THE PRESIDENTIAL COMMISSION on the HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC

HEARING ON Prevention and Education

March 1, 2, 3, 1988

August 24, 1988

TO OUR READERS:

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

The staff of the Presidential Commission worked around the clock, seven days a week to prepare and coordinate the hearings and finally to edit the transcripts, all the while keeping up with our demanding schedule as well as their other work. In that regard, for this Hearing on Education and Prevention, we would like to acknowledge the special work of Robert Mathias, Jane West, Sherry Kaiman and Cynthia Flynn, in putting together the hearing, and Jane West and Margo Payne, in editing the transcript so it is readable.

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

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

Sincerely,

Polly L. Gault
Executive Director

Gloria B. Smith
Administrative Officer

PRESIDENTIAL COMMISSION ON THE HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC

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PRESIDENTIAL COMMISSION ON THE HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC

HEARING ON PREVENTION AND EDUCATION

The Hearing was held at the
Interstate Commerce Commission Building
Hearing Room B
12TH and Constitution Avenue, N.W.
Washington, D.C.

Tuesday, March 1, 1988

COMMISSION MEMBERS PRESENT:

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COMMISSION MEMBERS NOT ATTENDING:

JOHN CARDINAL O'CONNOR

COLLEEN CONWAY-WELCH, PH.D.

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P R O C E E D I N G S

MS. GAULT: Ladies and gentlemen, members of the President's Commissioner, 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. Yesterday we completed our first business session on the Chairman's recommendations for the content of the Commission's interim report. In the interim report we address areas of intravenous drug abuse, medical care for HIV in infected people, including education of health care providers and research needs for new drug and vaccine development. The full Commission will vote on these recommendations after allowing 2 days for public comment. At the close of THursday's hearing, we will commence preparation of the interim report from the entire Commission for delivery to the President early next week.

Today, however, we are going to take up a new subject, a subject that all experts agree is of critical important to altering the course of this epidemic. That subject is prevention and education. We have already laid the groundwork for an education strategy by recognizing the educational needs of health care providers in the interim report. These are the people from which information about the HIV epidemic needs to come. They are the horse that should be pulling the HIV education cart. We are now ready to start filling that cart, as we address the educational needs of such populations as the nation's work force, the unemployed, hard-to-reach youth, minorities and our schoolchildren. During the course of this Commission's work, we have spent a majority of our time examining those aspects of the nation's response to the HIV epidemic that can best be characterized as predominantly reactive. We have been looking at what needs to be done after the fact.

Today and on the two days that follow, we are going to look at that portion of the nation's response to the epidemic that is predominantly proactive. We will examine those strategies that can be pursued before the event takes place, strategies that can be effectively utilized to stop the spread of the HIV infection. The reality today, as we are all too painfully aware, is that there is no cure for AIDS. There is no vaccine. During the next 3 days, the Commission will examine in detail areas of prevention and education. We have spent considerable time gathering 60 of the best minds in the nation to present testimony on these critical areas.

We will examine the response of the nation's public health and education systems from the federal to the local level. We will look for both model programs that can be successfully replicated and for the obstacles to effective prevention and education efforts to determine what we can do to eliminate them.

During these hearings, we will hear witnesses speak about laboratory support for HIV prevention services and the use of contact notification of those who have had sexual contact with an infected individual as a preventive measure.

The issues of testing reappear consistently as the epidemic is examined in detail by the Commission, but it needs to be clearly understood that this is not the only context in which we will be addressing testing. Two weeks from now in Nashville, Tennessee, we will be holding additional hearings on testing nd the related issues of discrimination that so often surround those who test positive for the virus. We could not, however, fully examine the prevention efforts of the public health system without including contact notification here.

Other issues that will be addressed during the next 3 days include the relationship between other forms of sexually-transmitted disease and the human immunodeficiency virus, appropriate strategies for reaching minority populations and hard-to-reach youth, as well as the role that the media can play in education of the population at large and the educational efforts of community-based organizations those groups who have been at the frontlines of the epidemic since the beginning. We will, also, hear testimony from educators who will present their views as to what type of information is appropriate to provide for our nation's schoolchildren and what is the best way to deliver it. These children are tomorrow's adults, and they quite literally represent the future of our nation, and by giving them the right kind of education about AIDS now, we can help their generation avoid the tragedy we are witnessing today.

Today, we will hear testimony regarding the prevention efforts of the nation's public health system. I use the term "prevention" here with its broad definition to include a variety of strategies to stop the spread of HIV.

Tomorrow and Thursday, we will hear testimony on that aspect of prevention, the education of our nation's adult and school-age population that has such great potential as a weapon against this disease.

We have got a full agenda, and I would like to begin now. So, I am pleased to introduce our first witness this morning and welcome him to the Commission, Dr. C. Everett Koop, Surgeon General of the United States.

Dr. Koop has been in the business of healing for many years. Before joining the Federal Government in 1981, he was a pioneering pediatric surgeon at the University of Pennsylvania in Philadelphia. Dr. Koop has been a courageous and visible leader in the areas of prevention and education, and I am delighted that the Commission has this opportunity to hear his views directly.

Thank you for being here this morning, Dr. Koop, and please begin.

DR. KOOP: Thank you, Admiral. I welcome this opportunity to appear before you and discuss prevention and education issues concerning AIDS and the HIV infection. My remarks are brief, and I will rely on your questions to bring out those things that you would like to hear from me. First, I would like to congratulate you and the members of the Commission for the manner in which you are exercising your critical role in the national effort to contain the epidemic.

Since October 1986, when I released the Surgeon General's Report on AIDS, this country has done much that we can be proud of. The news media, print and electronic, have rendered tremendous service in getting out clear information to the public. The entertainment media have, also, put out the AIDS message in ways that can change behavior and save lives. The Administration and the Congress have given high priority to the greatly increased resources for the fight against AIDS and HIV infection. The research and the health care communities are working hard on these problems. It is the highest level of activity and commitment to a public health problem that I have seen in my lifetime. There is an increasing public awareness of this health issue, and a strong desire to take personal and public action, but there is much more to be done and many issues which we must enjoin if we are to contain the spread of HIV.

Let me share a few issues of special concern. I am concerned about needle sharing among IV drug abusers. A recent National Institute on Drug Abuse study of heroin addicts admitted to Methadone treatment programs indicated that 93 percent had shared needles (most in the last year) and 26 percent reported daily needle sharing: yet only 14 percent reported the use of condoms.

These figures have alarming implications for both IV drug users and their sexual partners, not to mention the children that are born of such unions. It is currently estimated that there are about 1.1 million intravenous drug addicts in this country. The solutions are not readily obvious. IV drug abusers lead disjointed, fragmented lives, and many of them are functionally illiterate. It is critical that we find the right combination of strategies to get people off drugs and away from contaminated needles.

Additional drug treatment capacity is needed, but simply providing more dollars does not immediately translate into additional slots available for addicts. There needs to be increased sharing of expertise and programmatic experience between federal, state and local governments working in close conjunction with community organizations and the professional

provider community. Our only hope lies in the solutions that come from this type of collaborative activity.

I continue to be concerned about the spread of HIV among heterosexuals. I am outraged at recent newspaper and magazine articles stating that there is no danger of heterosexual transmission from "normal vaginal intercourse." Although homosexual sex and IV drug abuse are the principal modes by which most cases are transmitted, it is just not true that there is no danger from normal vaginal intercourse. What is unknown is the level of that danger. There is always danger wherever people engage in casual sex. To date there have been about 2100 cases of reported heterosexual transmission out of something over 53,000 adult cases of AIDS. That is about 4 percent. If you exclude the foreign born, the figure drops to 2.3 percent, nd most of those cases are the sexual partners of IV dug abusers.

The Centers for Disease Control estimates that by 1991, heterosexual transmission will account for 5 percent of the total adult caseload; that is 5 percent of about 300,000 cases. We know from the infected spouses of persons with hemophilia that HIV can be spread through normal vaginal intercourse. What concerns me is the potential for more rapid spread of HIV infection into the general population.

This concern about a more rapid spread is reflected in the reported increase of infectious syphilis cases by approximately 30 percent just from 1986 to 1987. The greatest increases were in Florida, New York and California, areas of high HIV incidence. Relative increases were greatest for females and heterosexual males of all racial and ethnic backgrounds.

I want to take this opportunity, sir, to add a special word of praise for those who dedicate themselves to the compassionate care of people with AIDS and ARC -- physicians, nurses, teaches, social workers and others, especially in areas with the highest concentration of AIDS cases -- specifically the cities of New York, San Francisco and Los Angeles. However, even there and in many other cities across this country, we are seeing a number of instances in which health professionals refuse not only to treat persons with AIDS but turn away patients alleged to be identified with high-risk behavior: homosexual and bisexual sex and intravenous drug abuse.

The decision by some health professionals to deny care to homosexuals, IV drug abusers or others suspected of carrying the virus is historically uncharacteristic and unworthy of anyone in the health or social service professions. For government, for the professions involved and for Americans generally, this kind of behavior even by a small number of health professionals must be a cause for grave concern.

Of course, the reasons most often given are that AIDS is contagious and fatal and "I don't want to get it." But the plain fact is that the risk of contracting HIV from an infected patient is extremely small and virtually always preventable.

Of the nearly 7 million Americans in health professions, we know that fewer than one dozen have become infected with the virus while doing their jobs. And in most of those cases, HIV exposure could have been prevented if the persons had followed the workplace guidelines published by the Centers for Disease Control several years ago.

I cannot overemphasize it is essential that all workers be required by their employers to follow the CDC guidelines, and that they be provided with protective material where necessary.

In 1988, the Federal Government will spend a total of $1.465 billion on AIDS, including $375 million through Medicaid on AIDS treatment, $931 million on AIDS research and education; and an additional $159 million on treatment and prevention efforts. THe President's budget for Fiscal Year 1989 includes $2.026 billion for these efforts, a 38 percent increase over 1988.

In addition, there are social costs, such as human capital, and these are often translated as lost wages and productivity. But even if you put to one side these indirect social costs, we still face in the year 1991, a national bill of 3 to 5 billion dollars for the cost of AIDS-related care. Both inpatient and outpatient, hospital and hospice. These 1991 costs will result from the care of an estimated 145,000 persons with AIDS who will be in various stages of a terminal illness. Clearly, we must do a great deal more to develop alternative, less costly, but highly effective ways to care for AIDS patients. We need to do this in light of the specific AIDS-related diseases and conditions we know about and the different stages through which they progress. I believe the challenge today is to give the country a way of caring for AIDS patients while preventing an escalation of costs.

I would also like to make the critical point that one of the complexities of AIDS is that it is an epidemic characterized by related issues, a number of them social, such as homosexuality and IV drug abuse. We must develop our strategies to meet the specific dimension of each issue related to the epidemic, if we are to contain HIV infection in this country.

In my remarks I have limited myself to just a few critical issues. There are many others. They must all be addressed if we are to interrupt the chain of transmission of HIV and spare our people and the people of the world the pain, the suffering and the deaths from AIDS. We need to stop it in a way

that is effective yet consistent with American law and tradition. We can do it by making certain that the American people have a clear understanding of the threat posed to them by this disease and that they are ready to fight back with the best weapon available to them: their intelligent choices about personal behavior.

As a Presidential Commission with high public visibility, you have the ability to market good disease prevention, good science and good health care practices to the public.

The American public look to your final report for leadership vision of those things we must do to contain the epidemic. In this way, I believe you will have served the very best interests of the American people. Thank you.

CHAIRMAN WATKINS: Thank you very much, Dr. Koop. I would like to commence the questioning this morning from my left, your right. Mr. John Creedon.

MR. CREEDON: Thank you, Dr. Koop. I guess we have been hearing for quite some time now that what we need to do is prevent the spread of the disease, and the main vehicle for doing that now is education. It seems to me there has been a lot of education over the past 6 to 9 months -- television programs, television advertisements, newspaper articles, magazine articles, efforts made in the schools to put curriculum in. What else needs to be done, as you see it, specifically? What specifics can we recommend as a Commission to improve the education of the different groups? It seems to me there is a high level of education about the problem in the homosexual community, less so in the IV drug user community, a community that is much more difficult to reach. What specifically do you see as something that we could recommend?

DR. KOOP: Admiral Watkins mentioned some of the things that are on my mind, in his introductory remarks. I thing the first thing is to recognize the people you are trying to reach and to develop the message in such a way that it reaches target groups.

I think that messages have to be targeted to the homosexual, to the heterosexual and to the IV drug abuser. From an AIDS point of view, I think we have three different challenges. The message has to be different to those who are college age and above, and certainly different for those who are pre-adolescent. I would like to take a moment to talk about that. If we had proper value-laden, responsible education about human sexuality undertaken in pre-adolescent years, which is the primary responsibility of parents, with parent reinforcing parent, parents being reinforced by schools, schools being

reinforced by churches and community organizations, I think it is quite possible to raise a generation of adolescents down the road that would be far less sexually active than the present one. That brings us to the teenagers of today. Many people are discouraged about teenagers because some of them are so sexually active. However, those who have remained abstinent and are looking forward to monogamous relationships need to have that decision reinforced in every place that we can. I think it is also realistic to understand that sexually-active teenagers are unlikely to reverse their pattern and go backward. Therefore, the prevention for them has to be our third line of defense, which is to teach them about the protection of themselves and others through the use of condoms and spermicides.

Now, I know that that goes against the grain of many people in this country, but we cannot abandon more than half of our teenagers because they are sexually active. We have to reach them where they are and tell them about those things that they have to do.

My greatest concern has already been well enunciated in Admiral Watkins' report last week. That is, the epidemic is spreading most in the IV drug abusers, and they are the hardest people to reach. I have made it a point to work with IV drug abusers in Newark and New York. I traveled to Scotland late last year to look at the clean needle experiments in Glasgow and Edinburgh, and we have problems that they don't face at all. If you talk to Edinburgh drug addicts, they are all of one culture. They are Scottish. They live in housing developments. Many of them are married and have children, and they are all literate. They read, they understand, and they follow directions. You try that in New York City where you are dealing with a fragmented individual who has had very few choices to make in life. Those he has made have been poor; he is now addicted to a very difficult drug habit to kick. He cannot read and his life is so fragmented he tends not to congregate in a place where you can show him a video tape or talk to him.

I think one of the most effective things that can be done with these people which is high labor intensive, is to have former drug addicts talk with them one on one and convince them about the problems of needle sharing. We have had some successful experience with this in some parts of the country. The reason for its success is because somebody who understands their problem and kicked their drug habit is now able to tell them what the challenge is of this epidemic. That is hard to do. Also, some of the things that were mentioned in the preventive efforts of Admiral Watkins' paper last week are very difficult to bring about in communities. Although everybody is in favor of getting rid of drug abuse, nobody wants to be the person involved with doing it. Money is also terribly important. But as you know, as well as I, a lost of the money that has been already

appropriated to the states has not been used because they cannot find the places to put the drug abuse clinics. They cannot find the counselors with skills to be able to talk to these people one on one, and counseling is very much a part of any Methadone treatment. Those are the problems that I see.

In closing, I would say that the one thing that I wish I saw here, that I saw abroad, is visible posters in those communities most likely to reach the illiterate which speak to them in sign language. I don't see those here. I do see them in Liverpool, and I see them in Edinburgh, and I see them on the Continent.

MR. CREEDON: Thank you.

CHAIRMAN WATKINS: Ms. Gebbie?

MRS. GEBBIE: One of the issues within any public health effort in this country is the pluralism of the system, and that is local government, state government, the Federal Government, each of them not necessarily working for the same bosses but trying to work together. That sometimes appears complicated to people at the state and local levels when it appears as if the various components of the federal public health system aren't pulling together or all in the same direction. Could you comment a little bit on that process of getting the elements of the Public Health Service coordinated and your sense of direction and the effectiveness of the coordinating process that is going on today?

DR. KOOP: There are two mechanisms already at work. One is the Association of State and Territorial Health Officers, a remarkably fine group of people who do work well together and who work well in tandem with the Federal Government. In addition, the Public Health Service divides the country into ten regions. Each has a regional health administrator who is part of a regional structure that carries on much more inclusive activities than health. These two mechanisms already are at work. What I think is needed, and what I have been calling for, for over a year, from every podium I have had the privilege of using in this country is the need for dialogue of the most statesmanlike variety. We need to bring federal, state and certain municipal people together. There is no doubt that the burden of AIDs is being borned by municipalities. They can lean only so long upon state help, and the states have to lean eventually on federal help. The problems that these people could discuss, in addition to prevention, are how much it is going to cost? Who is going to pay what part of it. Where does insurance fit in? And then, as I mentioned in my prepared statement, what is an alternate cheaper method, but compassionate way, of dealing with terminally ill patients?

MRS. GEBBIE: Could you carry that a little further within the federal system? I really would appreciate some comment on the dialogue within the various components of the federal Public Health Service and whether you are satisfied with the coordination that is in place there or are there some additional things we should be recommending?

DR. KOOP: I am satisfied with it. Any bureaucracy is cumbersome, and AIDS is getting to be such a problem its own little bureaucracy is becoming cumberson. The Public Health Service exists within the Department of Health and Human Services. It is composed of five major agencies to which the Indian Health Service has just been added. The five you are familiar with are the Centers for Disease COntrol, National Institutes of Health, Food and Drug Administration, ADAMHA and finally the Health Resources and Services Administration. Each of the components of the Public Health Service has representation on an Executive Task Force on AIDS which meets for 2 hours on alternate Mondays. Reports from various pre-established committees that have to do with every phase of AIDS are presented at these meetings. In addition to that, there is an HHS interagency task force which meets weekly. This task force has representatives from all components of HHS such as the General Counsel's Office, HCFA, Social Security Administration and so on.

So I think there is a good communication network in place within the Public Health Service and within HHS and that it is being used actively and appropriately.

CHAIRMAN WATKINS: Dr. Lilly.

DR. LILLY: Dr. Koop, I think you made a brilliant presentation on this point. I want to go just a little bit further. Somehow or other are we in this country, as you suggest, thinking that if we can just start now teaching our kid to live properly that another 50 years from now there will be no extramarital sex whatsoever; if we can just now start working on our kids to teach them not to use drugs, 50 years from now there will be no drug abuse of any kind? I am not sure I believe that, at least in those extreme terms I have mentioned. I am quite sure that we have a problem now and that the plans for raising a future generation are not addressing the problem now and I am very worried about that. I have no quarrel with the future plans. I think they are wonderful. We must do those. Those are very high priority activities. I think that in a sense, since the problems of trying to deal with the present drug abusers, with the present people who still practice sex, that in a sense we are abandoning those people. We don't have enough courage to do something for them, and I am wondering if you can tell us, do you think that plans for things like eliminating needle sharing by perhaps even going to the extremes of eliminating the laws

against possession of injection equipment, do you think that things like that are feasible or desirable? Do we need more research on those issues? Do we need to research the business of needle exchange for current IV drug abusers who cannot get into treatment programs and who will not be able to get into treatment programs for months down the road? Do you think that sex education for how to behave now for people who, as you say, are not going to go back and change their behavior, is called for? We need research on the effectiveness of trying to give a simple explanation of how to use a condom? Do we need research or do we know now what to do there?

DR. KOOP: That was a lot of questions, sir. I never meant to imply by my enthusiasm for teaching youngsters about their own sexuality that you are going to eliminate sexual problems in the next generation of teenagers --

DR. LILLY: I was aware that I was exaggerating your --

DR. KOOP: -- any more than I think you can totally eliminate smoking, no matter how hard you try. You can, however make tremendous inroads in it, and that is what I was trying to get across. I think we need research in many things that we don't know about. One is human behavior. A part of that is already being addressed by the mental health division of ADAMHA. Some things ought to be coming down the road in a couple of years that will help us, but that is still a long time away. Whenever you get into the problem of drug abuse, you run into tremendous problems just in having people willing to consider alternatives. There was a very brilliant editorial in the Post recently about the free distribution of drugs. That gets rid of everything in the way of the supplier and knocks the props out of immoral governments in South America. However, I don't think that you are ever going to sell that idea to the American people.

Look at the difficulty in getting them just to discuss the possibility of clean needles, let alone to not make it a crime.

I would like to tell you a couple of anecdotes that I think are worthwhile. The Scottish experience can teach us many things. The Scottish Department of Health is under the UK, but is rather independent. The Health Department decided to try a clean needle experiment in three cities. All of the cities have a pretty homogeneous cultural and ethnic composition and are within one-hour driving distance of each other. The cities were Dundee, Glasgow and Edinburgh; the plan was for addicts to exchange their dirty paraphernalia for clean equipment.

Now, in Dundee, the program never got off the ground because the physicians in that town said, "It is immoral to aid and abet an illegal practice. So, we will not take part in it,"

and it never started. In Glasgow, the drug addicts said, "It is a great idea. We have heard you. We will do it, but we are not going to be labeled as IV drug abusers in the public eye. So, we will buy our own equipment in the pharmacy." You can do that in Scotland. You cannot do it here. In Edinburgh they lined up in queues in front of the dispensing office like they were getting on a bus. They went in one door, and out the other with their stuff, and listened to the message. The great difference between that experience and ours is literacy and illiteracy.

In response to the questions of transferring that kind of information to our country, I think it is hazardous. I am very impressed with what was done in Amsterdam, but that is an entirely different drug population than you find in Newark or New York or the District of Columbia or in Miami. One has to be extraordinarily careful in not stating a program until you have tried it out in your own ethnic backyard to see how it works. It must be pilot-tested, well-monitored and evaluated before you say, "This is what we should do." One of my great concerns about the New York experiment is where they find their volunteers to go into the free needle program. I don't think you should approach a person waiting in line for Methadone treatment. That person has already made the commitment to kick the habit, and is willing to go into a program. To approach that person and say, "Hey, I have got something neat for you, some clean needles. You can go back to what you did before, and you won't get AIDS." I think there is a certain immoral twist to that.

I don't think that I am in a position, sir, to have the knowledge to tackle some of those other things you mentioned about taking this problem out of the criminal justice system. I would say one thing in conclusion. I don't think many people realize the reason that the United Kingdom can go into a clean needle program and can deal with things apparently much more quickly and efficiently than we can is based upon two separate concepts about drug abuse. The UK has always dealt with drug abuse as a health problem that had to be dealt with by health people. We have always dealt with drug abuse in the criminal justice system, and we in health are Johnny come latelies to a well-engrained system, and it is going to take a long time before we are able to mesh our objectives and our goals.

DR. LILLY: May I just ask one very simple straightforward question? If the possession of injection equipment were simply to be legalized, do you think that significant numbers of people who would otherwise not have taken IV drugs would do so?

DR. KOOP: I rather doubt it, sir. I have talked at great length with the Minister of Health of the Netherlands about this. Their great concern was because they have so many itinerant drug abusers in Amsterdam that if they made free

needles available to everybody, a lot of people would take up the habit. They found that was not the case. They did not do that.

DR. LILLY: I wasn't thinking of free needles, but simply making it legal to buy them in the drug store.

DR. KOOP: My answer is still good because if they don't do it with free needles, they won't do it with the kind they buy.

CHAIRMAN WATKINS: Ms. Pullen.

MS. PULLEN: What do you think is the appropriate form and message of AIDS education to first graders?

DR. KOOP: I think first graders are told answers to their questions. Toddlers begin to ask questions about themselves, and the questions are the same until they are 6. There are only two: Where do I come from? Why do I look different than my brother or sister? I think those can be answered very frankly by parents without telling children more than they want to know.

I think that you start a first grader with an understanding of his own body. They need to understand it as something that is marvelously made, that it needs to be respected, and that other people have bodies like that for which they should have great respect. You can play games with kids at that age. There is one that I think is worth mentioning. It is a game played by youngsters in kindergarten. A teacher designates five children to carry out the roles of a mommy, a daddy, a baby, a doctor and a nurse. This game is played just before dismissal with the idea that children will go home filled with their subject and tell their parents. The parents can then add their ethical, moral or religious perspectives.

The game that they play has to do with the birth of a baby. Many kindergartens have a plastic tunnel through which kids run and play. On the occasion of this game, it is called the birth canal. Mommy and daddy put a baby in one end of the birth canal, and the doctor and nurse take it out at the other end. The doctor and the nurse give the baby a sex and a weight, andthe mommy and the daddy give the baby a name. Everybody has a good time, and they go home.

The point is, that when they get into the third grade and begin to learn some anatomy, and are talking about parts of the body in medical terms and they come to a new word, such as vagina, it will not be something frightening or dirty or threatening to them. It won't be because they say, "Gee, I know what that is, that is the birth canal. Remember, we walked through it when we were in kindergarten."

