nurses needed by 1990, more than we have today, how do we do all these things?

So, it seems to me the National Health Service Corps has an option here for a variety of health care delivery concepts like this one. We would certainly entertain some specifics because it is our information that we are going to drop from the nominal 2,500 plus that you talked about today. If we don't really so something about this thing and bring it back to life, we could go down in six years to as many as a hundred and I don't see how we are going to handle the underserved areas unless we find incentive packages for the participants.

I don't want you to get yourself in trouble, but I would appreciate it, if you stepped out for a minute and explained the position on budget restrictions, then go into your personal opinion.

**DR. MANLEY:** Mr. Chairman, I couldn't agree with you more. I think, though, what I tried to explain is that even though the scholarship pipeline is phasing out, the new legislation with loan repayment, we feel at this point, even though we are just in the process of drafting the regulations, that we can replenish those providers to the field, through a loan repayment mechanism, rather than a scholarship mechanism.

I have visited the Belleglade site and I have seen our scholars in action there on a site visit with the Robert Wood Johnson Foundation, so I know how crucial they are to what is going on in the AIDS arena.

Again, my fourth recommendation I would underscore. We have $1.9 million this year towards the loan repayment program. We feel that the loan repayment package is going to be a competitive package and that we can recruit through loan repayment to replenish those providers in the field. So, I would again underscore the recommendations that I put before the panel.

**DR. CONWAY-WELCH:** Let me be clear. When you say loan repayment. That is a new funding mechanism for new students to secure money for tuition, which then would be paid back rather a than scholarship.

**DR. MANLEY:** In addition to that, we know that we have a large cadre of scholars, both medical, nursing and otherwise, who have received their education through government loans and we feel there is a significant number who will respond to an opportunity to participate in a loan repayment program.

**DR. CONWAY-WELCH:** So, you mean from loan sources, other than -- scholarship sources other than the National Health Service Corps.

**DR. MANLEY:** Exactly. We, in addition, feel that some of the problems that we encountered in the National Service Corps will be eliminated. Many scholars signed contractual obligations as freshmen, when they were 21 and 22 years old, many of the problems we experienced with implementing that program resulted, when these scholars became available for service, some seven or eight years later. By going towards a loan repayment mechanism, we can get them when they are more readily available to go into service and we can eliminate some of the problems that we have had that deal with related to changes in their personal family situation.

**DR. CONWAY-WELCH:** I agree with you, but I suspect that those problems are more physician-related than nurse-related in terms of the time span from the time you would sign the contract to the time the service would need to be paid back. I applaud you looking at creative ways to --

**DR. MANLEY:** I wish I could agree with you on that. It seems that many young women, who have married and have stationed themselves in geographical areas, have much more difficult responding to their service call than have the men.

**DR. CONWAY-WELCH:** Does that mean that you have a high rate of non-compliance by the nurses who receive those monies?

**DR. MANLEY:** No higher than physicians, no.

**DR. LILLY:** I am wondering, you say you have 1.9 million for this program. Since, as a medical school professor, I am aware of the fact that a large percentage of medical school graduates have accumulated approximately 40 to 50 thousand dollars worth of indebtedness; 1.9 million is not going to go very far.

**DR. MANLEY:** Exactly. As I said, we are planning -- in my testimony -- we make 40 awards this year. This is the beginning of the program, but I think it is clear that, there is a lot that remains to be done.

**DR. CONWAY-WELCH:** Thank you very much.

**CHAIRMAN WATKINS:** We are going to close out the hearings today. We very much appreciate your testimony before our committee. As we have told each of the panels, the Commission is open to you on a continuing basis between now and the 24th of June. So, if things come to mind or you feel that we need to have additional information perhaps that we did not probe into today, we would hope very much that you would communicate with us, by letter, by personal contact. We have a good solid staff that can pull more information from you and I think it would be helpful to the Commission. So, we would like to keep that door open. We will now stand adjourned until tomorrow morning at 0900.

(Whereupon, at 5:12 p.m., the meeting was recessed, to reconvene at 9:00 a.m., the following morning, Friday, January 15, 1988.)