MS. PULLEN: What do you think is appropriate AIDS education for third graders?

DR. KOOP: Third graders? Talking about parts of their anatomy. However, no matter what you do about teaching anatomy in the third grade and about reproduction in the fourth and fifth grade, you always have to do it, as mentioned earlier, with an emphasis on respect for one's own body and other people's bodies. You talk about relationships between the sexes in the family context and in the context of loving, kind, caring and considerate relationships.

MS. PULLEN: What about the sixth grade?

DR. KOOP: By the time a child gets to the sixth grade, the child is 12 years old. What you say is going to be old hat because the child has already heard it many, many places and has read about it in every magazine article which glorifies sex. If you aren't sexy, you don't make it in this country according to advertising. In addition, the child has seem problems of human relationships depicted on television. Studies done on this in our own department, have revealed that a child in the sixth grade gets to see sexual intercourse depicted or talked about or mentioned by innuendo about 10 or 12 times in the course of a day -- and that is in relatively modest places like Michigan. Therefore, we are hiding our heads in the sand, if we don't realize that our children have been exposed to a kind of sex education to which we wish they weren't exposed. My concept is that if you can counterbalance that with family input and responsible understanding of their own sexuality, you might be able to blunt some of those things you would rather not have them know.

MS. PULLEN: Do you have any concept of AIDS education in terms of a general more broad context of health and wellness and personal responsibility or is it just about parts of the body?

DR. KOOP: No, everything that I talk about in reference to health from a public health point of view is to maintain wellness, and that is wellness not only of body but of mind. Mental hygiene is tied into all the things which you are talking about. It is not specifically just to tell people, "Don't do this, and you won't catch that," but it is built into an entire concept of wellness and how people can stay well through personal responsibility. Being as old fashioned as I am, I build that into family context that have to do with love, consideration and marriage.

MS. PULLEN: What are the public health strategies that should be used in the face of this epidemic, other than

education in public schools and posters on subways and that sort of education program?

DR. KOOP: We have the obligation, which I think we are satisfying, of providing educators with everything that they have to know about the problems of the epidemic of AIDS, or the transmission of syphilis, or hepatitis, or anything else. We are not educators. We don't claim to be experts on that matter. We do, however, have the obligation to provide pedagogues with the information so they can use their skills to turn the information into the proper type of teaching approaches for different ages.

CHAIRMAN WATKINS: Dr. Lee.

DR. LEE: Dr. Koop, two broader questions. First of all, much of our task has been trying to unravel bureaucratic problems for the agencies, trying to speed things up in many different ways. I won't delineate all of the problems. You know them. Why, given the percentage of the budget of the health industry in the United States and the magnitude of your job. isn't the Surgeon General a member of the Cabinet? Why isn't he split off from Health and Human Services? Do we need that additional bureaucracy on top of you?

DR. KOOP: Nobody every asked me that question before. The Surgeon General has never been the same in any two successive 4-year periods for many, many years. I have been a more visible Surgeon General than most people remember for specific reasons. I will go backward to show you why. My predecessor, Dr. Julius Richmond, had two impossible jobs at the same time, Surgeon General and Assistant Secretary for Health. I don't know how you could do either one of those well, if you had the other over your shoulder. There was no Surgeon General for 8 years preceding Dr. Richmond. There was an Acting Surgeon General. This was during a time when certain parts of government were trying to get rid of the Corps whose uniforms I wear.

Before that time, the focus of the Surgeon General was much narrower, and that is decided upon by whomever happens to be the Secretary of Health. Nobody has had the freedom that I have had since about 1966, and I have been in that position for a number of reasons. First, it took a long time for me to be confirmed. Therefore, by the time I was confirmed, it was November of the first year of this President's Administration, and people sort of forgot I was still waiting in the wings. Plus, nobody told me what my job was. So I did what Secretary Schweiker said to do. He said, "If you see any balls out there that you want to pick up, do so and run with them," and I did.

Second, I am the kind of a person who is in a sense a poor loser. If I undertake a problem, I try to wring it dry.

Third, I happened to be standing on the right street corner when AIDS came along. When the President asked me to do an AIDS report to the American people, I became the spokesman almost overnight.

That is far and above what most Surgeon Generals do. I am fond of saying that the Surgeon General, by law is mandated to do only one thing, inform the public of those things they can do to promote good health an tell them what they can do to prevent disease. That is the only mandate I have from Congress, except to be at certain places at certain times as the Surgeon General.

I think that it would be great to have a Surgeon General who was freed from any kind of political duress who could be, in a sense, an apolitical health officer who stuck to that job of communication. I think it is a very important role. People appreciate what I am doing because I have not politicized the health issues of the country, and I have tried to do the job with integrity.

I don't see that a person in that type of position should ever be on the Cabinet. There is already a member of the Cabinet who is given the responsibility of health and human services. If you want to talk some time about whether that job should be divided in half with a Secretary for Health, and a Secretary of Human Services, I have some opinions on that.

DR. LEE: That was my question, but I won't press you further. I will defer my second question in the interests of time.

CHAIRMAN WATKINS: Dr. Koop, it is 10 minutes until 10. We don't want to impose on your time beyond the scheduled hour. On the other hand, I think that from the Commissioners' point of view, we would like to continue with the questioning, certainly get all the Commissioners in, if your time permits. So, could you give us some idea of how much time you can spend with us?

DR. KOOP: If I don't get in the car by quarter after 10, I am in trouble the rest of the day.

CHAIRMAN WATKINS: Okay, we will only go to 14 minutes after 10 then, and I would like to shift all the way to the right then with Mr. DeVos.

MR. DEVOS: I respect what you are saying and what you are doing. I guess my concern in this whole problem, Dr. Koop, is that we have vehicles for the schools, and we have vehicles for reaching children, for their family involvement. Our whole problem is with the other 10 percent. We don't have families that dropped out of schools at early ages, and at Ford Hospital in Detroit, you know, they said, "You had better get them by the

third grade or they won't be around by the fifth grade anyway." It was staggering disappointment to find that the schools just aren't reaching the ones who are the problem area, and I guess I am looking for a methodology to reach those, and we are struggling with it together. Your insights on all of that are most helpful.

DR. KOOP: I struggle with those things, too, Mr. DeVos. I have said in reference to the household mailing, which has gathered so much publicity and impetus, that the real people we are trying to reach don't have mailboxes.

MR. DEVOS: We just have to keep finding them, keep looking, I guess.

CHAIRMAN WATKINS: Dr. Primm.

DR. PRIMM: Surgeon General Koop, you noted that the CDC predicts that in 1991 5 percent of the diagnosed cases of AIDS will be among heterosexuals, and I wonder if you could comment on that in view of the fact that there is an 11 to 1 ratio when comparing white heterosexual cases with black heterosexual cases. Aren't you alarmed about that? Has the Public Health Service done anything to focus on that issues? and could you give me an estimate of the number of blacks and Hispanics and unknowns that will be so affected in 1991?

I have another question. It has been mentioned in the media that you had suggested testing college students for the presence of the antibody to the HIV. Would you comment on that for the Commission?

DR. KOOP: Yes, sir. In reference to the disproportionate number of AIDS patients in certain minorities, I have been trying to address this as a spokesman for public health for a year and a half by calling attention to the fact that whereas blacks make up about 12 percent of our population, they make up 24 percent of our AIDS patients. Hispanics or Latinos make up 6 percent of our population but 14 percent of our AIDS patients. you could break that down into other groups like black and white homosexuals and the babies born to mothers who are HIV positive. My point in doing this is to call for a response from the black and Hispanic communities with whom I have worked to the best of my ability. I traveled to Boston several nights ago and spent time with some prostitutes and some former IV drug abusers who are HIV positive. All were black or Latin. We were trying to find ways that we could get the message out to those who could prevent the spread of this disease by changes in personal behavior.

In my days in Philadelphia as a pediatric surgeon when I wanted to get a message across to the black community that didn't seem to be absorbed, I went to the clergymen, and they

were marvelous. For something like immunization of children, they said it, and it happened. They are a little reluctant to get involved in the problems with AIDS. Everything that the public does or thinks about AIDS is affected by three overlying elements of this problem. One, in spite of all we know about it, it is still very much of a mystery. Two, it has 100 percent fatality. Those two things make people uneasy. Three, and most importantly, people get AIDS by doing things that most people don't do and don't approve of. Therefore, black clergymen hesitate to get down to the eyeball-to-eyeball situation with IV drug abusers and homosexuals. I think we have got to overcome that. I think we need black doctors, Hispanic doctors, entertainers, sports figures (especially those who are role models for your people) to pick up this effort and do something with it.

As far as my talk about testing at colleges, that has been greatly misinterpreted and overblown. I started this discussion back in the summer of 1987, when we were trying to get a handle on the prevalence of HIV in certain groups of the populace. We talk about heterosexual transmission. We talk about sexual promiscuity in college people. One of the things that we thought it would be a great thing to do is have an AIDS awareness day on an urban campus of a major university, say 30 to 35 thousand students, and have so much hype that everybody joined in. In a sense those who didn't want to be tested would be embarrassed into being tested, totally anonymous. It has nothing to do with the health of individuals but to help us answer questions that you ask, such as what is the prevalence of HIV in college people. It was a purely public health gimmick to get an answer.

DR. PRIMM: My question was more on the prediction of the number of black heterosexuals in 1991. If you predict that 5 percent of the total number of cases in 1991 are going to be heterosexual cases, I would think then if there is an 11 to 1 ratio between blacks and whites now, that in 1991, that number is going to be even more enormous.

DR. KOOP: I would agree with that.

DR. PRIMM: Unless we and the Public Health Service, me in my position here on the Commission, me in my position privately in New York and everywhere I go to speak, if we don't speak out about that, we will not be prepared. I suggested that to you so as to try to convey a message that we need to prepare whatever health delivery system there is for this onslaught of cases and to, like you say, involve the clergy, sports figures, celebrities or whomever else. I just need that being said from your perch.

DR. KOOP: I have said it over and over again from my perch, sir, but I have gone one step further. I made allusion in my prepared remarks to the fact that we would be spending between 3 and 5 billion dollars in 1991, for only 145,000 people. Twice that many die every year from smoking which is still a major public health problem. This is our greatest challenge. But the thing that I have been concerned about, sir, as I said in my report to the public in October 1986, is that the day will come when this epidemic will impact upon everybody in this country in some way, certainly as taxpayers. New York City is going to feel it this spring, when the beds run out. My great concern is that so many of the civil rights that blacks and Latinos have struggled so hard with some of us to obtain are going to be threatened when people say, "Why am I not getting the health care that I want for my child?" and someone says, "Because those beds are all filled with people of minority groups who have AIDS," and I think that is what you and I are both concerned about.

DR. PRIMM: Yes, we are. Thank you so much, Surgeon General Koop.

CHAIRMAN WATKINS: Dr. Walsh.

DR. WALSH: Dr. Koop, before I pose my question, I certainly want to commend you for what you have done in regard to AIDS because as you well know, when you step out front, you get the heat with the praise, and you certainly have taken both in stride. I think that in addition to bringing AIDS to the attention of the American public your forthrightness, has made some of our foreign colleagues in Western Europe be much more forthright in dealing with AIDS. This is a tribute, I think, to your own tenacity in facing this problem.

DR. KOOP: Thank you.

DR. WALSH: I want to commend you for what you have done, not only here but for all over the world. The thing that distresses me that I wanted to ask you about is that education for the next decade is probably the only and best weapon that we have. There have been discussions and arguments about the best ways of education. Two years ago, mailing out the report that you referred to, would have been effective for awareness. Today it is not going to reach the people, as you say, that it is most important to. We are down into a resource allocation situation in combatting this disease, and we have responsibility of making some recommendations.

What is really, in your opinion, that status of the preventive educational program that is going on in the United States? I am not talking about what we should be doing or what we may be doing, but if you had to grade the preventive educational program -- it seems to me we are not doing well

enough. I am not sure why. It is not because you haven't tried. What can we do to make it better?

DR. KOOP: Let me back up to where you said that you don't know why. A month ago, as many of you know, I attended the Summit of Ministers of Health of 193 countries. Over and over again I got the same criticism from people in Western Europe - we weren't doing enough, and we weren't doing it right.

I heard that all of my surgical life from those same people. I would like to call the attention of the Commission to the fact that it is extraordinarily difficult to reach 240 million people in the melting pot of the world with all of the problems that our freedoms have brought us. You compare that to a Scandinavian country who population is as big as the city of Philadelphia where I practiced surgery - they all speak the same language; they all go to the same church; they are relatively docile people. But, they have also been exposed to all kinds of freedoms in sexual matters for several decades. It is a very short jump for them to go to the kind of education that many people object to in this country.

I don't know the answer to your question. If I were to give us a grade on where we are today, I would have to give us about, on the basis of 10 at least 75 to 80 percent. We are at the present time following the mandate of Congress and preparing a household mailing for the people of America. If you want a real job sometime, try to get everything you would like to say into something that will fit through a letter slot and not be criticized by half the country for what you said and the other half for what you didn't say. By the end of June you will be able to make that judgment for yourself.

DR. WALSH: Now, in measuring the success or failure of it, you alluded to the increase, for example, in venereal disease, syphilis and so on. We have been hearing the projection of seropositivity in the United States of 1-1/2 to 2 million and I realize it is difficult without mandatory testing and that type of thing, nor am I advocating that, but has there been any evidence that new seropositivity is increasing despite our educational efforts? I am not talking about any one group. We know in the homosexual group it has come down. We know that what we are reading about in the minorities. Has the overall figure changed?

DR. KOOP: The answer to your question is no, Dr. Walsh, but it is too early to give you an answer. You see, we are talking about that 36 percent increases in penicillin resistant gonorrhea and infectious syphilis in the first 6 months of 1987. You are not going to see the results of that, as far as HIV is concerned, for at least 3 years but more likely 5-1/2. That is why I keep having this great hesitancy about supporting

people who say, "Don't worry about heterosexual spread." We just don't know.

DR. WALSH: But you do have a fear that it may well be increasing, but it hasn't surfaced yet?

DR. KOOP: That is right, because of the long incubation period.

CHAIRMAN WATKINS: Dr. SerVaas?

DR. SERVAAS: Dr. Koop, you are to be lauded for all the good things you have done on tobacco and attacking that problem, and my question to you is are there any studies in progress that would provide that cigarette smoking is suppressive to the immune system? Should we advise our HIV antibody positive individuals that smoking might bring on ARC or AIDS more quickly? Is that fair? Then what could we teach the HIV antibody positive person to prevent the spread of AIDS besides telling them not to get pregnant, if they are women? All married couples cannot use condoms or there would be very few babies. How, without testing do you know which women to advise, "Don't get pregnant," so that we keep babies coming? From your perch, can you give more press to the "Don't get pregnant if you are HIV antibody positive message" if we are going to have 10,000 babies in New York by the year 1991? My last question is are there things that needle stick victims or those who are sex partners of antibody positive individuals can be taught, or are there any studies in progress, to keep these people from seroconversion? Do we know of anything that is being done in that area? Thank you.

DR. KOOP: The answer to your last question is no. The answer to your first question about tobacco and knocking out the immune system is that there is no scientific basis that would justify your recommending that. The other questions having to do with HIV positivity, especially in women, go back to what I said earlier about the lives that these people live. Most of the children who are being born today who are HIV positive are being born either to drug-abusing women or to the sexual partner of drug-abusing men. Although they may not be addicts themselves, they are living in that disjointed, fragmented life that addicts live. They are, therefore the category that I said are very difficult to reach with a written message. They don't congregate where you can talk to them. They don't tend to go places where you can pick them up before they make a decision to get pregnant. Again, it is one of those imponderables and a very difficult group to reach.

I do talk about the necessity for people who are planning to have a child to be certain that both partners are HIV negative. But again, I suspect that practically all of the

pregnancies that you and I are concerned about are both unplanned and unwanted.

CHAIRMAN WATKINS: Dr. Crenshaw.

DR. CRENSHAW: I have two questions. Hopefully we will have time for both, but the first is relating to the comments you made about heterosexual spread. I cannot tell you how much I appreciate them. I think we need to change the misleading impression that exists today that there is some question about heterosexual spread. I want you to correct me if I am wrong. While we talk about 4 percent in the heterosexual population the figure is really closer to 25 percent. If we look at the percentage of those who may have acquired HIV through prostitution or IV substance abuse that continue to be heterosexually active and add that to the 4 percent who acquired it heterosexually, we actually have 25 percent of the existing cases of AIDS in the heterosexual community. Is that correct? Would that be fair?

DR. KOOP: That is my judgment about it, Dr. Crenshaw, and I think there are so many things that we could talk about. For example, there is a whole segment of people who say, "The only way you are going to get heterosexual spread is if you have some kind of a lesion on the male or female genitalia or you have chancroid or you have the chancre of syphilis. I think people forget the poor health of the American cervix which is probably the entry of the virus in most people. As I talk to gynecologists, they are frightened to death about the spread of this disease because so many people have had a bout of Chlamydia. There cervices are raw. Gynecologists tell me that when they take a Pap smear the cervix lacerates and bleeds because it is so tender. If that is the case, the transmission should be very easy. That is why I think we have to hold our judgment about where we will be 5 years from now on heterosexual HIV positivity.

DR. CRENSHAW: The other good thing is that if people keep their concern level high, we may be able to influence the shape of the curve in the future.

The last question is that since most of us agree that sexual transmission is the primary mode through which this disease is spreading and although we have got all sorts of mixed input from surveillance and prevalence experts, there is one thing that they all agreed upon, and that was to have a self-sustaining epidemic, it requires that a person infect only one person during their lifetime. That is what I was told, and that struck me very deeply. I have hard you say in the press or I have read in the press that you have advised that those who are negative not have any form of sex with someone who is positive. I would assume that also means vice versa. What I would

appreciate some help with is the dilemma of giving advice like that which sounds very harsh for the quality of life of someone who is living an perhaps handicapping and crippling their libido severely and the other negative alternative which is taking even a small risk of having someone else who is infected. How are you dealing with that? What are you advising?

DR. KOOP: I don't think I ever said that, Dr. Crenshaw. There are certain things you don't say, and I think that is one of them. I go through a certain litany whenever I talk about this so that I don't offend people who would misinterpret an answer that I give as being the only answer I can give. So, I always say someplace in answering a question like that that the only absolutely 100 percent guaranteed way of not transmitting AIDS is to be sexually abstinent. I follow that by saying that that is not a bad rule for kids in school, AIDS or no AIDS. Then I say, "However, it is not a viable way of life for most people. But fortunately, there is such a thing as faithful monogamy." The way I put it is, "Find someone worthy of your love and respect. Give that person both. Expect the same in return and remain faithful to him or her and vice versa."

DR. CRENSHAW: Thank you.

CHAIRMAN WATKINS: Dr. Koop, to keep you on your schedule, let me say that we are very proud to have had you here with us this morning. You are viewed in this country and worldwide as the premier leader in the education and prevention effort with respect to AIDS. We would like to dialogue with you much more as our final report begins to be put together, particularly in this area. So, if that is permissible with you, I will reserve my questions and would like to generate that dialogue as we wander through these next very difficult sets of issues, including such potentially contentious areas as testing and its relationship to education. So, thank you very much for coming. As the senior at Cardoza High School was quoted in the paper as saying, "You tell that general dude we are glad to have had him down here."

DR. KOOP: Oh, they said that I was a cool dude. That is different.

CHAIRMAN WATKINS: Oh, that cool general dude. Thank you, Dr. Koop.

DR. KOOP: Thank you, sir, and I would be very happy to come back. Let me just say that having worked with you for a couple of years on your Panel for Excellence, when you got this job, I said, "He will pull it off," and you will.

CHAIRMAN WATKINS: Thank you, Dr. Koop.

Our next panel is an Overview of the Public Health System. The witnesses are Dr. Bailus Walker, President, American Public Health Association, Professor of Environmental Health and Toxicology at the School of Public Health, State University of New York at Albany and Dr. H. Denman Scott, Executive Committee, Association of State and Territorial Health Officials, Director of Health, State of Rhode Island. A very cordial welcome to both of you. Just before we commence in hearing your statements this morning, I would like to have Ms. Christine Gebbie, our public health official on this Panel, say a few words.

MRS. GEBBIE: Thank you. It is a particular pleasure for me to see the agenda that we have for the next couple of days and to focus in starting today on the public health system. As we found, I think, in earlier testimony looking the illness care system or the system for responding to drug abuse, it is important to understand the components of that system and how they work together in general before looking at how they can relate to a specific disease such as AIDS.

I think we are going to hear a lot today about those components, about how decision making is structured within public health and about specific program elements but, also, very importantly, about the diversity of public health in our country and the way it is particularized to each state and to each community within a state. I am impressed by the panel of witnesses that staff has put together that reflects some of that diversity. I am hopeful that we, as a panel, will gain considerable additional perspective on ways that that system can be strengthened and that diversity can be capitalized on in constructing programs that will prevent AIDS and that will work in all of the various localities in the country. I do look forward to these 3 days of testimony.

CHAIRMAN WATKINS: Thank you, Ms. Gebbie. First then, Dr. Bailus Walker.

DR. WALKER: Thank you very much, Mr. Chairman. Let me hasten to commend the very progressive way that this Commission has carried out its responsibilities. Your vigor and your sense of direction is very encouraging to all of us.

Mr. Chairman, I specifically want to commend you for your progressive leadership of this important group. You may have my written statement. So, let me summarize it. I think it is very clear to even the most casual observers, that after all of the federal policy has been developed, and after all the technical advice has been heard and the regulations have been observed, it is at the state and local level of state and local health departments where the service is actually delivered. It is at this level that all the congressional deliberations and legislative appropriations and recommendations of commissions

such as yours, are reduced to their most common denominator: direct services to people and their communities. These services can be categorized in many ways. One can classify them as regulations, service and education. Another approach is to classify them as personal health services or health care, environmental health services and education. They are provided by a large group of specialists, including statisticians and epidemiologists, physicians, nutritionists, administrators, educators and a whole series of experts in a variety of health and disease problems.

While the state agency has primary lead responsibility for public health services, it is but one member of a very large and extended family concerned with health matters, and this family includes several other agencies in state government that carry out aspects of health services, as well as voluntary organizations.

There is a great variety of organizational structure ad functions in state health departments across this country. For example, in a number of states the state health agency is a subdivision of a super agency, which includes welfare, corrections and other rehabilitation services. In other states, the state health department is the mental health authority, and still in other states, the state health departments have responsibility for state Medicaid and other health care financing programs, as well as environmental protection.

Substance abuse and related addictive disease services are separate from other public health activities in numerous states. Two state health departments, for example, operate major biological production centers in which they produce their own vaccines and other biologics, and thus they were not affected by the recent shortage of vaccines.

At this point, it may be appropriate to ask is this variation in organizational structure and function bad? Not necessarily. I think it is fair to say that health activities and health problems vary from state to state, and the organizational responses must be suited to the real needs of a state rather than some mythical ideal model organizational unit. For example, several states have had to confront the issue of organ transplantation. Others have not. Some states have had to deal more extensively with the AIDS issues and toxic substance problems than have other states. In any rational rating of what measures have made the largest quantitative difference in the health of human population, I think those services or activities emerging from public health agencies would have to rate commendations of the highest order over those in a one-to-one medical care setting. But as public health needs of the nation and world have changed in the past several decades, so has the

mission and the scope of services provided by departments of public health.

For example, many public health agencies have had to become last resort providers of personal medical care, and this, to some extent, has drained away the vital resources from other population-wide services.

Turning specifically to AIDS, I submit that state health departments have had to confront a new maelstrom of social, moral, economic, legal, political and scientific issues unprecedented in the history of the public health service system, but reflective of the national interest. They have mounted a number of specific programs, and I would say pioneering programs in response to this epidemic. Permit me to list some of these.

First, state health departments have established more expansive systems of surveillance to provide the basic data needed to practice epidemiology, and those data not only helped the practice of epidemiology, but they have helped us to establish priorities and guided the allocation of resources and facilitated better targeting of services.

Second, state health departments have been very active in screening newborns, and these programs have provided information that we otherwise would not have had about the prevalence of the HIV in newborns, a most important piece of epidemiological information.

Third, AIDS patients with little or no health insurance are quickly impoverished by the catastrophic medical costs. State health departments have provided the leadership in creating networks of specialized care, quality insurance and emphasis on case management, and here, among the incentives for private sector involvement, have been adjustments in the reimbursement system. Many of these adjustments have been due to state health department involvement.

Fourth, from the beginning of the AIDS epidemic, state health departments have made a multilevel effort to educate the public about the disease, about personal protective measures, about facilities and services that are available for testing and counseling and care and to help the public put these into perspective. Health education is not a new activity of state health departments. It has long been one of our primary avenues of advance in the promotion of heath, and prevention of disease and dysfunction. Today several state health departments have a full complement of effective professional health educators and behavioral scientists. Fifth, AIDS has sharply delineated the importance of collaborative efforts and integrative action within and among agencies and organizations and the boundaries that tend to delimit them. Here state health departments have been a very

prime force in drawing together very disparate groups of organizations of the community for a cohesive approach to this problem.

State health agencies and state health policy makers and administrators are faced with an enormous task for maintaining this momentum at the service delivery front. Maintaining this momentum, will require several things. First, it is important that we continue to recognize AIDS primarily as a public health and scientific matter and that many of its dimensions should remain in the health and medical arena where the rules of debate are much different from those in the political arena.

The public interest is served best when AIDS and all the public health policies and programs are based on a scientific knowledge base and not on fear, prejudice, morality and political ideology.

Many public health agencies do not have the scientific or technical skills necessary to address the AIDS epidemic. Technical capacity at the state and local level is unevenly distributed. Some states and localities have considerable expertise. Others are seriously deficient. Resources are necessary for public health agencies to ensure that the necessary AIDS services are provided, either through the private or public sector, and to strengthen capacities to further understand the public health issues associated with this fatal disease.

Certainly, I would suggest that federal support for state level programs must be increased to help balance disparities in revenue-generating capacity and to encourage far more attention at the state level to the national AIDS program objective. The Federal Government, in my view, can do much to encourage federal linkage, coordination and cooperation among all components at the state and local level if it properly channels its federal resources.

Mr. Chairman, I think it is fair to say that at the state and local level there is the desire to effectively participate in altering the course of the epidemic. I think all state health officials are committed to this effort, and as President of the American Public Health Association, I can assure you that we are ready and willing to work with you and the Commission.

CHAIRMAN WATKINS: Thank you very much, Dr. Walker. Dr. Scott, we will hear your presentation, and then we will open the floor to questions.

DR. SCOTT: Thank you very much, Mr. Chairman. It is a pleasure to be here and I would echo Dr. Walker's comments

concerning the pace and vigor in which you are addressing this issue. I think for state public health officials it is an extraordinarily interesting time to be in this particular catbird's seat.

You should appreciate that the state health officer has a broad legislative authority to protect and promote the state's health, in a sense much broader than anything that exists at the federal level.

Let me just share with you the statute which we operate under in the State of Rhode Island briefly. "The Department of Health shall take cognizance of the interests of life and health among the people of the state, shall make investigations into the causes of disease, the prevalence of epidemics and endemics among the people, the sources of mortality, the effect of localities, employment and all other conditions and circumstances on the public health and do all in its power to ascertain the causes and the best means for the prevention and control of diseases or conditions detrimental to the public health and adopt proper and expedient measures to prevent and control such diseases and conditions."

So, there is the authority. I think it is very similar in many states allowing officials to seize an issue like AIDS and try to come to grips with it. Now, we cannot do it alone. We clearly need the help of the Federal Government, both from the point of view of gaining knowledge, expertise and money, but once you have the authority, how do you then, in fact, use it effectively? The health official has to do four things, basically. One is to define a public health agenda based upon the patters of morbidity and mortality in the community. Two, community concerns need to be listened to carefully as expressed by elective officials, individual citizens and professional and institutional groups. Three, to get this job done, surely it helps to have a very close working relationship with your Governor, whether you are a member of the cabinet, as in my situation, or part of an umbrella agency, as in other situations. The health officer, who brings a considerable amount of professional knowledge and experience, needs direct access to the governor. I have been very fortunate in working under both a Democrat and a Republican. I have had that access to both quite independent of any of the partisan wars which are a necessary part of our political fabric. You will be hearing, tomorrow or the next day, from my governor, Ed DiPrete. Rhode Island, in 1985, had only seven cases and no state resources committed to AIDS. Even with these low numbers, Governor DiPrete mentioned AIDS as an important problem in his 1986 State of the State Address. He proposed to spend $120,000, a modest sum, but symbolically terribly important. Now, in his new 1988-89 budget, he is proposing that we move to $3 million. So, we have gone from a nickel per capita spending to $3 per capita, which, in

association with federal assistance, will give us substantial support to deal with this problem.

Another crucial thing that we must do as health officials is bring current scientific understanding to the public health agenda. It is bringing this perspective into the middle of the legislative and public debates that is indispensably important in my view. We, also, have a very important function at the state level of convening key individuals and groups to work on the issues that are defined in the agenda. The agenda items need first to be defined rigorously in terms of scope. These key individuals then help garner the resource to deal with them, to implement the programs and eventually evaluate their effectiveness.

Then we have an enormously important task, which is operative at many levels, and I think we have heard Surgeon General Koop speak so articulately about the issue of educating the public at large, and one of the rubrics I operate under is really that in many ways we are trying to elicit concern where there is none. Then we are, also, very commonly trying to calm fear where it is excessive. We are also placing health issues into perspective with one another, which is a crucial function of public health education. I think we have all been properly obsessed with AIDS, but there are many other important concerns Dr. Koop mentioned smoking, but I'm thinking about environmental health issues. What do we do about pesticides and drinking water?

Now, let me give you just a couple of statistics here. If we just look at AIDS, we obviously and appropriately focus on the IV drug abuser, the homosexual male, and we are starting to worry about the heterosexuals, especially those who are mixing it up with drugs. But what about everybody else? We say that that is maybe not such a problem, and relative to the extreme statements, it is not. But I just came back a couple of weeks ago from a committee meeting on immunization in this country, and there is a big concern about the problems of reaction to pertussis vaccine. This is whooping cough. Now, with maybe 1 in 300,000 injections, you get a serious reaction. Some people think it is more, but that is a handful of children a year who may end up with brain damage as a result of that vaccine. I want you to keep that 1 in 300,000 figure in mind. Also, keep in mind that the cost of vaccines in this country for a child in the first year of life has gone from roughly $10 to $120 because we, as a society have said that we have got to pay for this through our tort system.

So, you should not get embarrassed about talking about big numbers. This business of going from 10 to 240 million just for vaccine costs to compensate five children or so a year is an incredible imposition of expense.

Consider what we want to gain in controlling pesticides in drinking water. There the benchmark is that we want no more additional deaths due to cancer -- 1 in 1 million over and above what we have over a lifetime. So, this means that the risk assessment models that are put forward are couched in very conservative terms.

Now, to move your pesticide level from, say, 100 parts per billion which might give you, say, 10 extra cancer deaths in a given community down to 10 parts per billion which would only be one death, is often an enormously expensive proposition. In the environmental health movement now, we are spending billions of dollars to mitigate these risks.

I don't argue against that. I think there is much rationale for it, but again, this is a matter of putting all this into perspective. So if I hear people saying, "Infection 1 in 10,000 people or 1 in 100,000 people is not a big problem," well, baloney. It is a sizeable problem when you contrast and compare it to the problem of vaccine injury or the problem of environmental health.

Finally, let me offer one comment on our relationships with the CDC at the state level. This has been, over many years, a very, very constructive business. Needless to say, there are communications problems, but CDC has provided technical assistance, financial support and free, easy access for many, many years and continues to do so in the context of the AIDS epidemic.

This relationship I am sure will flourish. It is now institutional, and it always needs to be thought about and preserved, but it is something that is really grand. Another thing that the CDC has done is recruit through the program called the Epidemic Intelligence Service, EIS, many health professionals, mostly physicians, who over the past 30 years have been pulled into the field of public health when surely they would have gone in other directions. I am one of those; it really introduced me to the State of Rhode Island for the first time, and I have circled back into public health, and I must say that it is singularly interesting. So, with that, let me close. Thank you.

CHAIRMAN WATKINS: Thank you very much, Dr. Scott. We will start the questioning from the Commissioners this morning from my right. Mr. DeVos?

MR. DEVOS: Gentlemen, as I understand the role of the public health positions you fulfill in either the national, local or state level, you are really more facilitators and coordinators as opposed to precise deliverers. Is that correct? In other

words, you don't actually run the hospitals? You coordinate between agencies, the political side, the financial side, and isn't one of your primary roles education and hopefully, raising the level of awareness of various diseases in your community so that these organizations can function?

DR. WALKER: Certainly one of our major roles is education, but I think we are, also, providing a wide range of services, and if we do not provide them directly, we try to make sure that they are provided somewhere in our state or in our community, that is in the private sector or the public sector.

MR. DEVOS: That is what I understand, but my question then is your emphasis on the need to communicate with the communities you represent in more efficient ways. We are working today on education here primarily, as well as prevention. You mentioned smoking. You mentioned all the various diseases. We make few inroads in some of them, make great strides in a few, but we are looking for models here that work on education that we could translate into action for other cities and states in this nation.

Can either one of you give us a model that you are using effectively in your community that is cost effective in getting the job done that relates to AIDS?

DR. SCOTT: I think that we don't have any model right now which has been evaluated. However, Governor DiPrete did use his influence as governor to urge that the State Board of Secondary Education to introduce a curriculum in all the cities and towns of the state from K through 12. Now, you don't just learn from state programs. You learn from messages coming from Washington, from all over the United States. What we really want to find out is whether our community is getting a fuller understanding. Now, we have two surveys back-to-back which shows that gradually people are learning about AIDS. There is still a lot of misunderstanding. There is still a lot of fear about casual transmission, but it is less so. So, we are beginning to see some positive impact on the public side.

MR. DEVOS: My only concern is that when you do find effective means that you communicate them to this body or to somebody that they can transmit that to the rest of the people. We have got to find cost-effective ways, and the sharing of that information will be most helpful. I thank you.

CHAIRMAN WATKINS: Dr. Walsh?

DR. WALSH: I have one question for each of you. Dr. Walker, we have heard form many federal and state health officers on the same sentiments that you echo and that is that AIDS is primarily a public health scientific matter and should be

treated, looked at in this way. Yet, the more we learn about this disease, we find there are tremendous amounts of societal, behavioral and environmental problems. Our interim report, which has received such praise, goes into everything, from building low-cost housing to expanding all sorts of things which are in the political arena. The Congress has at least 45 bills before it, most of which deal, not with the scientific and health aspects of AIDS, but with the fringe problems with it. I just want to be sure that I am not misinterpreting the phrase that it is "purely a health and scientific matter" that we have heard so often because it is obviously far more than that. Would you comment on that, please, Dr. Walker?

DR. WALKER: I think the point that we were attempting to emphasize is that the policy decisions and decisions that are made in the political arena should be driven by the science or the epidemiology of the disease, and we should rely on the scientific community to provide us scientific data. They now can translate it into policies and budget decisions. My concern is that this disease be treated as a public health problem and not be mired in the political arena where the rules of debate, as I said, are somewhat different from those in the scientific realm.

DR. WALSH: But given the geometric progression of the disease, as a public health officer looking at it purely scientifically, would this (if you did not think of the political significance and the civil rights and public issues) alter your approach to this disease in regard to confidentiality, testing and the like?

DR. WALKER: I am sorry?

DR. WALSH: Would it alter the commonly-held views that confidentiality must be preserved? Some of this legislation before the Congress doesn't even permit a wife to be informed if her husband is infected and there is a penalty if the doctor divulges that.

Now, my experience as a physician is that if you apply the purely scientific basis, then this is at some variance with what is commonly-held practice today.

DR. WALKER: But I think this disease brings a somewhat different dimension than other diseases we have had to deal with in the history of public health. The stigma attached to this disease is one that certainly we must be concerned about, and I think we, also, recognize that there have been some social actions such as discrimination in housing and jobs and other areas adversely affecting AIDS patients.

DR. WALSH: But is the stigma worse than syphilis? The end result is worse, we know. It is death. But is the stigma worse than syphilis?

DR. WALKER: It is at this point, in the course of this epidemic. In earlier days when we were dealing with syphilis there was a stigma attached. I am not so sure that we have that kind of stigma attached to syphilis now.

DR. WALSH: Okay, one question for you, Dr. Scott. You raised this point about the pertussis vaccine and I share the view that 1 in 300,000 is a lot when you get right down to it. The recommendations with which we are confronted include liability relief for treatment IND's, applicable to vaccines and others. Obviously if we get liability relief accepted for this one, there will be an effort to extend it to all vaccines. We know that one of the reasons for the high cost of vaccines is that liability has driven the production of them abroad. I think there is only one company basically making this type of vaccine in the United States today which drives the costs up. Do you feel that we are wise or unwise in seeking liability relief for this, with the implication that goes along with it?

DR. SCOTT: Dr. Walsh, I think that the liability problem in society is very broad gauged to be sure. The Vaccine Compensation Act, which passed a couple of years ago and has been funded this year with the vaccine tax, actually provides some liability relief for pediatricians in the administration of the vaccine. That is one of the main reasons I think they supported it. I have some trouble with this piecemeal approach to the problem and yet, I think that the impediment is so powerful to getting drugs and trials and vaccines going that it is important to the Commission to consider it.

DR. WALSH: To advocate it?

DR. SCOTT: Yes, to advocate.

DR. WALSH: Fine. I just wanted to be sure after your testimony because we feel strongly, fairly strongly about it. I don't know what other answer there is. Do you have any comment on that, Dr. Walker?

DR. WALKER: No.

DR. WALSH: Thank you, Mr. Chairman.

CHAIRMAN WATKINS: Dr. SerVaas?

DR. SERVAAS: My question is to Dr. Scott. You pointed out that vaccine accidents, I think you said, "One in 300,000 caused costs for each baby to be vaccinated to jump to $120." My

question is will we see costs of blood transfusions go up as those who get AIDS from transfusions bring legal action against blood banks? We have in Indiana a lawsuit against our local blood bank, and we, also, have two AIDS patients who had their transfusions in 1986, long after our antibody testing was in place. If a blood bank lets high-risk patients slip through, is this going to cost a great deal of the blood banks to reimburse those who received blood from high-risk individuals?

DR. SCOTT: I think already the cost of blood transfusions has been affected dramatically. I don't know if it has doubled, but it is close, largely because there has been a scarcity created because a lot of people are afraid to give blood. Much blood is being discarded, not only because of HIV positivity but because of new tests for hepatitis. If there are successful lawsuits because of HIV-tainted blood, the cost of such lawsuits will likely be passed on to the price charged for blood.

DR. SERVAAS: Do you have any knowledge of the incidence of suits like this in the country now?

DR. SCOTT: No, I don't. I think people have been screening the blood properly since the introduction of the test in March 1985, that is, screening potential donors, and this has been regular policy. They have been giving people an easy way to get their blood out of the system through questioning about high-risk behaviors and so forth. If those procedures are quire tight, they have done everything you can humanly do to screen the blood, and that would reduce the liability. This is in contrast to the time prior to the test, when many people were convinced that the blood was tainted, but we didn't have the test to provide it. Some people said, "Stop using it or use another alternative screening test." From that period I am sure some suits will emerge, and I imagine they are in court now.

DR. SERVAAS: Thank you.

CHAIRMAN WATKINS: Dr. Crenshaw?

DR. CRENSHAW: I will pass.

CHAIRMAN WATKINS: Mr. Creedon, on the other end of the table. Questions?

MR. CREEDON: This is a follow-up, in a way to the question that Dr. Walsh had addressed to Dr. Walker. You said that AIDS should be treated as a public health scientific matter rather than a political matter. I guess the question that we have been struggling with, to some extent, is what is the proper balance between treating it as a public health matter and recognizing the civil rights implications of areas, such as

confidentiality? I just wonder what your view is as to whether the proper balance is being struck now in the different activities that are going on in the various states in particular?

DR. WALKER: I think we are moving in that direction. We have more scientific information about this disease which helps the public understand many of the related issues. I think we are moving in that direction to strike a proper balance. We are not there yet, but I am very encouraged about the direction in which we are moving.

MR. CREEDON: Thank you. Dr. Scott, in the testimony of Surgeon General Koop dealing with the question of education, he stressed the fact that the educational efforts have to be directed toward particular groups. So, the homosexual community is one effort that needs to be made, and in the IV drug user community, it is a different effort, and in grammar schools and public schools and high schools and so forth. I wonder whether you have had any experience in Rhode Island, in particular, with respect to education of the IV drug users. If so, would you share that experience with us?

DR. SCOTT: Yes. We have a special testing and counseling site which serves primarily IV drug abusers, and we reach them largely in two ways - by their coming in voluntarily and, also, through some Methadone maintenance plans.

The very fine young woman who staffs this site is a nurse and despairs about getting the message out. She now (and I have met with her on a couple of occasions) is pessimistic about really how it can be done, and she doesn't know how, yet she is very much in touch with a number of these people.

The stupefaction that comes from using the drug and the drive to fulfill the craving represent an enormous impediment. I think that eventually, when the IV drug community which in some ways is fairly close knit in our state, starts seeing a number of their friends die, this will send a very powerful message. Then they will start talking about what is going to be of benefit and what they ought to pay attention to. They will be more sensitized.

Now, we are just starting to see a number of drug abusers die in this epidemic. We now have almost 40 percent of our cases falling into this category. But we face formidable obstacles. I don't have any real kinds of specifics to say, "Do this and do that." But being in touch with those who are in touch and listening to them is certainly an important source of information.

MR. CREEDON: Have you used ex-drug addicts on a one-on-one basis in an outreach program at all?

DR. SCOTT: We haven't, but we have plans. We are going to get extra money this year which will enlist ex-addicts and the like so we can really try to get directly to the people in a much more forceful way.

Now, we are more into the more passive recipient. If you come in, you get educated. We hope now to be reaching out more.

MR. CREEDON: Are there literacy problems in Rhode Island in the IV drug user community?

DR. SCOTT: We have a large Hispanic group, and there is some language problem there, but we do have people who know Spanish. Now, regarding the reading issue, I just don't know enough about that.

MR. CREEDON: Thank you.

DR. SCOTT: Could I comment just a bit about the politics, the question you asked Dr. Walker? To me, you are inescapably swept into the political dimensions of this, and I have felt it powerfully. I have been attacked vigorously from time to time by various groups, and you have to be steeled and prepared to debate. One of the things that strikes me is that there are two operating fears, principally, that we have to cope with. One is the fear of discrimination, especially on the part of the homosexual, so the stigma just isn't of terrible infectious disease, but it is the homosexual who, also, is being blamed by many for perpetrating this disease. So, it is a dual kind of tyranny and terror that they sense, and that has to be dealt with because if you don't start getting firm antidiscrimination statutes and protection under the law in place, that fear is going to impede our ability to deal with the epidemic, I think.

The other fear on the part of health care workers and other occupational groups is not only about getting the disease, but also if they are exposed in some way or another, not being able to find out if the person they were exposed to is, in fact, positive or negative.

We had a huge debate on that, and I think we are going to finally work it out. We have got every group - the occupational groups, the nurses, the doctors, the gay community, and so forth - to come up with a solution. If we can take care of those fears first in law and then in spirit and practice, we can move forward with a much more vigorous public health program than we have had heretofore. We have not used testing in the way I think we might have, largely because of these very real fears.

CHAIRMAN WATKINS: Ms. Gebbie?

MRS. GEBBIE: I have a question for each of you. First, Dr. Walker. We have heard over the course of our previous testimony from other professional associations about concerns that only limited numbers of their members know enough about AIDS to be comfortable caring for patients, to willingly accept referrals or to serve as community resources. We have discussed that about doctors, nurses and dentists from time to time. Could you comment on your sense of the APHA's membership, that is the broad cut of public health workers? Are they having some of the same fears and potentially discriminatory behavior in their work? How far are they toward being ready to be a real part of the prevention process?

DR. WALKER: I think some of those concerns are being addressed. Many of the affiliates of the American Public Health Association are holding regional conferences and regional seminars designed to help the health professional. People who are practicing on a day-to-day basis understand the dimensions, but I am not convinced that we have reached all 50,000 members of the Association with that message. So, there is still a group out there that has some reluctance about serving patients, with a lack of knowledge,, but we have an aggressive program under way to try to reach all of the practicing health professions.

MRS. GEBBIE: You haven't done any sort of membership-wide survey to get a feel of attitudes? What is your basis for planning those education programs.

DR. WALKER: I think the feedback that we have gotten from our members, in fact, we got some feedback at our annual meeting in New Orleans last fall indicating a real need for more information to filter down to health workers who are practicing in the field. That is why the Association in its headquarters here in Washington has moved this to the top of their priority list and are working aggressively to provide that information.

MRS. GEBBIE: You read the Rhode island mandate which is a very broad one. What I often hear from people once they have heard that kind of statute is something on the order of "then why didn't you get up and do something about this epidemic?" In the minds of many, official public health agencies were very slow to get involved. You have already talked some about that, but I would appreciate some more discussion of this appearance of inaction that some people sense in the public health community and whether there is a real reluctance to use the powers that exist legally?

DR. SCOTT: I think to use those broad powers you have to have a sense of agreement that you have applied them wisely and fairly because if you don't, you won't have any opportunity

to exercise the authority in the future. So, in a low incidence state like Rhode Island, one convenes key community people and explains the scientific issues and the nature of the epidemic. One sensitizes the governor and the legislature to these issues and says, "Look, this is going to be an issue. We are going to have to have resources," and then things start to take off. I think in Rhode Island we were in the relatively luxurious position of saying, "Look what is happening out there to other areas of the country," and so, we could say, "Let us get ready," and I think we have. We have been a little dilatory here and there. Those who were on the cutting edge of the epidemic really didn't know what was going on. It was so frightening, and in that remarkable book, And the Bank Played On, the whole political problem of using the authority was beautifully illustrated. You have to have a receptive community to use it, otherwise you are out.

CHAIRMAN WATKINS: Dr. Lilly?

DR. LILLY: I have a few questions. I would like to go back to something you said a little bit earlier, Dr. Scott about the need for discrimination statutes. As I recall, a few months ago, Secretary Bowen expressed reluctance on the part of the Federal Government to tackle the problem of anti-AIDS-related discrimination issues on the federal level, feeling that that should be left to the states. Could you comment on that?

DR. SCOTT: From my particular state viewpoint, I do think it is important for a state to address it and take it very seriously, in and of itself as an important recognition that we want to discuss discrimination in our society. But, also, the benefit here, is that by so doing, we can deal with AIDS in a more wholesome way. As to whether it should be dealt with at a federal level, there is certainly ample precedent for federal civil rights legislation. There are a variety of statutory provisions, as I understand it, which would protect people under federal law. But every state, I believe should seriously grapple with the question and if the Federal Government sees that it is not being addressed or is being stepped away from in various states, I think that would be a greater prod for federal action.

DR. LILLY: I, on that issue, am very interested in the idea that in the workplace we now have statutes that protect people against discrimination on the basis of having AIDS. They are considered to be handicapped. On the other hand if I, as an employer, have a gay man who has or is thought to have AIDS or be HIV infected, I can perfectly readily get rid of him by firing him because he is gay. There is nothing that says that I cannot do that. That is something that worries me a great deal.

Another quickie question, do know how many HIV positive people there are in the State of Rhode Island?

DR. SCOTT: My guess is, we have done the same kind of coordinate study as the --

DR. LILLY: So, it is a guess?

DR. SCOTT: It is a guess, but we do have seroprevalence data from a variety of sources, and then, trying to estimate the size of the various populations, we come up with between 4 and 5 thousand.

DR. LILLY: Do you need better data than that or is that adequate?

DR. SCOTT: Absolutely. I think that one of the questions that came up with Dr. Koop is, will we really know whether we are successful or not by the rate of occurrence of new infections in the community? So, in some way or another we need to find out what the annual new incidence of infection is. Because the incubation period is 5 years, the only way to do that is to put groups under regular periodic serological surveillance.

We just have no idea, as far as I know, anywhere except for some very small cohorts in San Francisco and maybe New York, as well.

DR. LILLY: Are you able to plan to get that information? Are there barriers to getting that information?

DR. SCOTT: Oh, yes, I mean the whole milieu around testing is an enormous impediment to it. I think out tendency now to go through all this anonymous stuff is really peculiar because when you do come up with a positive, for God's sake, you cannot get to the infected persons and advise them of their positive status, and the implications of, one, how they should conduct their lives, and two, what kind of medical surveillance they ought to be under.

So, we are doing all these anonymous surveys all over the United States in which we identify hundreds of people and have no way of getting to them to advise them, other than saying that we have voluntary clinics where they can come for help. That seems to me to be a screwy way to tackle the problem.

DR. LILLY: One last question, you have a budget for AIDS. I think you said that it was $3 million or whatever.

DR. SCOTT: We hope it will be $3 million.

DR. LILLY: I was wondering, what are the criteria that you use in deciding how to allocate that budget?

DR. SCOTT: There were two. One was our internal departmental sense of how rapidly we could reasonably expand the effort and not just throw the money away. So, if we are going from a budget of roughly $400,000 to $3 million, an eight-fold increase in one year, a major gearing up is required. The second is that the governor, did not say to this AIDS Commission which was created last fall and which I chair, "You guys tell me how much you need?" I mean, then the cookie jar would be just a little bit too big. Instead, he said, "Let us think about a number of 3 to 34 million," and that is how it came about. It is not very scientific, but that is how it was.

DR. LILLY: No, I meant once you have the figure, how do you decide how to allocate it, how to spend it?

DR. SCOTT: Oh, I didn't understand. We have put together a very broad-gauged AIDS advisory council which is the governor's appointed council. It has now been rigorously deliberating how to shape that spending tactic. The majority of it, roughly $2 million, would be devoted to prevention and education. The smaller million dollars would begin to shore up shelter and home care services, which are lacking as opposed to acute care which is really quite satisfactory.

CHAIRMAN WATKINS: Dr. Lee?

DR. LEE: My two main questions have been delivered by Dr. Walsh and Mr. Creedon, but let me amplify just a bit. I am happy to hear your attitudes about your responsibilities as public health officers and that you are not abrogating those responsibilities in dealing with a fatal infectious disease. It has always seemed to me to be a screwy way to operate from a public health point of view. I had been wondering, and I have been listening to you talk, and I am getting the answers to how you sleep at night with the decisions that have been made up until now.

The liability, I can assure you, remains a tremendous concern of ours. We are going to hold a lot more hearings on it, and we are going to coordinate our activities with, I believe, it is the AMA or the IOM who is holding a conference along these lines, as well.

One final thought to back up Frank Lilly, and I don't want an answer. It is just because it has no answer, but it is a difficult problem. If the gay population was assured of quote, equal rights, end quote, we would have much less of a problem with this discrimination business and much less of a problem with everything else we are talking about . Would you agree or not?

DR. SCOTT: My sense is that giving legal protection is a crucial first step. Then it is a matter of getting to people

so that their hearts can be purged of some of the hatred which is operative here. Now, that can come about by seeing people suffer with AIDS -- one-on-one human contact. The more we can foster that, the better we can deal with it. You have got to have that basic, fundamental legal protection to start with, and that will go a long way.

CHAIRMAN WATKINS: Thank you. Do the Commissioners have any additional questions before I have questions of my own? Would they like to continue? Yes, Ms. Gebbie?

MRS. GEBBIE: One other question, really for either or both of you, and that is the question of whether AIDS is distorting the public agenda. Are we doing so much on AIDS, we are forgetting other things? It sometimes gets mixed up with the question of whether if we conquered AIDS we would, also, conquer several other problems on the public health agenda, such as elimination of sexually-transmitted diseases in general or elimination of teen-age pregnancy in general.

Could you comment on that overlapping or distortion question? Are we doing enough to look for those common issues and to strengthen a broader public health agenda or ought we not try to do that? Is that only confusing the issues more?

DR. WALKER: No, I would agree with you that if we can address the AIDS problem, we can address several other problems, and I draw an analogy between that of treating the water supply. If we treat the water supply, we can eliminate a large number of disease-producing organisms, and I think if we address the AIDS question in a very effective and comprehensive way, I think we will address the teen-age pregnancy problem and some of the other related issues.

MR. CREEDON: I have one more question.

CHAIRMAN WATKINS: Yes, Mr. Creedon.

MR. CREEDON: My question is a related question, but dealing with the issue of discrimination. There is a federal law that presently prohibits discrimination with respect to disability in employment, for example. The discrimination issues that we have heard have related specifically to AIDS. Any legislation, should it be specifically addressed to AIDS or should it be more general discrimination legislation, having other implications, as well as for AIDS?

DR. SCOTT: Let me tell you what our AIDS advisory council has done on this. They came up with three recommendations. One, was that there should be specific anti-discrimination provisions concerning HIV infection. That in and of itself was considered important enough to single it out: two,

that there should be formal recognition of no discrimination against homosexuality, and three that the sodomy laws which still exist in our state should be repealed. Obviously, it pertains not just to homosexuals but to heterosexuals as well. If you want me to guess which way we will end up, I think that given the climate, the most likely statute to prevail will be anti-HIV discrimination. There will be certainly efforts, also, around the issues of homosexuality, and there is a broad coalition that is coming together to seek that. I don't know if it can happen this year in our legislature, and we are just right in the middle of it.

CHAIRMAN WATKINS: Dr. SerVaas?

DR. SERVAAS: I had a question, Dr. Scott. You talked about anonymous testing sites. How do you think that is trending in other states? In our state we still have anonymous testing, and it is hard to get a fix on how many times the same person has been tested. In California I asked these people how do they know how many HIV antibody positive people they have because they don't know how often the same person has been there. Isn't this a problem.

DR. SCOTT: Probably it is more of a problem in California than Rhode Island because we have a sense of whom the repeaters are, it being such a small community. But the anonymity does really create a lot of problems in terms of good surveillance. Still, the anonymity is awfully important, from the testimony of our nurse counselors and other counselors. They say, "Boy, a lot of these people wouldn't come in," and I really think that is probably true. It is also true that all the sexually-transmitted diseases have always created all sorts of problems and will continue to do so. But eventually we have to create a climate of trust with good legislation and good practice. That will allow us from a public health point of view to have this information, so we can chart the epidemic more accurately, and I think we will move in that direction, but it is a bumpy road.

DR. SERVAAS: Thank you.

CHAIRMAN WATKINS: Any other questions from the Commissioners?

DR. WALKER: I think there is still confusion when people talk about education as the most formidable weapon we have today, as to packaging it up in some way. In some minds, it is what goes on in the schools. In other minds, it is education of the health care providers which we have hit very hard in our interim report and which we think is the horse before the education care of the nation. What about the million youngsters each year that fall out of the high schools that aren't in the

mainstream at all? What about the people who are not in the workplace? We talk about AIDS education in the work place. What about those not in the workplace.

Do you have in your association with the other states in the nation any states that have dug into this think discreetly in a variety of modems of education? The cultural differences seem to make a great deal of difference, particularly if you get to the Southwest Region of the country and where there are a variety of cultures associated just with the Latino population alone, whether native born or foreign born, whether they are first generation or second generation. What is going on aggressively to package up educational approaches, so that the intervention strategies in education make sense as targeted to perhaps one dozen or two dozen different kinds of modems? Where do you see the leaders that we can go to and the states that have really done the best job at looking at these things in some sort of an organized collaborative with a variety of local and perhaps even city and state officials that would have come together to try to divine those strategies, particularly if they are going to be culturally relevant to the particular region of the country? One modem may be all right for New York and not be right for the Middle West. Who are the best in that field?

DR. WALKER: Mr. Chairman, I think you have raised one of the most difficult questions that we face out at the service delivery front. You are absolutely right. How do we reach people who are not in school, who are not in the military, who are not in the workplace, who are not in health care facilities? I am not convinced we have the answer.

CHAIRMAN WATKINS: Don't you think that is the most potentially high-risk area that we need to deal with?

DR. WALKER: Yes, it is.

CHAIRMAN WATKINS: It seems to me that we talk glibly about education, and we think in one term, perhaps those in school. We talked a lot about that today. I am, also, concerned that we are not focusing enough in our thinking about the variety of education concepts that we need to be really hitting hard on. I would like to really try to get specific to see if we cannot find where it is being done best today, along those lines.

DR. WALKER: I am sorry that I cannot identify a specific area where that had been done. Hopefully the National Academy of Sciences Commission on the Behavioral Aspects of AIDS will come forward with some recommendations as to what may be the best approach to reach some of these groups. I would thoroughly agree with you that a health education program in Detroit may not be effective in New York City, and I think we have got to take those differences into consideration and tailor make some

programs to try to reach these groups. I am not convinced that this broad-brush approach will be as effective as many of the proponents think it will be, and I am sorry I cannot say to you that community X has done this effectively. When I served with the State Health Commissioner in Massachusetts, we did find that small group discussions were very, very effective, and we had those group discussions with emergency medical technicians, with members of the gay community, with police officers, etc. We found that that was effective, but whether or not that can be used as a model for the rest of the country, I am not prepared to make that recommendation.

CHAIRMAN WATKINS: Can you give me any indication of where I might go? For example, on my desk in the office I have a number of recommended educational plans from states. The State of Maryland, for example, has put out a fairly large document which tailors educational programs for those in school at a certain level. What I haven't seen are the other documents that tailor educational programs to those not in school or not in the workplace.

We have good programs for AIDS in the workplace in many forward-thinking progressive businesses in the country. We have been formally exchanging views with them, and they are excellent in many cases, particularly several that come to mind in California that have really been very progressive since the early days and have been very effective in quelling the unwarranted fears that go along with this, in preparing the workplace, keeping the morale up and keeping the person on the job, being sensitive to their care, keeping them in the group health insurance systems and the like. We don't see anything coming across the board, it really is almost a one-on-one basis, like the kind of work that Dr. Primm may be doing in trying to intervene with IV drug abusers. But it doesn't seem to be a movement going to really focus heavily in that area.

I don't see conferences being held that really focus on that particular regime to try to come to grips with what those educational strategies should be. It seems to me more on the easy side of it rather than on the difficult side of it, in terms of any national conferences or coming together of the responsible groups.

So, I am still kind of probing for some help to try to lead us to some recommendations we need to make in that area because I really do believe there needs to be a lot more work done, and perhaps there is a role for the Federal Government to play to inspire that kind of educational approach. I don't know that there is. I am not talking curriculum so much as I am how do you get that ball rolling in a much more organized and disciplined way?

DR. WALKER: I think there are groups that are working on various approaches, at least testing various approaches. They have not published their results in the open literature yet because I think they are in the process of evaluating them. But the behavioral sciences community, I know is working very, very diligently, trying to come up with approaches to reaching various groups and models to educating Group X versus Group Y and educational programs in setting A versus setting B, the occupational setting being one of those, but that is --

CHAIRMAN WATKINS: Would it be inappropriate for me to ask you to go back and maybe within the next 30 days see if you can sample the water across the nation from your contacts with health through the Public Health Association and then write me a letter, giving me a little follow-up on that discussion to see if you might give me a better feel for how aggressive it is out there in selected areas or certain areas where you think there might be some merit to our taking a look a little more thoroughly at those kinds of strategies? Is that something that would be legitimate?

DR. WALKER: I would be most happy to do that. I will respond within the 30-day time frame.

CHAIRMAN WATKINS: Dr. Scott, you mentioned you were close in putting together the way in which to deal with the health care provider's possible need to know the sero status of patients. Could you comment a little bit further on that?

DR. SCOTT: Yes, one of the major concerns that was expressed by the front-line health care worker who works where there is lots of blood going in lots of different directions, and knows that there are a few people who have been infected, is what do I do if I am exposed? And then somebody says, "My civil rights tell me that I am not going to let you know what my status is." That is really troubling. Now, our first approach to this was to try to define whether the person's blood to which the health care worker was exposed was a person of high risk and that the high-risk criteria would have to be folded into some sort of epidemiologic and medical context. I then published some proposed regulations to say what high risk was, namely, a high-risk person would be considered a homosexual man, an IV drug abuser, a person with multiple sexual partners etc., the list we are all familiar with. Boy, oh boy, I really was cut off at the knees. I was accused of legislative treachery and breaking compacts and stuff, and I said, "What is the problem? How would you do it? What criteria would you impose?" This is right where we are in the discussion now. If, in fact, you are going to impose criteria, the epidemiology of somebody's background is inherently part of that decision. I said, "Why don't we do it this way? Look, let us forget about those criteria and recognize blood primarily as a dangerous substance in our society, and if

you are exposed to blood, that is the driving force for determining whether a person should be tested or not tested."

So, we are stepping away from saying, "Are you gay? Are you a drug abuser? Have you had 37 different sexual partners or whatever? " and saying, "If in the occupational health are a setting you are exposed to a patient, needle stick, blood splattering in the operating room or whatever, that would trigger a request for the person whose blood was involved to be tested. Most of the time the answer will be yes, but in the event that the person says, "no", a statute would come into play which says that this is a place where it is reasonable to override your rights in the interests of the rights of the health care worker. That would require a court order and whatnot, but that is our approach now and it has gained the acceptance of our gay community. It has gained the acceptance of our health care community, and we are not just going to say, "Health care." We are saying, "All occupations." It, also, stands away from the problem of intimate sexual exchange which is so personal. There has been the worry that if something goes awry, and one party get angry at the other, that they would say, "You have exposed me. I demand that I take you to the director of health and be tested." So, the personal transactions are out of this statute, and it will be along the lines that I described. I think that this will put into check that enormous anxiety that the health care worker would be left hanging out there without any protection. I hope I have made it clear.

CHAIRMAN WATKINS: Where do you stand right now in debating that particular statute in the legislature?

DR. SCOTT: It will be introduced this Friday into the legislative session. It has been vigorously debated in a large subcommittee involving all the constituencies of the AIDS advisory group. Then next week we are going to have the full council which is made up of 40 people further debate it. Then it will come up for legislative hearing. I have a sense it will pass. I mean, the big support is there.

CHAIRMAN WATKINS: Do you have any sense of where that kind of approach would have similar precedent nationally through the state territorial health officers perhaps? In other words, where do you stand? Are you out in front in the nation or are you doing something that is similar to a variety of other states, and if so, do you know how you stand relative to other states on this issue?

DR. SCOTT: This is so fresh in terms of our formulation that I haven't had a chance to share this with my colleagues like Kris Gebbie. You might know, Kris, whether other people have thought about this approach or not. I am not aware actually.

MRS. GEBBIE: I am not aware of a specific statute such as you describe. I think that the process you describe has been under debate in several states, and I had a follow-up question actually for you whether in your state the reciprocal side has come into the debate. That is, in hospitals in Oregon that have debated the subject, the question has been raised, well, if you as a health care worker have the right to override the patient's interest in testing and say, I need to know because you just exposed me." Does the patient likewise have a right to say to the health care worker who had just bled from a needle stick onto a patient, "I have a right to know your HIV status"? There ought to be a mechanism for communication both ways.

DR. SCOTT: No matter which way, if there is exposure to blood, that is the beginning of the whole discussion. Another part of it is that the health care worker who is exposed also has to agree to an HIV test, and that is logical for any number of workers' compensation issues and so forth. If the say that they won't play the game, forget it. So, that is part of the statute.

MRS. GEBBIE: I think this may be a leading edge debate in Rhode Island in the sense of having drawn on some of the ideas that had been discussed as policy in other places but moving it into statute and into fuller debate, and I think we could learn.

CHAIRMAN WATKINS: Let me ask, then, Ms. Gebbie, if you would pick up the burden of responsibility for the Commission to take a look at that across the country from your contacts, state and territorial health officers and see just where that sits, because it is a great area of concern right now, including such things as how do you treat someone? Is AZT, the heavy doses, for example, a protocol that might be utilized in such case to stem the transition of the virus into antibodies? There is some hope that there might be some sort of a procedure, protocol that could be followed under extreme conditions of health care provider exposure to infection. So, it just caught my attention when you where talking about it. It is something we had not heard before, and it seem to me within that, particularly if you are building something that has consensus within the state, that sounds as though it is somewhat precedent setting.

We appreciate very much both of you coming before the panel today. It has been helpful to us to have the debate. Thank you very much. There may be follow-up questions from the Commission to each of you that we would ask in writing. So, the dialogue should remain open for the remainder of the life of the Commission. Thank you very much, and we will recess now for lunch for the Commission.

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

AFTERNOON SESSION

CHAIRMAN WATKINS: The first panel this afternoon will consist of Dr. James O. Mason, Director, Centers for Disease Control, Assistant Surgeon General; Dr. Lloyd Novick, Director for Community Health, New York State Department of Health; Dr. Martin P. Wasserman, Director, Montgomery County Health Department; Dr. Lonnie Edwards, Health Commissioner, Chicago Department of Health, Chicago, Illinois.

The topic this afternoon will be the role of federal, state and local public health organizations in prevention efforts surrounding an epidemic.

Our procedure, panel members, will be to ask each of you to give your brief statements to the Commission first, and we will start first with Dr. Mason and move across the table, and then we will open the panel to questions from the Commissioners. So, with that, I would like Dr. Mason to commence.

DR. MASON: Thank you very much, Mr. Chairman and members of the Commission. I am happy to respond to the topic, the role of the federal, state and local public health organizations in prevention efforts surrounding an epidemic.

Our nation's public health system is built on a voluntary partnership of public and private health organizations, the former including local, state and Federal Government agencies. This structure, characterized by interdependence and cooperation has as its foundation individual physicians, local clinics and community hospitals.

In our country, the heart of public health action is at the community level. Preventive services are most effectively delivered at the local level. It is at the local level that illnesses are diagnosed and treated, and notifiable illnesses of public health importance are reported for national surveillance purposes.

The word "health" does not appear in our Constitution. The Tenth Amendment to that document states, and I quote, powers not delegated to the United States by the Constitution nor prohibited by it to the states are reserved to the states respectively or to the people, end quote.

The public Health Service Act states, and I quote, the Secretary (Health and Human Services) shall encourage, cooperate with and render assistance or other appropriate public authorities and promote the coordination of research, investigations, experiments, demonstration and studies related to the causes, diagnoses, treatment, control and prevention of physical and mental disease, end of quote.

At the federal level, the Secretary has general statutory authority to enact regulations to prevent the spread of diseases across state or national borders. However, the Federal Government has traditionally relied on the states, acting under their separate authority, to initiate appropriate action to control epidemic and other communicable diseases. Let me tell you how the system works within this framework. Each state has a commissioner or director of health and a state epidemiologist. Their jobs include statewide reporting of the occurrence of diseases. This is called surveillance. The states respond to county or city requests for assistance. They provide CDC with disease data which is published in the Morbidity and Mortality Weekly Report to share national data with everyone interested. States request assistance from CDC when it is required.

Let me provide an example. You may remember the Legionnaire's disease epidemic in summer 1976. It started as a widespread problem in Pennsylvania, and the local health departments called the state epidemiologist for assistance. Two CDC Epidemic Intelligence Service officers on duty in Pennsylvania started on the problem. Later that same afternoon an official request for epidemic aid assistance came from the Pennsylvania state epidemiologist to CDC. The Director of CDC called an evening staff meeting. A senior investigator was identified and relieved of ongoing responsibilities, and additional officers were sent to Pennsylvania the following morning. That investigation involved local health department personnel, local doctors, hospital assistance, state assistance and CDC assistance and backup, both epidemiologic and laboratory. As information about the outbreak and its spread became available, CDC kept all other state health departments informed. This was a classic example of how the public health is protected in times of disease epidemic.

To finish the Legionnaire's disease story, by January 1977, scientists in CDC laboratories had discovered the cause of the illness. Prevention measures are now well known, and the states handle most outbreaks of Legionnaire's disease without assistance from CDC.

Why does this system work to control the spread of disease? It works on the basis of mutual trust and cooperation that started 42 years ago with the establishment of CDC to control malaria in the United States. To do that CDC worked closely with the state health department laboratories for confirmation of diagnosis, with state epidemiologists for disease follow-up and in providing training for state and local health department personnel in disease control efforts.

Later we worked with cities and states in the 1950's and 1960's as the United States launched nationwide attacks on

polio. By 1966, CDC initiated a national program to control childhood diseases which could be prevented by immunization. The National Vaccination Assistance Act provides federal dollars to state and local health departments through CDC's Immunization Division. CDC monitors disease trends nationally and provides expertise in terms of professional public health administrators, medical epidemiologists and laboratory assistance. We receive the assistance of voluntary health groups and state medical society auxiliaries to augment local immunization initiatives. In 22 years through these cooperative efforts vaccine preventable diseases of children have been reduced to less than 2 percent of what they were in 1965.

How does all this fit into the picture of AIDS today? Although the AIDS epidemic has and will continue to be protracted, the response to the epidemic and the interactions among federal, state and local health agencies has been similar in many ways to most other epidemics.

In retrospect, isolated cases of the disease that is now recognized as AIDS began to occur in a number of cities, at least as early as the 1970's. In 1981, the first cluster of five cases in Los Angeles was brought to the attention of the local health department. After pursuing the investigation with the assistance of a CDC EIS officer assigned to the county health department, personnel from the health department submitted information describing the Los Angeles cluster to CDC. This was published in the MMWR on June 5, 1981, as the first report of this new epidemic. CDC contacted other health departments and physicians around the country to obtain information about other cases that might have occurred. The second MMWR report was published a month later. The third published in August 1981, reported a total of 108 cases. These reports represented a concerted response by the nation's physicians and local and state health officials. The efforts continued over the next 12 months to document the epidemic trends and to conduct epidemiological and laboratory investigations.

In September 1982, the first cooperative agreement was established to provide New York City, which had reported almost half the cases, with federal assistance to enhance their surveillance programs.

In Fiscal Year 1983, additional cooperative agreements were signed with the states and cities that had been most heavily affected by AIDS, and additional CDC personnel were assigned to assist at the local level.

In 1983, CDC worked closely with this Council of State and Territorial Epidemiologists to coordinate passage of a resolution at their annual meeting that AIDS be made a reportable condition. AIDS is now a national reportable condition in all

states and territories. Today funds from CDC are going to 37 states, cities or territories to conduct surveillance and prevention funds available to all reporting entities. Funds are, also, being made available to expand serosurveillance of HIV infection. Funds are being provided to conduct epidemiologic studies, to fund counseling and testing centers and to develop comprehensive prevention programs at the local level.

I have distributed for your reference copies of a booklet titled Centers for Disease Control AIDS Prevention Activities FY 1987, which summarizes CDC's activities relating to AIDS during Fiscal Year 1987. CDC intends to maintain its leadership role in national AIDS surveillance, epidemiology and laboratory studies. We will continue to use our traditional ties to the state and local health departments as is illustrated on Pages 6 through 17 of the Summary.

Our prevention efforts will include education at all levels, illustrated by page 20 and 21 and pages 34 through 37. We will continue to emphasize risk reduction efforts which are illustrated on pages 22 through 33 of the summary. This concludes my testimony. I will be happy to answer any question you or members of the Commission might have.

CHAIRMAN WATKINS: Thank you, Dr. Mason. Dr. Novick?

DR. NOVICK: Thank you, Mr. Chairman. New York State has over 14,000 cases of AIDS. In addition in New York State about one-third of those cases, 35 percent are related to IV drug abuse as a factor. We have been increasing our preventive activities. Part of that increase has been learning more about the problem through our seroprevalence studies. I would like to show you several slides which will illustrate the extent of the problem disclosed by the studies and then briefly discuss some of the preventive measures that we are putting in place.

This slides shows the results from our newborn testing. This is testing on available blood, and this shows the results of the first 52,000 consecutive newborns since last November that have been tested and shows a rate in Upstate New York of almost 2 in 1,000. A much higher rate is found in New York City. (approximately 1-1/2 percent)

Just quickly, these bloods were taken from infants, but what they showed is maternal infection. The infants themselves may or may not eventually be shown to be infected, and what this slide shows is a very striking increase in the percent positives as the maternal age increases which has implications for our preventive programs. This is a map of New York City. This shows the zip codes in which we have found at lease one positive newborn for antibodies to this virus.

This shows only the highest areas, those of more than 2 percent, and this is a similar slide showing neighborhoods with more than 2 percent.

The next map shows the gradations, with the heavy white color showing areas of more than 2 percent. Some of those areas are more than 3 percent or more than 4 percent.

The next slide that I will show, is very similar in geographic distribution to this slide but does not show HIV prevalence but rather a measure of IV drug abuse. I guess that is hard to see, but the red stands out.

Very briefly, six of these seroprevalence studies are of different population groups. It shows what the challenge is with respect to prevention.

I will highlight some of our major preventive initiatives. We have worked with the Department of Education. We have a mandated AIDS prevention education program in New York State. It is in the phase of training teachers. It will start in the next school year. We have a large media program. We have been engaged in planning efforts with the Cooperative Extension Service to put education through that service to adults and parents in a number of counties in New York State.

You have seen a health problem that is related to drug use, and your own Commission has called attention to this. We have outreach sites in New York City where we counsel, provide education and referral to IV drug users. In addition, we have efforts to reach physicians, especially all physicians who treat women of childbearing age. This includes women who are contemplating pregnancy in New York State, encouraging them to (with consent) receive counseling and testing.

With respect to prenatal care and family planning that is state subsidized, we are requiring through contract amendment that all of these facilities provide counseling and testing on site to women who elect such counseling after receiving information.

We are going though a large training program, training staff at all these sites in counseling, and we will provide reimbursement for the counseling and testing process once this is under way, and we expect it to be under way in the next 30 to 45 days.

In addition, in the areas that you have seen, highlighted on the map, we have planned to hire community health workers to train them not only with respect to HIV related disorders but, also, with respect to prenatal care because the

two run hand in hand in those areas in which we have demonstrated that there is an increased HIV prevalence.

In addition to that, as your own Commission has pointed our, we recognize the increased need for drug treatment programs. There are currently about 45,000 drug treatment slots in New York State. Methadone slots have been increased by about 5,000 and drug-free slots by as much as 9,000.

I will conclude my remarks by saying that we are both trying to get a better idea of the magnitude of the problem, where it is by looking not solely at case reports but looking at actual evidence of HIV infection. We are combining a community-wide effort in terms of prevention, using education and the media with more specific attempts to somehow break the cycle of infection in those areas which are shown to have a problem according to our seroprevalence efforts.

CHAIRMAN WATKINS: Thank you, Dr. Novick. Dr. Wasserman?

DR. WASSERMAN: Thank you, Mr. Chairman, members of the Commission. I would like to speak as a representative of virtually any county USA. I happen to be from Montgomery County, and I would like to tell you how we are dealing with this epidemic some 20 minutes away from where we sit right now, Montgomery County, Maryland.

I am, also, an elected official for the National Association of Counties. I believe that the kind of description that I will give you as to what we have done in Montgomery County is very similar to that being done by all local health officials in suburban metropolitan areas.

First of all, some statistics. The Metropolitan Washington area is the fifth largest area in the country. As of mid-February, there were 1721 diagnosed cases of AIDS, with 986 deaths. In our own community, some 650,000 people just to the north of Washington, we have had 159 cases with 90 deaths since our first case report in February 1983.

Our statistics differ somewhat from that of Maryland although not from the national data. We have had 24 percent of our cases identified in the black population. The State of Maryland has 51 percent in black population; 90 percent of our patients are males; 4.3 percent Hispanics, and surprisingly 23 percent of Montgomery County residents who have AIDS are over the age of 50. Maryland has 14 percent. As we looked at those data, we understood that a number of our older people got them from transfusion reactions.

As I looked through the history of how our community dealt with this problem since 1983, I noticed that it fell into about five or six specific categories. First of all, after our first case was diagnosed in 1983, after our surveillance was heightened, as you heard from Dr. Mason with reported cases in MMWR as early as 1981, from August through spring 1984 through, up until the spring of 1985, or over an 18-month period we began to educate and form an information plan within the community and began to target the predominantly gay community. Also, the health department collaborated with the local medical society in presenting information to the public at large.

In the spring of 1985, we began anonymous antibody testing at our STD clinic site. Since that time, we have performed more than 8,000 tests, the largest number affiliated with the health department in the State of Maryland, and have done more than 25,000 counseling sessions.

From August 1985 through January 1986, the community went through what I will call a major briefing session of all government agencies with the health director talking to the council, the county executive and our chief administrative officer, speaking then to county department heads and eventually developing under his leadership county policy through an intergovernmental task force and also developing policy in concert with CDC standards and recommendations through our school board in January 1986.

From 1986 until the spring of 1987, we honed in or our message, improved that message and expanded general community awareness. We began to work with local organizations, including HERO in Baltimore, Health Education Research Organization and Whitman Walker in Washington, D.C.

Montgomery County is in kind of a precarious situation. We don't know whether we relate to Washington or Baltimore, to the Metropolitan Washington area or to the State of Maryland sometimes.

Since 1987, the spring, we have tried to desensitize our community by frequently speaking before boards and commissions generally reaching into my pocket and picking out what I have now become somewhat notorious for, a variety of condoms in a variety of colors. The first time I spoke to our school board, eyes rolled all over the community. At this point now in speaking before the county council and others, it has become expected, and I think our community is somewhat desensitized towards understanding some of the modes of transmission and towards ways of stopping that transmission.

We have, also, gone through a process of comprehensive community planning and community services development. Over the

summer our Health Planning Commission set up a task force for community needs assessment and developed a series of recommendations. On January 20, this past year, just a month ago, we sat down and invited more than 300 community participants to our AIDS challenge, and I have some packets for some of you and can provide them to all of you.

At that point, we were looking at developing a 5-year plan. Several workshops were established including acute and chronic treatment services, public safety, AIDS in the workplace, information, education and training, home and community-based services, housing and funding levels.

The report should be out within the next 4 to 6 weeks. As we became more sophisticated, we began to target the high-risk groups. We began to develop contracts to approach minorities, IV drug abusers and those in prisons. We have made a concerted effort to involve the business community. Of those 325 people who attended the conference, 89 represented the business community in Montgomery County. We have actively pursued relationships with the Chamber of Commerce. In fact, the particular AIDS challenge conference was sponsored by the Health Department, the Health Planning Commission and our Office of Economic Development.

Speaking as a local health official, what I would like you all to recognize is the need for diversity in approaches amongst various localities. We need to be able to develop targeted approaches based on specific community problems. As I mentioned to you, our population with AIDS is older, and we don't have the same mix of minorities as does the State of Maryland.

In San Francisco the gay population is the most seriously affected and has strong political influence in that community. In New York City there is a high rate, as you have just heard, of intravenous drug abuse, and in that community the Mayor is permitting the distribution of clean needles. In the Metropolitan Washington community we were able to distribute, at least in Washington, D.C., Clorox for drug abusers. That has not gone to the suburbs as of yet. Colorado, a more conservative state, has permitted a more traditional public health approach of contact tracing which I would consider more conservative in line with some of the approaches that I would like to see developed in some of the other communities, but it is not right for all areas of this country.

Just to look at the diversity in the Washington Metropolitan area, we can look at some recent developments of children with AIDS infections and their ability to get into the school system. In Fairfax County, a child was not admitted in the school system which created a controversy and required court action in order to bring that child into the system.

You will be hearing from Dr. John Grant from Caroline County in our state of Maryland in Nashville as to the success that they had in integrating the student immediately into the classroom setting. In Prince William County I think they have had two separate instances, one where the school board excluded and then after learning how better to deal with the situation the child was integrated without any difficulty.

I think we need to maintain both anonymous and confidential test sites. I think we need to maintain continued funding for outreach counseling, materials preparation in a variety of languages and the development of a regional and national clearinghouse. I think we need more funding for public service announcements that are locally specific and that are sensitive to the needs of various minority communities and local diversity.

We need to sensitize the public to the disease issues so that we might minimize the panic issues, and when I speak to the community I generally focus on the two-pronged approach. One is the very difficult medical problem that we have, but the other one that is preventing us around the public health table from providing the kinds of services that we need to, is the hysteria in the community that sometimes has been fueled by the media, so that in addition we need to continue to develop strategies to better work with the media on public health issues.

There are two or three other points that I would consider controversial that we are beginning to wrestle with within our own community. At various times when I have had opportunities to represent the National Association of County Officials on various policy-formulating boards outside of my community these have come up. I think we need to look at the issue of duty to warn. I believe later on this afternoon we will talk about partner notification. I think you need to go one step farther than mere partner notification and expand that. We are wrestling with that with our own Governor's Council on AIDS, and I think we either need to at least adopt a permission to warn posture or look at the duty to warn, and we might be able to discuss more in the question and answer period.

I am very concerned about public safety worker protections. In this locality and in my previous job as local health official in Arlington County, it was very difficult to get to those people in the front lines: police officers who have been splashed with blood, rescue workers in the field, and correction officers who are affected by this disease. When they are exposed, and there is a very clear-cut definition of what an exposure is scientifically, they have concerns, and I think we need to address those concerns, perhaps even by mandatory testing of those people who expose an individual in the line of their

performance of public responsibilities, after, of course, we have tried all of the appropriate methods of trying to get voluntary compliance, if nothing else but to ease the mind in anxieties, reduce the anxieties of the public safety worker, recognizing that we would still have to continue testing that worker as well.

Finally, as I have stated, in our community, we have involved the business community. That sector, I think, is, extremely critical toward expanding the general knowledge and support for these activities within the community.

I would also, like to conclude by recognizing that there is a large partnership, a general partnership, as you have heard, between the Federal Government, state government and local governments, and we need to have the funding; we need to have the communication; we need to have continued support, but recognizing that in the variety of communities there are throughout these United States there will be a diversity of approaches, and that will required both analysis and evaluation of all of the activities that are going on throughout the United States. Thank you.

CHAIRMAN WATKINS: Thank you very much, Dr. Wasserman. Dr. Edwards?

DR. EDWARDS: Thank you, Mr. Chairman and members of the Commission. As Commission of Health for the city of Chicago and representing the United States Conference of Local Health Officers, I am, indeed, pleased to have the opportunity to come before you today to provide a perspective from the local public health department for one of our nation's largest cities addressing this problems. I have also provided written testimony which I submit for your consideration.

As a background to my comments, let me tell you about Chicago's situation. Chicago is that nation's third largest metropolitan area but ranks eight in the number of AIDS cases reported. To date, slightly over 1,100 cases of AIDS have been reported in Chicago since the first case was detected in 1981. This compares to over 13,000 cases in New York and nearly 5,000 each in Los Angeles and San Francisco. The scope and growth of AIDS in Chicago appears to be approximately 2 years behind that of these major coastal cities. This 2-year time lag, relatively few number of cases and the experience of other cities has allowed Chicago to talk a more deliberate and less crisis-oriented approach in addressing the AIDS epidemic. We have emphasized the development of policy to guide a long-range approach along with short-term action-oriented initiatives.

While the public health department is taking a leadership role, the major focus has been to build the capacity within community-based agencies to address this problem as it exists at the community level. Chicago's approach to AIDS has

developed in an evolutionary fashion to take on the focus and direction it has today. This approach has several components. Prevention through intensive and targeted public education is the backbone of AIDS efforts in Chicago. This is augmented by an aggressive surveillance and monitoring system, and a limited but responsive HIV antibody testing and counseling capacity. As I noted a central feature of our approach is to act through and in conjunction with a network of community-based agencies which operate within those communities most affected by AIDS. These agencies are key in delivering the risk reduction health education message. Community-based agencies are also the source of many of the outpatient health care and special support and residential services needed by persons with AIDS. More traditional medical support, both inpatient and outpatient, is currently being provided within the existing health care system.

The major obstacles that we face at the local level include insufficient resources and the type of population groups that are most vulnerable. Societal prejudices and preconceived notions about why the disease has taken place and what should be done about it is a third obstacle.

Finally, the obstacles presented by the disease itself you have heard before and I won't dwell on them. Quite simply, it is a disease that we do not completely understand. It is not easily diagnosed nor easily routinely testable. There is no cure. There is no vaccine. We have little in the way of effective treatment or therapy. It is seen as a scourge from the public health past which should not have occurred in the 20th century, so we thought these conditions alone give rise to public fear and public questions of confidence in the medical and public health professions.

That the disease affects population groups not considered mainstream, that it is transmitted by sexual behavior or by IV drug use only makes more difficult our job of erasing judgmental overtones. While our earlier fears that the disease would spread rapidly beyond known high-risk groups into the general population have not been realized, we will increasingly be seeing greater number of cases among women and among children as the proportion of IV drug use transmitted HIV infection increases.

Our prejudices regarding those of differing sexual preferences, of different life styles and those who use drugs have gotten in the way of effectively coping with this problem. We have seen this reflected in a flurry of legislation enacted by states across the country which has been often contrary to public health principles, and has wasted resources. These ineffective approaches which largely have been driven by attempts to allay public fears, and in many cases the legislation has created more obstacles than it has overcome.

Resource obstacles are simply that we as a nation have not faced up to the massive expenditures that treating the increasing number of AIDS cases will entail. We need to adjust our health care financing mechanisms or create new ones to provide the comprehensive and expensive care that persons with AIDS will need. That the high-risk groups are homosexuals and drug users, and that we have prejudices about how this disease should be addressed makes resource allocation decisions even more difficult. The vast amount of money that has been allocated by the federal government has been allocated for research, and indeed, this is important. It is felt, however, that research is being conducted at the expense of research into other public health areas.

Local public health departments have labored under these obstacles, and it needs to be remembered that while AIDS represents a public health challenge of enormous proportions, it is more than a problem solely for public health departments, especially those at the local level. AIDS affects more people than just a limited number of clearly identified population groups, and while there are high-risk behaviors, AIDS must be seen as a public disease affecting all people for which society at large must be responsible. It has become too easy for us as a society to see the disease solely in terms of homosexuals or drug users or other groups which we don't feel particularly comfortable with and then to enact reactive laws to deal with these groups.

Addressing AIDS must involve a response from all levels of our society: at the local, at the state, as well as the federal level. Responsibility cannot be shifted solely to the medical or public health community. In absence of a true medical miracle, AIDS will be with us for a long, long time. And while Americans have come to expect medical miracles in the past quarter century, such a wait-and-see attitude will likely see us both disappointed and unprepared for reality.

If the focus then is not just on public health departments but on all elements of our society, we must attempt to gain direct community involvement of agencies and institutions at the grassroots level. Our greatest weapon is indeed, prevention-oriented eduction to change behavior, and this weapon cannot be applied in a top-down fashion. It must emanate from respected sources within the community. Thus, we must empower as many of our community leaders and local organizations as possible to become involved and take an active role in fighting the disease.

The federal government has a crucial role to play. The federal government can be instrumental in overcoming every one of the obstacles that I have mentioned. First, we need leadership

at the national level in combatting AIDS. AIDS must be seen as a threat to the entire nation, not just a threat to certain large cities or certain population groups.

AIDS must take on a national concern. This threat lies not just in the spread of the disease but also in reacting to it in a fearful and negative way. Thus, the federal government must ensure that all of our citizens are protected from disease and from discrimination.

National guidelines are needed which are respected by state and local bodies. We find that local legislators are as perplexed by AIDS as the general public, and in the absence of guidance will reach for their own solutions, often responding to an atmosphere of public fear and a sense of urgency for some type of action. Most appropriately they should turn to local public health departments for expertise needed to guide them. However, local public health departments need the support of the national policy and an overall sense of direction at the national level if the weight of their expertise is to be sufficient to counter other pressures.

In practical terms, federal government can do several things. Federal civil rights and anti-discrimination laws should be appropriately amended to protect those who have this disease or who otherwise may be considered at risk. Where new legislation is not needed, administrative interpretation of existing laws through regulation need to make clear that it is the national policy to prohibit discrimination of any kind against persons with AIDS or at risk of contracting AIDS.

Establishing that expertise and confidence in local public health departments would be greatly enhanced if they would be recognized by the federal government as the local source of expertise. State legislators should be encouraged to turn to their state and local public health departments as a source of guidance. One method of accomplishing this would be to specifically fund an educational program for state and local legislators that will be conducted by public health departments. These workshops would provide us the opportunity to demonstrate our expertise and to get our message across on a one-to-one basis.

The federal government must also adopt more effective drug abuse policies as it is through intravenous drug use that AIDS will more than likely spread in the future and while emphasis on strict law enforcement is necessary, we must see drug abuse as more than an evil in itself, but as a symptom of deeply-rooted problems with socioeconomic and psycho-social causes. We cannot ignore those problems, as unpopular as they may be. I do want you to know that we must find ways to improve the socioeconomic conditions within the inner cities of our country,

and we must shake the strangle hold that drugs have on our young people. This is a long-term solution and might very well be an expensive one.

There are other things that we can do right now. One is to ensure that there is an adequate number of drug treatment facilities available especially for low-income citizens, those most likely to be the victims of drug abuse. It is appalling that so few of these treatment facilities exist across the country. In Chicago, my city, there is only one publicly funded, publicly operated inpatient drug abuse treatment center for adolescents, and that has a capacity of only 20 beds in a city where thousands of teens could benefit from such a service, and there are only 20 slots available. The reason is quite clear and plain. There simply isn't the money, and while the federal government has spent tens of millions on the law enforcement aspects of drug abuse, the dollars for treatment, indeed, have been inadequate.

I also cannot believe that in a country where advertising and the media are so successful in persuading consumers to purchase products of questionable value, the best we can do to persuade our young to avoid destruction of their lives is to say, "Say No to Drugs." It rings hollow by comparison. If we are to reach them, we must reach their consciousness and seriously address their problems of frustration, hopelessness and confusion that the young face in growing up in today's world. The same dedication and expertise that is used to sell this year's newest line of automobiles or fashion design or whatever trinket the commercial world latches onto, must also be used to reach our young, to bring hope. Introducing sophisticated behavioral research techniques into these means of persuasion requires funding and sponsorship. Their critical importance suggests that the federal government must take the lead, and until we are willing to improve the socioeconomic and the psycho-social conditions in which our young mature, we must provide them with the means to resist the negative forces and not become lifelong victims.

The schools must play a central role, and this is where there is greatest contact with our youth. Schools, too, are looking for guidance in dealing with AIDS, and while eduction in this country has been largely a local concern, a national problem requires national leadership, and the federal government needs to insure that minimum standards for health education are adopted nationwide. Health education should, also, include sex education. Thank you very much.

CHAIRMAN WATKINS: Thank you, Dr. Edwards. Mr. Creedon?

MR. CREEDON: I have one question first with respect to education. In this booklet on AIDS which was published last year sometime, there are two tasks that were identified, 2.31 and 2.32 on Page 26. One, the task is to work with local education departments and other agencies that serve youth in cities with the highest incidence of AIDS to ensure that school-age populations who attend and who do not attend schools or colleges in the area receive effective education about AIDS 2.3.2. which is along the same lines says, "Work with the education departments and other agencies that serve youth in three cities and one state with the highest incidence of AIDS," again, with this educational effort being directed at both those who attend school and those who are of school age but are not in school."

The collaborating organizations are identified with local and state education and health departments and other agencies, and the beginning date is identified as September 1987. I guess the question I have is whether these two tasks have really started. How far along the line they are? What are the results so far? Is what is being done adequate or do other things need to be done? I assume that these were pilots in a way and that they are limited to specific cities or states, and whether this Commission which is concerned in our educational review about specifically reaching the young adults who are of school age, not adults, young people who are of school age but who are not in the schools getting the benefit of a school curriculum; how do you reach those; what is happening now; what in addition needs to be done, and some of these will be drug users, and what specifically is being done to reach them, especially if they are student dropouts who may not be literate?

DR. MASON: I will try to address that question. Please go to Page 34 in the CDC AIDS Preventive Activities Booklet. While you are looking that up, let me say that we believe that information about AIDS appropriate for age should be included in a comprehensive school health education curriculum for all children. By comprehensive health education I mean kindergarten through 12th grade, comprehensive health education doesn't mean talking about condoms in first grade or second grade, however if there is an infected child in that class, there ought to be instructions appropriate for age as to how the disease is and is not transmitted. I would leave the content of message up to the local school board. But we do believe that that comprehensive health education should be provided to all of the nation's children.

Turning to Page 34 in the booklet, these activities already happened last fiscal year. You will see that a total of $11 million was included in our first grants for school AIDS education. Its distribution included, 51 percent to national activities and 49 percent to state and local activities.

If you will turn the page, you see that we awarded about $2.6 million to 15 state departments of education, $2 million to 12 local educational agencies, and about $700,000 to two states and one city for training and operation of demonstration centers. A total of $1.8 million was provided to 15 national organizations for assistance to schools across the national to deliver effective AIDS education, particularly to minority youth and those not in school. Finally, we developed and distributed "Guidelines for Effective School Health Education to Prevent the Spread of AIDS." One million copies of these guidelines will be distributed in FY 1988.

Page 36 shows the School Health Education Fund awards by states and cities. During this 1988 fiscal year, we will provide grants through an augmentation in those funds to every state educational department and many cities. Every state department of education will have money, and cities with the highest AIDS prevalence, will also receive direct grants.

It takes time to bring up these comprehensive school health programs with specific AIDS messages. Page 37 shows what activities are being supported through the money awarded in FY 1987. Many of these grants are for outreach beyond those who attend school so that we can get to the dropout who is more likely to be involved in IV drug abuse.

MR. CREEDON: What specifically is being done for the dropout, for the ones who are not in school?

DR. MASON: These grants were specifically for the purpose of developing programs to attempt to get to our of school youth.

MR. CREEDON: At the local level?

DR. MASON: At the local level.

MR. CREEDON: There are no recommended guidelines or suggestions coming out of CDC itself?

DR. MASON: We have recommended approaches, but these funds are for demonstrations. We need to get down to the local area and find out how you get school dropouts. We don't have all the answers yet.

MR. CREEDON: Then I guess I would ask the other members of the panel whether they have done anything pursuant to these federal grant along the lines of trying to reach the children who are not in school or who are the IV drug users.

DR. MASON: I will just comment that these funds got out during the latter part of FY 19878.

MR. CREEDON: So, the money is not out there yet.

DR. MASON: It is there now, but most of the grantee are early in their program development.

MR. CREEDON: It says, "Conduct programs for out-of-school youth," and that seems to cover many of the states.

Would you comment on that Dr. Novick?

DR. NOVICK: Yes, New York State is one of the states that has gotten the grants that Dr. Mason has talked about, actually two of the grants, one in New York City one in New York State. New York has made good progress in developing a statewide program, K through 12. I think on the issue of dropouts, however, there is quite a bit of difficulty in knowing how to approach dropouts. I worked closely with that effort, and I am not aware of definitive plans yet to reach the dropouts. The amount of money, also, that states get, while it totals in several millions, it is not enough to provide for these educational programs on a statewide basis.

Our own department of health has provided some funding for the training, but even so more resources are needed, and there is not, I don't think there is a clear approach, certainly not in New York State to the problem that you are asking about.

DR. WASSERMAN: Perhaps I can tell you that first of all I think that what has been stated is that it is very difficult to reach that hard-core dropout population. Last spring was really the first time we even had a concerted effort in the schools where we worked with out school health program and were able to get the schools to have a major program to educate staff and children with permission.

This Thursday the state department of education and local schools, together with the state health department and local health officials will be meeting to develop an augmented plan for health, for AIDS education within the school system to deal with high-risk youth. What we did this particular year was to take some money and to work through the Whitman Walker Clinic on a contract, we brought an individual in who is working in the jails, on the streets, working with the recreation program to try to identify networks to be able to work and find people who are not in the traditional school settings and then educate them on a one-to-one basis. It is a very difficult challenging job just being heard, just being accepted. He happens to be a minority member himself, and so he has been more effective than the traditional approach that we have taken previous to that.

MR. CREEDON: Dr. Edward?

DR. EDWARDS: We have found that you certainly cannot use traditional methods of getting to these youth, and this is true as a whole in this disease. What we have done is to work with the grassroots organizations in communities that have developed confidence with these dropouts and can call them together within homes, within other social institutions and can talk with them and convince them.

We feel that it is impossible to talk to this group unless you empower grassroots community organizations with reputation to gather their confidence according to thier methodologies.

MR. CREEDON: Thank you. The other question I have is more on the prevention side, and Dr. Mason, you indicated that sometime back, I guess in the early eighties AIDS was identified as a reportable condition to CDC. I wonder whether it is feasible and desirable to have HIV seropositivity as a reportable condition. You know, one of the results of our hearings has been that nobody really seems to know how many people are out there with the virus. There are different estimates, and some of the estimates might be good, but they vary considerably, and looking at this as a public health matter, would it be desirable and feasible to have HIV status reported rather than AIDS status?

DR. MASON: My own personal belief is that we ought to be working toward what I call normalization of AIDS or making AIDS like other epidemic diseases as rapidly as possible. By normalization I don't mean business as usual. But using the time-honored techniques. We generally support, as long as one can guarantee confidentiality, that states and local governments develop a system of reporting not just cases but infections. This is a development that will have to move at a local community and state basis as they arrive at levels of confidentiality that they feel will permit reporting on infections.

In talking about comprehensive reporting we have no problems with the ability of the public health system to guard confidentiality. Seropositivity reporting involves physicians, laboratories, and hospitals. I am not sure that in all communities we have the mechanism in place to guard the confidentiality at all levels.

We ought to begin, as a first step, with separating names from reports so that we have numbers on anonymous type of reporting. For example, we we never ask for the reporting names at the federal level because it is of no use to us to know a person's name. We do need to know age, roughly where they live, sex, race, and their behavior that may have led to their becoming infected. You have to determine what you want reported.

Even with reporting of antibody positive persons I am not sure that we would comprehensively understand national seroprevalence or seroincidence. The reason I say that is because many people are unwilling to be tested or to put themselves into test situations because of their concern about confidentiality. Where voluntary testing has been compared with anonymous or blinded testing, we find that voluntary testing picks up about 50 percent of the infections. Putting into place a reporting system for infections in no way would guarantee that we would really get a comprehensive view of how much infection was occurring in that nation or how rapidly it was spreading. That is why we are embarking, in cooperating with state and local government on a series of sentinel city surveys where we test blinded specimens. By blinded I mean blood specimens that are collected for other reasons than for AIDS testing. For example, at hospitals in sexually-transmitted disease clinics, family planning clinics, tuberculosis clinics, drug treatment centers, etc. In other words, we don't receive the names of those providing the blood sample. The person doing the testing never knows the name. By those approaches, as well as by following military recruits and blood donors and by carrying out the pilot test of a national random household seroprevalence survey, in combination those approaches will provide the nation with a better idea about seroprevalence and seroincidence than individual reporting would. We have got to try all of those approaches or we won't have good knowledge about seroprevalence.

MR. CREEDON: Dr. Scott who was a witness this morning and who is the Health Commissioner from Rhode Island, in talking about test results was kind of lamenting the fact that it is unfortunate to do a test and find out that an individual is seropositive and then not do anything about it which apparently is often the case. He indicated the main problem, of confidentiality might be solved if there were legislation either at the state level or at the federal level to effectively prohibit discrimination in whatever areas it should be prohibited. I guess you still wouldn't need it at the federal level. Maybe I should ask the other panel members about seropositivity and then acting on it in a way that is appropriate for the chief health administrative officer of a particular state or locality would be the way to go.

DR. MASON: Dr. Edwards has very eloquently spoken about the problems of discrimination whether real or perceived. Fear of discrimination has a chilling effect upon the willingness of people to be tested. These are people who should be tested. It would be in their own best interest to be tested. Anything the Commission could do to encourage activity at the local, state of federal level to do away with both discrimination and the fear of discrimination would help in our total activities to control this epidemic.

CHAIRMAN WATKINS: Mr. Creedon, I think we really have to get to -- Ms. Gebbie?

MRS. GEBBIE: This is really a question for all four of the panelists and one that you may want to follow up in writing on because I know we don't have a lot of time for long answers here.

We heard this morning testimony about the desirability of grounding public health policy in public health medical science rather than in the political processes. I have some trouble with that because I think public health is inherently political, since it is a governmental operation to a certain extent. We have, also, seen over the years a number of criticisms of the public health establishment of having been negligent in the early years of this epidemic, not responding quickly, perhaps because of that politicization. I would be interested in comments from each of you about the extent to which you think either prejudices or political activities have interfered with public health action and whether there is a chance at some point of getting back to something that might be called pure public health that is not so political.

DR. WASSERMAN: I am not sure that particularly with this disease that you can get to pure public health. If I could pick up on the last comments, ultimately the public health approach that I would see would be to be able to have reportability, be able to go forward with contact tracing, ultimately to stop the transmission, the person-to-person transmission of this disease. However, as people have stated, you have to do this balancing act between the effectiveness of reporting ultimately to do contact tracing to stop it, versus the other side of the coin that because of the fear of discrimination and the failure of confidentiality statutes to be, or just confidentiality, to be accepted, that people might not come in to be tested, and then we would have stoppage at the first place, and we wouldn't be able to identify anybody.

If we can work toward reducing the level of discrimination that occurs in making the general population more sensitive and more compassionate to those people who have the disease rather than to their fears of getting it through misunderstanding of how it is actually transmitted, then I think we might be able to go back to a pure public health approach, but that ends up with each locality and each state having to wrestle with that problem. I think that is where we are today.

DR. NOVICK: We spent a lot time talking about issues such as contact tracing or duty to warn which do have a certain political interest attached to them, but I think the major things that one has to do to counteract this epidemic are things such as were talked about earlier by Dr. Edwards, like greatly expanding

our education, having it available through all grades and doing something about IV drug abuse, not only treatment of IV drug abuse because there is a high seroprevalence in many areas by the time these individuals get to treatment but by doing something earlier perhaps in the school, certainly in the community. It is hard to understand the sort of political forces that would protect against doing those things. I think it seems evident that they should be done. We talked about contact tracing and reporting. We will gain something on the margins here. They will be important in a person-to-person interaction. Whether they will be important if one models this in stopping this epidemic, I tend to think not. In terms of health departments and politics, I think there is another side to this, and that is health departments have been universal almost in trying to stop discrimination and, also, trying to stop action that is based on non-scientific theories about transmission, such as food handling or transmission in schools which may be taking place. So, I think they have played a public health role and counteracted what we may term a political role in some instances.

DR. EDWARDS: I am a strong believer in the political process, and as you know, I am very strong believer in public health. I think one of the problems we have had in this country is we have sought a bonding between the political process and public health. Certainly I feel very firmly I do not believe in a pure public health status. That isn't the way this country is designed to function. I think we need a bonding and partnership between the two so that public health can function comfortably within the political process, and if there is one thing that is going to be positive coming out of the AIDS issue, I think that bonding process will take place, and my recommendation, of course, is that the Federal Government sponsor workshops for legislation, so that they are not required to quickly act upon something from a health standpoint.

DR. WASSERMAN: Could I make just a couple of comments and just give you three political issues that we certainly have tried to wrestle with, and I don't think we have been very successful. In a pure public health, and maybe other would disagree with this, but if we had the best of all worlds, we would be able to distribute condoms in the schools, if we are talking about recognizing that sex is going on in that age child and that you would be able to prevent that. I don't think that is possible, and I don't support that. We would be distributing clean needles or bleach in the streets, recognizing again, that IV drug abuse is going on. We would be distributing them in the jails. I don't think right now that is possible either for political reasons, and finally, we would have many more Methadone programs. I suspect, that in this next fiscal year we will have a Methadone program in Montgomery County, but it has been a long time coming. We would, also, have expanded drug treatment programs, and they would be in a variety of

neighborhoods. We would not hear, "Not in my backyard." So, I think there are three or four political reasons right there that prevent us from a full scope of public health armaments.

CHAIRMAN WATKINS: Dr. Mason?

DR. MASON: Just a quick comment. CDC has worked since 1982 with many experts, including representatives of local and state government, in promulgating a series of AIDS guidelines. They include guidelines on who ought to be donating blood, school enterers, health care workers and related subjects, we have tried to make these exclusively scientific recommendations. Although CDC listens to the various pros and cons, ultimately the CDC cut after listening to these experts has been on the side of the science and public health rather than politics.

CHAIRMAN WATKINS: Dr. Lilly?

DR. LILLY: I basically just have one question. I would like some comment from any of you. There is some data, not extensive data, that suggest that sexual transmission of HIV among gay men has very much declined. As far as I am aware, the gay population if the only one that has tried extensively to put forward safer sex education. I, personally, tend to make a relationship between those two things, though I am not sure that that necessarily holds. I would like your opinion on that and your opinion in general about safer sex education for practicing adults, sexually active adults.

DR. NOVICK: You know, there is information, as you are undoubtedly aware from a number of studies, some information from John Martin's study in New York City at the Columbia School of Public Health that has shown really a very strong change with respect to over a period of 3 or 4 years in various sexual practices that would contribute to infection, and we hear the same, I think, anecdotes about less infection. But we haven't been able to document that yet in a case reporting system. I think in terms of smaller groups such as the one that Martin has studied, it shows a change in sexual practice.

DR. LILLY: Do you think that safer sex eduction by the gay groups, for example, has been a factor in that?

DR. NOVICK: Yes. I think it has been a factor. We have done studies of a group at the New York State Health Department, as well, and it shows that it is a percentage of people who have changed their sexual habits, not all of them but a percentage, maybe 50 to 70 percent. That is the good news. I guess the bad news would be the 30 percent or 40 percent who haven't.

DR. MASON: If you will turn to the next to last graph in the CDC booklet, it shows the rates of primary and secondary syphilis in homosexual men in selected sites, 1980 through 1987. For most of these cohorts in these cities, and we didn't select cities to show any particularly pattern, but to indicate what is going on generally, there has been a decline in primary and secondary syphilis rates in homosexual men which certainly has to be attributed at least partially to safer sex education.

Now, when we look at primary and secondary syphilis in heterosexuals, we have an epidemic on our hands. New cases of syphilis have gone up nationally as the Commission knows.

When we have looked at primary and secondary syphilis in homosexual men in Miami we find increases like in the heterosexual population. Here many of the homosexual men are black and Hispanic and are perhaps not part of the "in group" where safer sex education has more effectively occurred.

We have to be careful that we don't generalize data. But studies in cohorts of homosexual men that CDC is following show declines in incidence of new infections with time. The decline in syphilis in homosexual men is consistent with that.

DR. WASSERMAN: Dr. Lilly, to respond to the same second part of your question, Carol Doyle who is in the audience who works for HERO and works for us in Montgomery County, in addition to having prepared this extensive background briefing book for you, when she gives her lectures to groups, she has coined the work "outercourse." It is all of those fun kinds of things that you can do physically without spreading bodily fluids through intercourse. I am sure she would be willing to give you her lecture at some time at a break.

DR. EDWARDS: I think to answer your question, in Chicago, we definitely feel that the safe sex program among gay white men has caused a decline and has a very pronounced effect. When you go into the minority communities, you have a different culture, and you must use different methods to produce that same effect, and that is what we are attempting to do now, but to answer your question, yes, safe sexual practice, indeed, has had its effect, positively on the spread of disease.

CHAIRMAN WATKINS: Ms. Pullen?

MS. PULLEN: Dr. Mason, can you tell me how widespread is the practice of newborn testing and if it is not universal, in how many locations it is and perhaps where some of those are?

DR. MASON: I am sitting next to one of the world's experts in newborn testing.

MS. PULLEN: He can tell us about New York. I want to know about the United States, if you will excuse me.

DR. MASON: There are a number of ways that we go about testing newborns. One can test babies when they are born after getting informed consent from the mother. There are a number of city and hospital-based programs doing this. Seroprevalence rates in the newborn reflects the status of the mother. You are not measuring the infection rate in infants because they derive antibodies from the mother. A positive mother will give birth to a positive infant, whether or not the infant is infected. So, when we test newborn infants, we are really testing the antibody status of mothers rather than the child. You have to wait for up to 6 months to know whether the child has been infected.

One of the novel ways of getting at mothers through their newborns was developed in Massachusetts. Massachusetts has had wide experience in AIDS antibody testing the filter paper dots that are collected for PKY testing. New York and New Mexico have already used this same procedure. CDC is working with other states to see if this technique cannot be more universally applied across the nation. The 30 sentinel cities where we are bringing up a very carefully engineered seroprevalence surveillance system newborns will be tested on a blinded basis to find out how many mothers are infected.

MS. PULLEN: How many states are you working with to develop the PKU-HIV testing?

DR. MASON: At least twenty-eight states will receive funds this fiscal year from CDC or NICHD. In addition to the states cooperating with CDC in the Family of Surveys, 8 additional states have started or will soon start testing filter paper blood specimens from newborns for HIV antibody. Seven of these states will be supported by monies from CDC and one (Massachusetts) is being supported by monies from NICHD. For the states participating in the Family of Surveys, 22 different states and territories received monies from CDC at the end of January 1988 to initiate filter paper testing of blood from newborns. The number of states that apply and will be funded should increase in the future, and we anticipate that at least 28 states will receive funding either from CDC or from NICHD this fiscal year to conduct such studies. Most states and communities need additional resources to move into this testing mode. They have to set up the new procedures and add laboratory staff.

CHAIRMAN WATKINS: Dr. Lee?

DR. LEE: First of all, Dr. Wasserman, I like this "outercourse." It has a catchy ring. I am not sure it will catch on though. Second of all, on incidence, this is something that escapes me, listening to these statistics the last 6 months.

If you listened to Landesman talk about 5 percent or 3 percent of his women in delivery units wherever he works downstate; if you listen to this 2 percent newborns in Manhattan; if you listen to Steve Joseph swear that we have 600,000 HIV-infected people in New York City, am I correct; isn't that the number that is usually given 5 or 6 hundred thousand?

DR. NOVICK: Five hundred thousand. Steve Joseph usually gives 500,000.

DR. LEE: We should be really on the avalanche part of the curve where we are developing AIDS patients, but this does not seem to be the case, looking at the CDC statistics, and is it that we are just not really measuring true incidence here, that we are measuring very specific populations?

DR. NOVICK: Yes, the true incidence is the HIV infection, and nobody knows how many people there are or who are infected with this. So, instead of knowing, we have engaged in sort of making up these speculative estimates, and you are absolutely right. An estimate of 1/2 million for New York State doesn't match with case generation, and it is probably too high by a significant amount. We are doing the seroprevalence studies of which the newborn is only one. We are doing one-half dozen of them, and we will get a better idea. Already our idea has been changed, for example, based on the data that was up on the slide before. We could roughly estimate the number of infected women in New York State at about 25,000 compared to the 50,000 that was in that 500,000 estimate. So, I think you are going to see these estimates revised downward but getting at the exact number without a random door-to-door survey like Dr. Mason described may be attempted, is not possible.

DR. LEE: One last thing. We all have our own constituencies here. I am from New York State and New York City, and I notice that California has half the AIDS cases and got 50 percent more money from CDC than New York. Why Dr. Mason, are you shortchanging New York?

(Laughter.)

DR. MASON: There are a number of reasons for those difference. I will have to submit to you in writing because I don't follow them all that closely.

DR. LEE: Submit them to Mayor Koch.

DR. MASON: We are very cognizant of New York State and New York City's problem, and I will submit in writing why those differences exist.

To determine whether a state or local health agency has received a fair share of federal funds for program operations, it is important to include all the types of funding received by the different areas, not just to focus on one type of award.

In CDCs booklet, AIDS Prevention Activities FY 1987, the monies awarded to state and local health departments for surveillance is listed on pages 8 and 9. California health agencies received $807,824 for these activities, compared with $772,716 for New York. The award to New York City of $335,080 for case surveillance was the largest single award to these areas, in addition to which New York City received an award of $137,053 for HIV surveillance. This latter amount was almost 6 times higher than the amount awarded to San Francisco for the same activity.

The monies awarded to state and local health departments for risk reduction activities is listed on pages 25 and 26 of the booklet. All areas of California received $5,443,873 compared with all areas of New York receiving $8,517,717. The largest award to a local health agency was a grant of $3,545,274 to New York City, and the largest award to a state agency was $4,489,655 to New York state.

The monies awarded to state and local education agencies for school health education is listed on page 36 of the booklet. In this area, the state of California and the cities of Los Angeles and San Francisco received a total award of $1,203,423 compared with a total award of $839,686 for New York City and New York state. Of the 27 awards made, the award of $540,000 to New York state was the largest single award.

CHAIRMAN WATKINS: Mr. DeVos?

MR. DEVOS: I am on a track, gentlemen. It is kind of old but maybe new to you, but I keep trying to find methods to solve the problem. I used to give a speech on the four stages that business goes through. One is the creation of the business. The next one is managing it, and we spend all of our time managing it, and pretty soon, when it doesn't grow or go we have got to blame somebody, and so, we defend the growth or the non-growth, and then pretty soon we descend to blaming, and blaming is the stage that seems to follow a lot. I remember talking to President Ford one day about the government over here being very busy trying to defend their turf or blame somebody for why something else went wrong somewhere else, and I keep trying to get us back to finding a solution. I get concerned. I ask a question. Is this solution going to be people driven or government driven, and it is because I hear everybody talking about what the government should do or is going to do, but maybe you could help me. I haven't found a way to ever help anybody who doesn't want to help himself, and I think we all agree with

that in principle. So, when I come down to it, how in the work do we reach people to make them want to help themselves, and I am not here to discuss testing because there are other panels on that, but we say, "We ought to have more testing so we get this data." I want to be tested so I know where I am at. I am not an animal to be tested for some statistical study. I am a human being, and I want to know for my sake. I understand the confidentiality problem, but just seems like we get carried away with the study of it, and we talk about it, and we have got numbers, and we have figures, and we talk about societal problems. We spend, I don't know, $500 billion a year in this country on it, and all I do is is look down my list, and I don't care whether it is alcohol or drugs or homelessness or hopelessness or unemployment or underemployment of divorce.

We don't seem to make much progress, and so, I, am no an AIDS panel, and what I want to ask is if you can help me find a solution to prevent it. Now, one solution in prevention, it seems to me is to make sure somebody who has been exposed or who has likely been exposed knows he has got it so that we can work with it. Now, is that not a valid thing? These are people who care about other people like anybody else. They may have a high-risk pattern, but I want to get down to dealing with human beings and work on behavioral change, and I think we all do.

DR. WASSERMAN: In a variety of settings we try to emphasize what the high-risk behaviors are in a very sensitive way so that people will come forward. You then let them know that there are eight anonymous and confidential place where they can go to be tested to find out; basically what you want to do in a non-threatening way in the schools, out in the streets, wherever you can go to people where you know professionally there is a high risk, is to let them know that this is a behavior: multiple sexual partners, the sharing of needles, you want to educate that group, make them sensitive to where or not they fit into that high-risk pattern and then to very sensitively engage them and have then come in.

MR. DEVOS: You are talking of specific things that you are doing, and I think we need development of that.

DR. WASSERMAN: I think that has to go on and be broadened in scope on a national basis.

MR. DEVOS: I agree, but I need, and we need your specific work, your results, how you are doing it so we can amplify it. One of these days this Commission is going to be over with, and we are going to have tons of paper, and finally we have got to get down to something very specific on reaching the human being where he lives so that he changes his behavior or he knows that his action is going to kill somebody else. We have

got to find these people and help them, and I salute you for what you are doing. I just want to hear more about that.

DR. WASSERMAN: Let me suggest that I don't know whether you have a panel like this, but you could use Carol Doyle who is in the audience and others like her who represent a variety of approaches, from a variety of communities across the country. Let them give you their approach and see whether you think that would be effective, if you were one of those population members at risk.

MR. DEVOS: I cannot address that, but you are in that marketplace. You are working hard in there. We are trying to reach them, whether we need better advertising like the man from Chicago said or whatever, but we need models that work, and we sit here day after day, month after month, and I will tell you, it is hard to pull up models that are really getting down, and I don't care whether it is homelessness or hopelessness or unemployment or all the rest of these things.

DR. WASSERMAN: I am going to send Carol to you before the end of the day.

MR. DEVOS: I want to know what you are doing, how you are doing it and how it is working. That is all I want to know. Then we can share it.

DR. EDWARDS: We are beginning to do something in Chicago that I think you might be interested in. First of all, we know that behavior is not a simple process. We know that some things we take for granted in behavior. We are not aware of how we developed in terms of helping one's self. That is not an automatic thing. There was something that occurred in your life, in your up-bringing that instilled that within you. Now, we are raising families with a lack of that thing. We are attempting now to deal with them -- especially pre-adolescents -- and getting them to understand who they are and to deprogram them from thinking that they are worthless and nothing and hopeless. We are starting there, and I think we are going to demonstrate something, and it is not involved in any funding that we have but a firm belief that I have.

MR. DEVOS: That is the stuff we need. I have another little talk I give, and it is called the three A's. I think action is the result of attitude, and attitude is the result of atmosphere, and we have got to put those people in an atmosphere of hope.

DR. EDWARDS: That is right. You have got it.

MR. DEVOS: And how we are going to fashion that, and you are working on it, that is the stuff we have got to get to,

and then you begin to unravel some of the other problems, and so, I am delighted to hear what you are doing and we have got to share specifics on things that we have got working in our communities, and then we can spread that out across the land, and we can tackle some of these things. So, I salute you for what you are doing, and I am not minimizing the need for data. I want to try to get down to a person whose life we can impact and get on with something.

CHAIRMAN WATKINS: Dr. Walsh?

DR. WALSH: In trying to reach the atmosphere that Mr. DeVos is talking about, we do need data. I am impressed with, Jim, your attitude of not mandating things but advising, collecting, providing data, collecting data and so on, and leaving a great deal to the states.

One of the things you said interested me. When you said that we want to normalize this disease and I believe I understand what you mean, unfortunately, there is something about this disease which is a little different than most other diseases, in that it kills relatively soon, and at least in our present knowledge of it, we don't hold much hope for those who are seropositive who may get sick down the line, and we know the disease is easily transmissible. We are all aware about confidentiality and such, but by the same token, as public health officers you, also, have in your mandate the responsibility of the health of the public.

Now, anonymous testing by number as one of the other Commissioners has said, not identifying someone, even though you have a seropositive because it simply gives you another statistical picture seems to me to be the worst thing in the world that we could be doing to create the atmosphere that Rich is talking about. I wonder, for example, what is your attitude towards more extensive testing with the degree of confidentiality, of course. Those of us who practice medicine always practice in an atmosphere of confidentiality and maintain it with our patients, but we have an obligation to not let this disease spread, to contain this disease as much as possible. What are your attitudes towards the expansion of contact tracing and towards the expansion of almost creating an atmosphere? (I hate to use the word "mandatory" on anything because I hate mandatory anything of any kind.) But there has to be a way in which we can persuade these people that they are endangering other people. There has to be some contriteness in this whole picture by the people with the disease. Otherwise, we are simply going along with kidding ourselves with accumulating numbers.

We are testing prenatally, but how many of the poor, for example, are actually getting prenatal care? So, this becomes sort of a false statistic because the underpriviledge in

the major cities, many of then never get any prenatal care. We have no idea what is existing among this population, and I share a degree of impatience that Rich demonstrated because we have been listening for 6 months to why we cannot do anything, rather than why we can do things, and somebody's feelings may in the long run be hurt; yet the gay community has demonstrated that you can change behavior. Granted you have to do it in a different way in other minority groups, but I think, also, while confidentiality has been one of the great demands of the gay community, the gay community obviously exchange information with one another so as to bring about a diminishment of the spread of this disease. They must have. There is no other way it could have been done, and I am just wondering what can we do from the standpoint of making contact tracing more of a policy, making testing more of a policy.

We are doing random testing and anonymous testing, and we have heard testimony, for example, by an official in New York that they did random testing on 50 persons at Riker's Island and got 64 percent positives of people who are in prison an average of 47 days. When they leave prison, what is the first thing they look for? They look for a sexual partner. Don't we have an obligation to stop this as a public health officer? I don't know. I mean I should think we would, but these are the problems that you have to tell us because, at least I don't feel this Commission should be the patsies that come out and make all the hard decisions for you because as Kris Gebbie said, someone told us this morning that everything should be mandated by the fact of public health and science. When you get a killing disease, you have got an obligation to protect the public until we can find a prevention or a cure, and I don't think that we are doing that. I think we are playing games, and I would welcome any comment.

DR. MASON: I would be happy to start those comments. First of all, we have got a lot going on in this country. Who is discouraged? I am not. We have a bad epidemic going on. It has taken a while to build the structure that will combat it and get grants and information out. In the last few months the people of this nation have been hearing how the disease is transmitted and how it is not.

You say that this disease is easily transmitted, I don't agree with you. One has to be involved in a very intimate kind of contact where semen, vaginal secretions or blood are shared. You have to do it probably repeatedly, unless you are very unlucky. So, it is not easily transmitted. It is a disease that is transmitted only in intimate behavior.

DR. WALSH: Which should make it easier to control, Jim.

DR. MASON: That is what I am saying. There are many people who feel that all we have to do is test, and the epidemic will stop. That isn't true either. What we have to do is get people to change their behavior, and although testing may help to change behavior for some individuals, we would like to help everyone change their behavior whether or not they have been tested. There is no guarantee that because you have been tested you will change your behavior. In the Commissions interim report, it recommended opening up additional treatment slots for IV drug abusers, "It does little good to tell an IV drug abuser that they are AIDS positive if in a few hours they are going to be willing to do about anything to get their next fix. If we test and don't give them a treatment slot, what good have we done? Everything has to be put into perspective. We often test them in prisons, and then we don't provide separate facilities. It is like the dog that chases the car and suddenly catches it. It doesn't know what to do there. If we do more testing and we must, then there is, also, a responsibility to have the counseling, the treatment slots and the other resources in place that then these people will need.

DR. WALSH: Jim, I am not saying that. I am saying that the fact that you test them in prison, and you find them positive and you say to me, "So what?" I am saying to you that it is your obligation to make a recommendation that has teeth in it that would prevent these people from spreading the disease. Are you suggesting criminal penalties if they go out and engage in behavior? No.

DR. MASON: The point is that all you can do to absolutely prevent them from transmitting disease is to not let them out of the prison. Maybe that is what you want to do, but then you have to segregate them, and so far few have been willing to put that kind of money into the Nation's prisons. I am <u>just</u> simply saying that with every decision there is a series of other actions that have to be put in place to make that decision rational.

With regard to testing generally, CDC guidelines, recommend that everyone who comes into a series of clinical settings be routinely tested. We have recommended partner notification. I don't believe there are enough resources to begin to do really comprehensive partner notification on a national basis. We are not beginning to approach that magnitude of resources because of their labor intensity.

DR. WALSH: Are you opposing contact tracing?

DR. MASON: No, we are recommending it in the documents.

DR. WALSH: Then you must believe in partner notification.

DR. MASON: Contact tracing and partner notification, are similar concepts. We get mixed up in our use of words. Unless antibody positive individuals are willing to volunteer the names of their partners, you never get them. In other words, the bases for partner notification or contact tracking has to be a comfortable, sensitive, voluntary type of approach. How many health departments with large numbers of cases such as New York City of San Francisco have the people resources to go out and find the contacts that are named. People who test positive are generally asked to notify their own partners and ask the to come into the counseling and testing clinic. With syphilis in the past, we have had to ask people to notify their own partners and encourage them to come in. Without establishing sensitivity and trust the whole system breaks down. Coercion as it relates to any STD including AIDS fails. We don't put people on the rack here in this country. In an atmosphere that doesn't engender trust and confidence you don't have addresses if we are talking about IV drug abuse. We have to depend upon the infected person to make the system work. CDC is asking each state, in receiving an FY 1988 AIDS grant for risk reduction, that they prepare a plan for implementing partner notification or contact tracing. Each local government entity as we have heard today will approach that differently in relationship to their AIDS cases and total population. These gentlemen who are here with me are approaching partner notification on a rational basis. They are more interested in the public health than they are in simply social or political issues. That is what they are paid to do, and that is why they are here.

DR. NOVICK: Yes, I think in terms of just the impression here. Confidential testing is really sharply increasing in New York State, not on the decrease, must more so that the other forms of testing. In our state, as I mentioned earlier, we are going after all the public sort of facilities where there might be high risk; all the family planning clinics to have the capability to do confidential testing. We don't permit anonymous testing. All the prenatal sites are working with Medicaid. As Dr. Mason mentioned, our STD clinics in the counties are doing this, and they are following this up where we have the staff on site. But at STD clinics, for example, we permit partner notification. Contact tracing would be another word for it, as long as there is participation; it is voluntary, and there is confidentiality. So, I do think that what you have indicated is taking place.

DR. WALSH: That is what I was trying to get at because, again, in the recommendation that comes out of this Commission, with limited resources, we have to have the judgment of people like yourself on what are the priorities. It would be

ideal if we could put everybody in the country in a treatment slot on drugs. It would be ideal if we could provide individual counselors for everyone and so on, but as public health people in the trenches which is the best way for us to go? Let us say that we go to Congress for X amount of dollars or recommend it in this report, where is the best way to spend it prioritywise, so that we give them some choices rather than have them make, I mean we give them firm recommendations on the best way to spend whatever they are willing to appropriate. That is what I am after, and I think that you have, in part answered that.

DR. EDWARDS: I feel, if I might, doctor, that if we are going to be effective in dealing with this problem, we have to think about it as a societal problem. We cannot think about it in the traditional methods by which we have dealt with other problems. We must, first of all, understand that keeping busy and doing things to satisfy the public is not necessarily accomplishing what we want to do. We know that if we were to demand testing and so forth that a lot of people would go underground. We know that, and will accomplish little or nothing. We know the best solution, if we can get some of our expertise centered on educating the public. As I mentioned in my talk, we know how to sell everything. We know how to change people's behavior about buying, but we have not transferred this expertise into health.

Now, if we can convince people to be responsible for sex partners, all the prisoners in the world can get out there, and people will protect themselves against it. We know that, but we have not spent the resources and used the expertise that we already have of how to sell people ideas, how to sell people concepts.

For the first time we are being forced to deal with society as a whole. That is the only way we are going to conquer this disease. Drugs will be here to stay. We have to teach our young people how to walk among drugs and not be affected by them. Sex is here to stay. We have go to bring sex back to more of an individual responsibility, you see. We can do that, I think, by dealing with society and a whole, and that is to commit our resources to educating and refining society as a whole, and it will take care of itself.

DR. WALSH: I agree with you.

CHAIRMAN WATKINS: Dr. Walsh, we are really going to have to move along. We have several other members. I don't want to keep the panel more than one-half hour beyond.

DR. WALSH: Did Dr. Wasserman have a comment?

DR. WASSERMAN: Just a very quick comment. After I finished medical school, I went to law school, and I feel an overwhelming need when I see a patient who has the disease who might go back and spread that disease to a sexual partner, I feel this obligation of duty to warn. I learned about the duty to warn in law school. I brought it up at our Governor's AIDS Conference. It is a very difficult concept to understand. Under Kris Gebbie's guidance I worked on an AIDS confidentiality workshop and her antidiscrimination principles that were presented from ASTHO. Let me just read to you our warning of persons at increase risk of infection. In exercising its authority to protect individuals at increased risk of infection, the public health agency, and I think it is our obligation because we are training to do it, should warn such individuals that they are at risk. Prior to conveying any such warning, the public health agency should urge the infected person to notify voluntarily his or her sexual or needle-sharing partner, not coerce but first try to get them to voluntarily do it. If the public agency warns the endangered person, that is if there is no voluntary movement, then we must undergo our obligation and warn that third party. We should do so by providing the person with the minimum information necessary so that we don't necessarily have to disclose the identity of the person who put that innocent party at risk, and I feel that very strongly. We have enacted that within our health department. How much farther it is going to go, I don't know, but that is the message that I carry with me.

DR. WALSH: I think that is excellent.

CHAIRMAN WATKINS: Thank you very much. Dr. SerVaas?

DR. SERVAAS: My question is to Dr. Mason. Most all states now, I believe, have PKU testing for babies. You mentioned that, even though black babies don't, mostly, have PKU, and galactosemia, don't most state have that, even though it is only 1 out of 30,000 or even greater lack of incidence? Do you believe that most mothers would object to having their babies tested in this blind study you are doing?

It just seems to me that in line with what Rick DeVos said, that it is getting later for us still to be doing blind studies. Could we not deduct out the percentage who would refuse? Have we ever tried, and could we not then start testing and telling mothers so that they could use the precautions to prevent spreading it or in handling the blood from the babies or putting on Band-aids, and a lot of things? I just feel sorry for the mother who has an AIDS positive child and doesn't know it.

DR. MASON: We have encouraged testing of women in family planning and prenatal settings. It is important to determine if a woman is positive before she get pregnant. Then

you can counsel her on the risks of having a baby. As the community acquires the resources they ought to start with high-risk mothers -- the mothers that are most likely to be positive -- and then fan out from there. New York determined how many women with positive tests were being delivered by using blind filer paper discs. That led to a policy decision to provide testing services to at-risk women. Blind testing provides the intelligence and information you need to start targeting routine testing in family planning and other clinical settings for women.

CHAIRMAN WATKINS: Dr. Crenshaw?

DR. CRENSHAW: In the interests of time, Dr. Mason, I am going to ask if I can get a response to my question in writing. I appreciated very much your thoughtful comments about the normalization of public health and medical approaches to the disease, and particularly in concert with developing available and responsible confidentiality systems that aren't in place everywhere yet. Could you put in writing to us how we, as a Commission can best help you accelerate that process. There must be some model communities where they have gone from no resources to rather widespread effectiveness in short order and perhaps even some suggestions on how this can be achieved where we shorten our learning curve?

DR. MASON: I would be happy to respond to that.

CHAIRMAN WATKINS: Let me close out this hearing with one question. You have each touched on it, and it seems to me there is a very fundamental principle underlying the points that you made. With the flow of information coming down from competent technical authority on what is involved in this disease to give you the ammunition you need at the public health level (state, county and local) is it not possible that if you three public health officials were to devise the proper curriculum that you would like to see mandating from that technical advice that you might find in Belvedere, Illinois versus Chicago, Illinois; Montgomery Country versus Calvert County; New York City versus Boonville or Ithaca, New York, well thought through strategies in those local areas with those same guidelines that would be significantly different cultural, the way you target, the interest in the local community organizations, health officials, PTA, families and so forth? If you were each to go into those different areas yourself and help define those strategies, educational strategies, prevention strategies, you would find yourself turning your hat around and coming up with different answers for those communities and find it quite acceptable. In fact, you would turn around and give yourself an A for both, and they would both be totally different, not in the fundamentals but in the way you apply those fundamentals to meet the cultural needs of the society around you. If that is the case, then it seems to me there is a limit to which the federal level should

try to impose themselves on the way you decide to run those and give you full credit, if you will, to come up with some different answers to the same set of fundamental questions like a quiz, not like a quiz. You can have different answers for the same question. Isn't that the way our pluralistic society runs, and shouldn't that be a general underlying approach so that there is a cutoff level to which we are trying to come up with some curricular level which we do not try to do in other educational fields but allow the diversity of the nation to focus on this in such a way that we don't need to inflict ourselves on others. You are kind of telling us that there is going to be a different approach in each of the areas, and we should allow you to take those approaches even though he is going to give you guidelines that say, "Here are the elements that should pop into view at the right points, right times in your life sciences continuum, your human biology continuum of education, trying to get all the various settings: in schools, out of schools, in the workplace, our of the workplace people." Could you give me a comment on that, the three of you.?

DR. NOVICK: I think you are correct. If the fundamentals are the same, I think the approaches may be somewhat different, particularly where some communities have different risk factors than others, but Dr. Mason is not giving us all the guidelines we need through no fault of his own. I am sure it gets back to Dr. Edwards' comment that there are a lot of areas here that go beyond the transmission of the disease. They work on how we change behavior, how we change society, how we prevent drug abuse. These are difficult questions. I certainly don't have the answers to them. There is no concerted approach, I don't think, to give us the answers to some of these very difficult questions that Dr. Edwards posed, and I think Dr. Mason would admit that the technical guidance we get from the Centers for Disease Control is not giving us the answers either.

CHAIRMAN WATKINS: Is there some other federal level involvement then, other than Centers for Disease Control you are telling us that you need guidance from, and if so are there certain elements that say, "Yes, we need this kind of guidance, and then let us alone, and we will define the right answers for the right community, for the right ethnic cultures?"

DR. NOVICK: Our whole scientific literature about behavior change with respect to health and schools is limited. I mean we have some data in certain ways that has been applied to small groups in terms of substance abuse and cigarette smoking, but we don't know enough about that, let alone the out-of-school individuals whom you asked about earlier. I think if we are talking about education, I think if we are talking about those factors that make an individual susceptible to drug use versus not and how we influence that, we don't have guidelines nor do I know where they are really being formulated.

CHAIRMAN WATKINS: Then you are saying, Dr. Novick, that you think that the Federal Government should be focusing on certain areas unknown to this point or where there is inadequate information that would be useful to you to come down from that level, whether it is research, whether it is legislation or other kinds of things?

DR. NOVICK: Certainly research. I think there needs to be must more in terms of demonstrations in these areas that we are talking about that are now presently funded. I think you have heard about the grants we get for schools; yet we don't have well developed models yet because of an absence of research and an absence of demonstrations on what changes behaviors for the school child.

CHAIRMAN WATKINS: Okay, this is a very informative panel, very important panel, and this is why we asked you to stay with us a little bit longer than initially scheduled. We don't have this kind of talent assembled at one table very often. So, it has been important, and I would assume that we will have more questions that we would like to exchange answers with you on, and if you could keep this hearing open, effectively, for you individually and let us get back to you for individual questions that we might have. We have all been enlightened by this performance today and we want to thank you very much for taking the extra time to stay with us and hope we can continue the dialogue with us. Thanks very much.

CHAIRMAN WATKINS: We bring to the table now Dr. David Hendersen, Chief, Hospital Epidemiology, National Institutes of Health; Dr. Al Saah, Johns Hopkins Hospital, Baltimore Maryland and Dr. Michael Ascher, Deputy Chief, Virus Lab, Berkeley, California. The subject will be laboratory support for HIV prevention services.

I am sorry. We also have Dr. Brooks Jackson, Assistant Professor, Department of Laboratory Medicine and Pathology, University of Minnesota; Medical Director, AIDS Lab, Minneapolis, Minnesota. Dr. Hendersen, would you proceed, please, with your statement.

DR. HENDERSEN: Yes, sir. Thank you very much.

My mission with you and for you this afternoon is a difficult one. I have been given the charge of essentially providing you with an overview of the function of the human immune system and then specifically to discuss how the virus causes this disease, interacts with the human immune system, in about 15 minutes. That charge is a prodigious one, indeed. What I am going to do, if I could have my first slide, is to mention briefly some aspects of the human immune system that we won't really delve into in any detail.

As I am sure that many of the panel are aware, there is an entire aspect of human immunity that we don't commonly think of as immunity, referred to as nonspecific immunity. Included in this category are physical barriers, such as the skin, mucous membranes and so on, that aren't traditionally thought of as belonging to the immune system, but, nonetheless, protect us from a variety of microbes that would ordinarily have easy access to the body.

What I will do instead is to focus specifically on aspects of the immune system that relate to this virus infection. We will spend a fair amount of time talking bout antibody-mediated immunity, primarily because the rest of the afternoon will focus on the test kits that are useful for detecting the antibody to HIV and detecting who in society is infected with this virus.

I will also mention cell-mediated immunity or cellular immunity, primarily because that is the aspect of immunity that is defective, or at least, primarily defective, in people who are infected with this virus.

We might note before we move on that under the column of "Nonspecific Immunity," a line mentions -- "Complement." "Complement" is a series or a system of proteins that do participate in both the specific and nonspecific immune responses. May I have the next slide, please.

Dr. Anthony Fauci, who is the Director of the National Institute of Allergy and Infectious Diseases, has made what I think is a very clever analogy -- comparing the human immune system to a symphony orchestra. If you think of the immune system as a symphony orchestra, T-4 lymphocyte or the helper/inducer cell would function both as the conductor and the principal violinist in this orchestra.

Other cells or cell systems that are responsible for providing immunity, including humoral immunity, nonspecific immunity and so forth would represent the other players in our symphony. Next slide, please.

We will turn first to antibody-mediated immunity on the right part the slide. This slide depicts humoral immunity or immunity mediated by antibodies.

Let me spend just a moment talking about what antibodies are. These are specific proteins produced by the body in response to a stimulus. Any microorganism, whether it be a bacteria, virus or fungus or whatever, has a variety of determinants both on its surface as well as inside of the pathogen, which will provoke antibody responses. Each one of

these determinants will provoke a family of antibodies and each response ultimately will narrow to a few antibodies that have the highest specificity for the particular immunogen that the antibody is directed against.

In terms of specificity, the response is one that is very similar to a key and lock specificity, such that an antibody directed against an antigen that has a defined shape will take a shape to match the shape that is formed by the antigen. One can imagine that this would be a very specific response. On the other hand, it is also the case that, in the human immune system, at least, there is a limited repertoire; antibodies that are cross reactive might also be found. Those are antibodies raised initially against a single protein or antigen that also react with another one.

It is this kind of cross reaction that could result in one kind of false positive in the test for HIV antibodies that you will hear about later. Next slide, please.

Antibodies provide immunity through a variety of functions. The first process that provides immunity is a process called opsonization. Opsonization is basically the process of "sugar coating" the pathogens to make it easier for cells to ingest and kill pathogens.

A second way that antibodies contribute to immunity is through the activation of the complement system that I mentioned earlier. In a situation in which an antigen reacts with a specific antibody, the antibody opens up a bit and this opening up of the antibody activates the complement cascade. Complement gets deposited on the surface of the microbe and the complement itself can be responsible for killing directly.

A third example of a mechanism through which antibodies participate in immunity is the concept of toxin neutralization (e.g., tetanus toxin or diphtheria toxins -- are toxins produced by bacteria). If an antibody binds to the active site for these toxin, it neutralizes the effect of the toxins, even though the toxin still may be circulating in the blood stream.

A fourth protective mechanism is the binding of the attachment site of the pathogen. A virus, which gets into the body, has a given host range; that is, it will attach to the organism via a certain mechanism. If the antibody binds in just that area, it could, in fact, prevent attachment and, therefore, prevent infection or abort the infection should it start.

A fifth general way through which antibodies participate in immunity is the concept of viral neutralization and I will leave that until last.

The final issue listed on this particular slide is the notation of the concept of arming killer lymphocytes for a phenomenon called antibody-dependent cellular cytotoxicity (ADCC). I am not going to go into detail to talk about ADCC; just to note that antibodies also participate in other aspects of immunity; in this instance contributing in some way to cellular immunity. Next slide, please.

When we discuss HIV infection we are talking about a virus infection. For this reason it may be worthwhile to talk in some detail about mechanisms of viral neutralization by antibodies. That happens essentially in four different ways -- first, as we mentioned earlier, with the fixation of complement. Complement, by itself, when activated, can directly inactivate some viruses.

Secondly, antibodies may neutralize viruses through the inhibition of viral attachment to target cells. This inhibition can occur through the mechanism that I described earlier; that is, through blocking of the host range of the virus.

A third, mechanism of viral neutralization is interference with normal virus functions; for example, the virus function called unenveloping; that is, as the virus gets inside the cell, the first that happens is it opens up its cellular envelope to allow the insides of the virus to have access to the inside of the cell. If an antibody is sitting exactly on the point where the virus would open its envelope, it can prevent that function and prevent the cell from becoming infected.

Fourth, the physical presence of an antibody molecule attached to a virus may, just on the basis of its size alone, prevent the virus from entering into its target cell. Next slide, please.

To talk just very briefly about how the antibody response develops, again without going into detail, I would note, that, on a superficial level, this appears to be a relatively simple process. Antigens, which are in the bloodstream or in the circulation, are engulfed by a macrophage. The macrophage will ingest these antigens, processes them some and will array them on its surface and present them to either a B-lymphocyte, which ultimately will differentiate into an antibody-producing cell, or to a T4 lymphocyte, (the helper cell that we mentioned earlier,) which can initiate cell-mediated responses and also augment or amplify the B-cell responses; (that is, the antibody-producing responses.) Now, all this takes time. The antigen gets into the circulation, gets processed by a macrophage. There is a process which takes place ultimately resulting in the production of a family of antibodies that have specificity for the infecting pathogen.

This period of time, (i.e., the time from infection until the development of detectable levels of antibody), has been referred to in the past as the so-called "window of infectivity"; that is, the time during which someone is infected with HIV, for example, and infectious, but not detectable using the conventional antibody detection kits.

Recently, some investigators have suggested that this window of infectivity may be opened a bit wider than the initial three to six months that was suggested early on. Use of new technologies that detect parts of the virus itself or perhaps the genetic material associated with the virus may ultimately resolve this issue. It should be pointed out, however, that people in this window of infectivity are both infected and infectious. Next slide, please.

Turning now to cell-mediated immunity, this is the arm of the immune system that works primarily against intracellular pathogens. These are organisms that get into the body and directly infect cells. Once inside of cells, such organisms are not easily accessible to antibodies. Thus, we have to have a second mechanism available to kill such infected cells.

Cellular immunity is primarily the domain of the T-lymphocyte. T-lymphocytes are divided into sub-populations based entirely on protein markers found on the surface and these markers are associated with the function of the marrow sub-populations of cells. For example, we refer to the T-helper/inducer cell as the T4 cell. That is because it has this molecule CD4 present on its surface, which identifies it. Those cells provide a series of specific functions.

The T8 cells, suppressor cells or cytotoxic cells function primarily to damp or suppress immune responses. Also those cells differentiate into cytotoxic lymphocytes, the cells that are actively involved in killing the cellular targets that are infected with viruses.

T-cells respond to antigens in a very similar way to that I described for B-cells; that is, the antigen is engulfed by a macrophage, presented, arrayed on its surface; processed initially and then presented on its surface. The T-cells are triggered. They divide; specific T-cells are recruited into this area and the cells become activated, secrete a variety of protein messengers, which activate other cells, including macrophages, to come in and kill off these infected cells in this area.

The cells that are activated include the local macrophage population. Other cells are also recruited into this area, including killer lymphocytes that we talked about earlier that participate in so-called antibody-dependent cellular

cytotoxicity, and also natural killer cells; cells which kill by direct contact, virus-infected cells. Next slide, please.

Turning briefly now to the interaction of the virus, human immunodeficiency virus, with its target cells, the two cell lines that are predominantly infected are T4 lymphocytes and macrophages. Both these cells express this receptor CD4 on their surface. The virus attaches to CD4, unenvelopes, and puts its genetic material into the cytoplasm of the lymphocyte. Its genetic material, you will recall, is ribonucleic acid, RNA, that uses this unique enzyme -- called reverse transcriptase, to make a backwards, single stranded copy of DNA off of the viral RNA template. This simple strand of RNA is then complimented by the host cell, and, ultimately, this double stranded DNA, provirus, gets inserted into the genetic material of the cell and becomes a part of the genetic material of the cell. The provirus will sit there until the cell is triggered or some other event causes activation of the cell, at which time instead of doing the normal business of the cell, this cell will produce many more copies of the virus, become lysed. The liberated viruses then will go on to infect other T4 lymphocytes and other macrophages.

In terms of an immune response to HIV, you will hear a lot the rest of the afternoon about antibodies produced in response to infection with this virus. During the process of this virus infection, a variety of virus associated proteins are uncovered and exposed to the immune system including parts of the viral envelope, parts of the core of the virus and certainly proteins associated with or coded for by the genetic material of the virus, such as reverse transcriptase and the other endonuclease enzymes that are present.

It should be pointed out, however, that some antibodies have been found that if you have them in high enough titer, can, in the test tube, at least, neutralize the virus. Our hope would be that through immunization, one might raise a high enough titer of these antibodies, to prevent infection. So, if we could immunize someone and give him or her a high enough level of neutralizing antibodies prior to infection, the virus could be bound up and done away with without producing infection.

It also may be possible through the use of some immunomodulating substances to rev up cellular immunity. In the laboratory, one can demonstrate specific cellular cytotoxicity, that is, cell killing, of virus-infected cells by T8 lymphocytes from people that have been sensitized to the viral antigens.

That is a very quick tour through the human immune system. We are now going to focus for the rest of this panel, on the tests to detect antibodies to HIV. I give you Dr. Alfred Saah, who will discuss in some detail the tests for anti-HIV detection.

DR. SAAH: Thank you, Mr. Chairman, Members of the Commission. My testimony is essentially contained in the briefing book. It is a chapter that I wrote on the serological diagnosis of HIV infection that was published in a monograph by the American Medical Association. What I will do this afternoon is to -- rather briefly because I know time is short -- go through the process of antibody detection in the currently licensed ELISA kits and use that as a paradigm for the way in which antibody is detected in the so-called confirmatory or validation assays that are available. Chris, if we could start with my slides.

Now, what happens during natural infection is that first there is exposure to the virus through either sexual intercourse or IV drugs. Infection is established. After infection is established, antibodies are produced usually within four to twelve weeks. We know this from studies of individuals who have received contaminated blood and others with known single exposures.

Following virus replication for a period of four to twelve weeks, antibody is produced as the body's response to recognizing the invading virus. Next slide, please.

The enzyme linked immunosorbent assay is the assay that is known colloquially as the ELISA or the EIA for enzymeimmunoassay. What is done in this particular assay -- next slide -- is that HIV, the viral antigens that are grown up in cells, are broken up and put into little plastic wells. The antigen, which is designated by the triangle, can be taken as a generic form of HIV antigen. Next slide.

When the patient serum is added to the well, if there is antibody present to the specific antigens of the virus, they will attach in the bottom of that well. You might also note that if the patient has sticky antibody or antibody that may stick to plastic, that antibody will also stick inside that well. But, for the most part, the idea, the premise behind the assay is to measure antibodies that are specifically attaching to the virus in the bottom of the plastic well. Next slide.

Now, what we have is the patient's antibody attached to the viral antigen in the bottom of the well. How do we find out that that antibody is really there? We use a second antibody. The second antibody is an antibody that is usually made in goats and the goats are immunized against human being immunoglobulin, so that the goat makes antibody to human immunoglobulin and can detect human immunoglobulin that is attached in the bottom of the plastic well. That antibody from the goat can be labeled, it can be tagged and it is tagged with what is labeled up there as these "E's" and those "E's" stand for an enzyme. Next slide.

That antibody attaches to the human antibody and then you need to give the enzymes something to work on. This something to work on is substrate and the substrate can be a substance that changes color if the enzyme is present. What you do is allow the reaction to proceed -- next slide -- and then you stop it and after you stop the reaction, you are able to read the color development in a spectrophotometer; simply shine a light through the well and measure the light that penetrates through the well.

The process involves detecting antibody that is directed against the virus and finding the color change if the enzyme has had, first of all, established residence inside the well and, therefore, worked on the substrate that you added. If the individual who is tested does not have antibody to HIV, there will be nothing for the goat antibody to attach to and there will be no enzyme left in the well. There will be nothing left for the substrate to work on and the test will be negative. Next slide.

Now, that detection system is used in slight variation for everything else that is used in detecting infectious agents when you wish to measure antibody. The Western blot is simply a slurry or soup of antigens that is in the plastic well, but they are separated electrophoretically. They are separated by being put across an electrical gradient and when the antigens are separated, they are characterized by their molecular weight.

You have heard of antigens such as P24, P55, GP41. Those numbers stand for thousands of daltons and a dalton is something like 10 to the minus 24th gram. It is a very small amount. And the "P" simply stands for "protein." The "GP" simply stands for "glycoprotein" and those elements as you see on the slide, although not very well because this slide is rather small -- these elements are part of the virus. GP41 is the part of the virus that is the transmembrane protein . GP120 is the part of the virus that hangs off the edge of the virus and attaches to the CD4 molecule.

P31, P51 and P66 are polymerases. They are enzymes that the virus uses to reproduce its own genetic code. Those antigens are identifiable on a Western blot -- can I have the next slide, please -- because the antigens are separated and a very similar detection system is set up to measure the antibody in a Western blot, as in the ELISA. What we have here are essentially paper strips that the antigen is blotted onto from the gel. The gel is what is used to electrophoretically separate the antigens and then the antibody is reacted on the paper in the same way as it would be in the bottom of the well and then a second antibody is added that has some kind of detection system. The method for that detection system, to tell whether antibody is

there or not, the substrate, is added. If there are antigens present in the specimen that you added, then you will find dark bands on the Western blot.

The Western blot labeled A is a Western blot that is tested against a serum specimen that has no HIV antibodies in it. You see no bands on that Western blot. The label, Specimen B, is a positive control and Specimen A is a control specimen from someone who is known to be HIV positive. Those Western blots you see have many bands on them and that simply means that the patient's serum recognizes the specific antigens that are on that piece of paper and the detection system has allowed that antibody to be developed in a way a photograph is developed. Next slide.

Now, this slide is an indirect fluorescent antibody slide and it is another method of confirming or validating the presence of HIV antibody. What this slide shows are cells that are infected with HIV. They are either H9 cells or CEM cells. I think they are H9 cells and they are infected with HIV and they are put on a glass slide.

The individual who you wish to test for the presence of antibody, you take that serum and you put it on this spot of cells that are on that glass slide and then you use a second antibody, much the same way as the process in the ELISA, only the detection system is not an enzyme here. It is a fluorescent molecule, so that when you look at this under a microscope with a fluorescent light, you get this characteristic picture.

If you do not see that picture, then the specimen is negative. So that the presence of antibody is detected, again, by a system that allows you to develop, if you will, a picture; only in this case, it is on a glass slide instead of on a piece of paper or instead of in the bottom of a plastic well. So, the fundamental process is the same for the detection of antibody. It is simply amplifying a signal that you can detect, either with your eye or with an instrument in order to say that there is antibody against HIV in this specimen or no. Can I have the next slide, please.

There is another technique called the radioimmunoprecipitation assay. This is a highly complex technique that requires radio labeling of the virus. It requires five days of incubation on a piece of x-ray film and what you are seeing there is the radio label of the virus and the reacting antibody and what this procedure does is it reacts to antibody and radioactive-labeled virus specimens and only the pieces of the virus that are attached to antibody are separated and put on the piece of x-ray film. The piece of x-ray film is put away for five days.

When it is read, the radioactive label that is present on the virus is the part that develops the piece of x-ray celluloid below it and it is just simply another detection system that because it is radioactive and because it takes five days to develop is not used on a commercial basis. It is purely a research project. I will have a little bit more to say after Dr. Ascher's testimony.

CHAIRMAN WATKINS: Thank you. Dr. Ascher.

DR. ASCHER: Likewise, I will try to be brief and give time for questions. I prepared for the panel an outline, which is in two forms; a sketch on the front and an annotated version on the subsequent pages, which you can refer to. I am going to try to hit each of the items, at least superficially, to provide you with a starting point for further questions from the outline. I can enlarge upon any of the items. It is a hodge-podge of material.

The problem that Dr. Hendersen stated, which I can restate, and the paradox of this disease, which is unusual among infectious diseases, is that antibody equals infection equals infectiousness. Now, for those of you that aren't immunologists, this is a little strange. You were taught that antibody means immunity means recovery means resistance and that is the first paradox that we have to go through in terms of getting an understanding of what is going on. That is the bad news.

Now, the good news, and most of what I have to say is good news, is related to the state of the art of testing. Now, if you have been confused or received conflicting testimony or are trying to find out what is going on from the literature, a lot of the confusion has cleared as of this point in time. A lot of the issues in the literature up to today are being settled at this very moment and I will highlight some of them right now, particularly in relation to test kit performance. I will go through some of the concrete examples of how tests work very quickly. First slide, please.

Now, this is something that you may follow or may confuse you as well, but what I have done is put two populations on the screen; a negative population in blue and a positive population in red and shown you that the frequency of these will vary depending on the performance of the kit. An idealized kit will separate those two populations completely from each other. The next slide.

As you look at the way the test kit performs, depending on where you set the definition for positive or negative, the so-called cutoff, you can get any number of results. Next slide. The problem results will occur in that area between the

two populations where, as you can see, overlap is occurring. Next slide.

What happens is as the true negative and true positive populations overlap -- next slide -- and you generate the four populations that are frequently referred to; the true negatives, which are the blue ones below the cutoff, true positives, which are the red ones above the cutoff and the two conflicting or discrepant populations, the frequently mentioned false positives, those specimens above the cutoff but not confirmed in this case by immunofluorescence or the specimens which haven't been discussed very much, those specimens below the cutoff, but which are really from infected people and could represent quite a problem. So, the question for you is what does the actual data look like. I thought that might be helpful. Next slide.

The actual data were bad news. In the first part of 1985, with our assessment of the original ELISA kits, you can see with a cutoff of 1, there are a proportion of specimens over the cutoff that are not confirmed positive; and a significant proportion, as many as 2 to 3 percent, of true positives that are missed by this test.

Now, if you go back to the literature, even things that are published today, and think about how test kits perform and try to get a straight answer, people will cite to you data based on this original technology. That is not the present day situation, and I will document that as clearly as I have ever done anything. Next slide.

What we did in the summer of 1986 and subsequently is we took a kit that had those original characteristics as a starting point and took 200 positive sera and 100 negative sera and looked at them and, as you can see, 8 sera are falsely negative. Now, did anyone else worry about this? Well, if you will remember in the blood banks, the specimens are considered negative; the blood is used. In our public health situation, with very high seroprevalence, these were specimens that would have been missed. A lot of the problems in the literature about the test performance is based on this old data.

Working with the manufacturer -- next slide -- the kit was improved without a lot of hoopla, to give this change in performance in the summer of 1986. A third licensure of the same kit was issued in early 1987 and you can see there is a 2 logarithm improvement in separation to populations. This was done without public notice. This is all very good news. Next slide. Here is another kit manufacturer that had a very good separation to begin with and with a minor change -- again, without a lot of hoopla -- produced basically a perfect test. Next slide.

Recently, we ran this new reagent on a series of 2,000 consecutive sera from the San Francisco alternative test site and this is the separation. I don't know how much you understand these graphs, but I can tell you that biologically this is the cleanest separation of any test that has ever been done by mankind for anything. That is a very clean separation.

The issue of false negatives or specimens missed is no longer an issue. The issue of how close to the cutoff the negative population comes and how many false positives one might generate in the present situation, I will leave to further discussion by Dr. Saah and Dr. Jackson but, as you can see, it is a very, very clean separation and a big improvement. Some people have asked right now what is the role for additional tests, given the sensitivity of this issue, particularly the antigen test to detect virus. We ran on this same exact panel antigen tests and found no antigen positives in the negatives. Zero. Only 6 percent of the positives were positive. So, it does not appear at this point that antigen adds anything to an already virtually perfect detection of positives.

A second bit of information, which again has not received the attention it might have is that last spring or almost a year ago, the FDA licensed a standardized method for confirmation, of ELISA tests and this was one manufacturer's licensed Western blot.

It provided a standard against which all tests can now be compared. Now, we don't all agree as to whether it is perfect at this point, but at least it has been a major breakthrough to get people to agree on that in terms of what is going to be licensed. It took about a year and a half to get something licensed, but the licensing act itself was a significant step forward.

The issue of the quality of the test and its interpretation remained in the public health a very big problem. Progress has been made last month at CDC when a Public Health Service meeting was called of all the jurisdictions represented at this table to discuss the interpretation of the kit, now the standard, and some changes were made in the interpretation to broaden its use in jurisdictions other than blood banks.

Now, you remember this and all the other tests are licensed for blood and blood products only or primarily and those of us in public health had a big problem with this complicated procedure. But now to our satisfaction, we feel there is a compromise document that covers interpretation of this result in all situations, ranging from blood banks to high risk screening and certainly cover the situation of seroprevalence testing, which I am sure is on your mind.

We feel that in almost every situation a clear "yes" or "no" answer can be obtained through this test or a combination of tests behind that, that Dr. Saah went through. There should no longer be the issue of unknown or indeterminant specimens.

The document resulting from this meeting should be published in the Morbidity and Mortality Weekly Report in the next few weeks and a copy will be given to your staff as soon as it is available in draft. It is a very short document and to the point. Dr. Allen is the staff for that from CDC.

At the same time at that Public Health Service meeting, we had another bit of good news. A big concern in testing is what we call performance evaluation. It is a new name for proficiency testing. It is testing how labs do their job. CDC had dropped that in many areas because it was not shown to be cost effective.

A number of us in HIV testing were not so sure that it shouldn't be restarted. The good news is it has been restarted with a vengeance. It is coming on very strong. That is very good news. They have sent out their second panel and they are going to see how things have performed. It is a very important function and it is very nice that this is coming back.

The third thing is that the AMA, concerned about the practitioners' role in this, has commissioned a small panel -- two of us are here -- to work on putting a statement together for practitioners, which should be out in draft in the next few weeks and also will be available to this panel. It restates some of the principles that the three of us have said so far and tries to put some of this background information in writing.

The fourth thing is that the Association of State and Territorial Lab Directors has met twice and next week will meet for the third time to thrash over these exact same issues and a document from that group will be forthcoming, which will be referred to you for reference. These are all very timely meetings.

The fifth thing in this section is that at this very moment the FDA is holding a conference at NIH discussing the role of new technology in testing. A document from that meeting will also be available. There will be some issues settled at that meeting tomorrow.

As far as California in particular, there are a couple of new concerns that I would leave you with at the end. We have been tweaked recently by the appearance of applications for home testing kit. These are actually home blood collection devices that would put specimens into the testing system. We are talking about it a lot. We don't know what to do yet and it does, as you

can, I am sure, imagine, add some new dimensions to the issue of how do you find out who is tested or tests positive. We don't have an answer; a lot of discussion is going on.

A second concern is the second AIDS virus, the HIV-2 that hit the press a few weeks ago. There is no evidence of HIV-2 other than a visitor to New Jersey. We are looking actively around the country daily. You will know about the next one as well when it comes.

The last concern -- and this is something that the panel may have to consider as a jurisdictional matter -- the first of the human lymphotrophic viruses, HTLV-1, is not a cause of AIDS. It does, however, pass by the same mechanisms between risk groups, particularly among IV drug users. We have some recent information that has come out of California that at this point in time the seroprevalence of this virus in drug users may exceed the seroprevalence of HIV by a factor of 7.

We don't know really what to do or where this matter should be referred. Next week, in Kansas City, at the Lab Directors Meeting, a whole day will be given to this topic, but this is of great concern, particularly as it impacts on blood banks in terms of the screening for it. I will stop at this point and pass on to Dr. Jackson.

DR. JACKSON: Thank you for giving me the opportunity to testify before this Commission regarding the accuracy of HIV antibody testing, of populations at low risk for HIV infection.

Recently, there has been testimony before a House subcommittee by Lawrence Miike of the Congressional Office of Technology and Assessment in which he testified that the estimated false positive rate of screening Midwestern blood donors with the enzyme-linked immunosorbent assay or EIA in conjunction with the Western blot for HIV antibody may be as high as 80 per hundred thousand dollars; 80 false positives per hundred thousand donors. Based on this estimate one would expect 200 false positive HIV antibody results in screening 250,000 Midwestern blood donors.

However, I am here to report that actual, not estimated but actual HIV antibody testing of approximately 580,000 blood donations from 250,000 different Minnesota blood donors did not result in even one false positive HIV antibody result; let alone the 200 as estimated would occur by this recent testimony.

To be more exact, three Minnesota blood collection facilities screened approximately 580,000 blood donations from 250,000 different Minnesota blood donors from March of 1985 to September 1987 for HIV antibody using different licensed commercial EIA kits and Western blot for confirmation. During

this time, 15 donors tested positive for HIV antibody as evidenced by a repeatedly reactive EIA and a positive Western blot.

To examine whether there were any false positives in this group, we obtained blood from 13 of these 15 donors for HIV culture; all specimens were culture positive. The two HIV-antibody positive donors who were not available for follow-up culture admitted to having risk factors for acquiring HIV infection and one had developed symptoms of HIV infection at the time of follow-up interview.

These results demonstrate that the combined false positive rate for HIV antibody testing, utilizing the EIA screening test and Western blot is extremely low, at least in our population less than 1 in 250,000, even in these very low risk blood donors. Remember, these are donors who have already been screened for high risk factors or who have denied having any high risk factors for acquiring HIV infection.

Now, our results are similar to those reported by Dr. Donald Burke of the United States Army in which he found only 1 in 135,000 Army recruits had a false positive HIV antibody test utilizing the EIA and Western blot in sequence. Likewise, in a recent proficiency testing program conducted by the College of American Pathologists, none of the 83 participating laboratories would have reported a false positive test result when performing the EIA and Western blot in sequence.

In terms of false negatives, the College of American Pathologists' survey reported that 0 to 0.5 percent of 616 participating laboratories incorrectly reported a truly positive sample as nonreactive, using the EIA screening test. Or in other words, 99.5 to a hundred percent of the laboratories correctly identified samples positive for HIV antibody with the EIA screening test.

Based on the above data, I believe the sensitivity of the EIA screening tests is extremely good and that the risk of a false positive antibody using the EIA and Western blot in sequence in an experienced laboratory is much lower in practice than previously estimated. Nevertheless, I want to emphasize the HIV antibody testing should be performed by a laboratory with demonstrated proficiency. The Western blot in particular is difficult to perform and it is not always easy to interpret even for experienced laboratories. This difficulty has been lessened somewhat by the licensed kit. Furthermore, not all laboratories use the same criteria that indicate a positive Western blot and, at present, there are no standards or regulations to assure that laboratories are proficient at HIV antibody testing.

Therefore, I conclude that while HIV antibody testing of low risk populations is extremely accurate when performed by a proficient laboratory, I recommend that widespread testing of low risk populations be undertaken only if the testing is performed by a laboratory which participates in a reputable proficiency testing program and demonstrates proficiency at this testing on a regular basis. Thank you very much.

CHAIRMAN WATKINS: Thank you very much, Dr. Jackson. Yes, Dr. Saah.

DR. SAAH: There was a bit more testimony that I wanted to give. I wanted to follow Dr. Ascher, but I can give it now. It is only a couple of minutes.

CHAIRMAN WATKINS: Very short?

DR. SAAH: It will be, I promise.

CHAIRMAN WATKINS: All right. Go ahead.

DR. SAAH: Next slide, please.

About a year ago, the AMA asked me why a test that was 99 percent sensitive and 99 percent specific was wrong 95 percent of the time. So, I had to put together something to talk to a rather large group of people to describe this phenomenon. I think it is relevant insofar as what Dr. Jackson just said.

The sensitivity of a particular test is that when the test is done, it provides a positive result when infection, read condition, is present. Next slide, please.

The specificity is when the test is negative when the condition is absent. Next slide.

What I did was devise an example where we used a breath analysis instrument. Let's get away from HIV. Let's get away from antibodies and infection. We are going to talk about a breath analysis instrument, a breathalyzer for alcohol. The instrument is 97 percent sensitive, which means it will call 3 percent sober, who are actually drunk. It has a specificity of 98 percent, which means it will identify 2 percent of people who are sober as intoxicated. Next slide.

The test is performed in a population of 2,000 conference attendees at 10:30 in the morning. Two of the attendees are intoxicated. The proportion is .1 percent at 10:30 in the morning. The sensitivity of 97 percent means that we could identify many more intoxicated individuals than we actually have in the audience. But the specificity of 98 percent means that we are going to identify 2 percent of 1,998 sober

individuals at 10:30 in the morning as intoxicated; 2 percent of that number is 40.

We identified the 2 who are intoxicated, but we also mis-identify 40 sober individuals as being intoxicated at 10:30 in the morning, giving us a result that when the test is positive, it is correct only 5 percent of the time. Next slide, please.

Same population, 12 hours later. It is 10:30 at night. The 2,000 conference attendees have had an opportunity to have dinner and several glasses of wine, martinis, et cetera. Five hundred of them are now intoxicated. Same test, same population, different prevalence of alcohol. In this instance the 97 percent sensitivity means that you would identify 485 of the 500 as being intoxicated correctly. You would miss the 3 percent, the 15 individuals, and you would identify 2 percent of the remaining 1,500 unintoxicated individuals at 10:30 at night, giving you a predictive value for a positive test when you add the 30 individuals from the sober group to the 485 from the intoxicated group of 94 percent or 485 out of 515 individuals.

Now, the distinction that is necessary to draw and the reason why I felt it was important to go through this example is because if you prequalify your population, you make the performance of the test appear much better. If instead of walking into the room at 10:30 in the morning and screening every one of the 2,000 individuals, you first ask them to walk heel to toe or you ask them to recite the alphabet, you could eliminate a large part of the group and make the test performance a lot better and it is the notion of a testing program as opposed to a test that is vital here.

What Dr. Jackson described when the low rate of seropositives is the result of a screening ELISA, a follow-up Western blot done in proficient hands and in Dr. Burke's case, in the Department of Defense, a recombinant protein assay that confirms both the Western blot and the ELISA, the difference is a program of testing as opposed to a single test.

This is what will happen when you apply a single test. The performance of the test will vary enormously according to the prevalence of the condition that you are studying, but if you add successive tests, what you end up with at the end are very clean results. So, it is the program that you need to focus on, not the specific test.

CHAIRMAN WATKINS: Not being an expert in the field, Dr. Saah, I really need to understand. Are you saying the same thing that Dr. Ascher is saying or something quite different?

DR. SAAH: No, the same.

CHAIRMAN WATKINS: It is a program and yours is a program. And, Dr. Jackson, are you saying yours is a program?

DR. JACKSON: Yes.

CHAIRMAN WATKINS: Are we drawing some conclusions from this, though, that there are no more false positives and no more false negatives and we don't need to worry about that issue any more? Is that what I should conclude from this?

DR. SAAH: What I am saying is that given laboratory testing in proficient hands, with good assays, that the amount of false reactions can be reduced to very small levels. Now, this doesn't speak to the advisability of screening in any particular setting. What this speaks to is the potential for confusion that frequently comes up in this type of setting when individuals are describing false positive rates, based on essentially a single test, as opposed to false positive rates, based on a program of testing.

A good example is Dr. Redfield's testimony and Dr. Burke, where they cited two false positives in 135,000 individuals, who were negative. That final result came from a series of tests. The series of tests is similar in nature to prequalifying the population. In other words, instead of doing the breathalyzer test on everyone, you ask them to perform a particular maneuver to screen out those who you really don't want to test.

What this ends up doing is enriching the population for individuals that you wish to test and also by having successive points at which you cut individuals, because that is what all successive tests do if they cut individuals from the group, your test performance improves.

CHAIRMAN WATKINS: I guess I am confused as to whether we are at the point where that is the current situation that prevails in society as a whole today or whether this is something that you are about to give birth to on a new standard, on a new approach, on a program of testing, which is about to be born in the United States, which can eliminate the issue of false positives and negatives. I am really still having a hard time. Where are we in the presentation at this point? Are you coming up with something in a few weeks --

DR. ASCHER: No. You asked the question and the answer is we are here right now today.

CHAIRMAN WATKINS: We really don't have the false positives and negatives anymore?

DR. ASCHER: Yes. We are talking technical. We are talking about the capability of the tests to perform in good hands. If there are any problems in the overall program, it is not in the tests or their interpretation. However, it is our estimate at this point that other factors in testing, such as mislabeling of specimens, distributed mode, non-proficient laboratories may produce wrong answers, nothing to do with the tests, at a rate equal to the seroprevalence in the population, making the numbers of such a study difficult to interpret for those reasons.

It has become clear that in the presence of perfect technical tests from an individual, who is low risk, the probability of that result, being a specimen mix-up rather than a true positive is so high, that it is the community standard to always obtain a second specimen from that individual, as the military does. The military is working with perfect tests technically, but it happens frequently enough that they do not confirm someone as positive unless there is a second specimen.

We haven't yet heard any feedback from the states that are working with premarital screening, whether that is an issue, but it would be our estimate that if there is any fault in the tests, it is not at the level of the reagents themselves. I think we are going to put that to rest.

Any comment, Dr. Jackson?

DR. JACKSON: Just to reiterate, if you do the EIA screening test, how it is supposed to be done by the manufacturer's directions and follow that with a Western blot or an immunofluorescent assay, which is another confirmatory test and then if it is positive still, one gets another specimen just to rule out a specimen mix-up, a sample mix-up. This happens rarely, but it could happen. I think if it is done that way, I think the test is extremely good and also, like I said, laboratories that are doing these tests actively participate in a proficiency testing program and demonstrate proficiency on a regular basis through a program such as the College of American Pathologists --

CHAIRMAN WATKINS: Has such a program now been instituted nationwide in which all of the technical people agree, CDC, you are all together. You are now doing this out there so we can say there are no more false positives and negatives?

DR. HENDERSEN: It is important that the tests are good at doing what they do --

CHAIRMAN WATKINS: Okay. Let's write that off and say the tests are superb. Now, there is always cockpit error and there are always quality control issues. There are laboratory

differentials. We have found it in the military. We had to clean up a big act. Now, the question is are the other variables such that we have to worry about false positives and negatives? It has nothing to do with the test.

DR. HENDERSEN: Yes. There are people, who are in the process of developing antibodies, who are infected and infectious, who will not be detectable using the currently available antibody tests because they rely on the person who is infected producing antibodies on his own.

In that time from infection until you can detect those antibodies, those people will be falsely negative, strictly speaking. Now, they are not detectable. That is not something wrong with the test, but they are infected and infectious and not detected by these screening tests.

DR. SERVAAS: That is only false negatives, not false positives.

DR. ASCHER: We have a number on that you might want to be aware of. Actually, it was an estimate that we feel has some substance. It is what proportion of positives nationwide would be missed because of that factor. The upper limit of that is 2 percent. That is an important number. I don't want you to think about it too much, but what it means is that the tests biologically have a sensitivity of about 98 percent and that is based on the fact that about 2 percent of people who are infected are sort of getting into that short period. So, it is pretty darn good.

CHAIRMAN WATKINS: I don't want to hog the podium here but it was difficult for me to sit through the presentation because I am not technically oriented on it sufficiently to know what message we were to receive from this. It is still hard for me to grasp where we are. For whatever reason -- let's give you a hundred percent for the test, but are there other problems in the system so that we aren't ready at this point in time to say that we simply have eliminated all the kinks. Whether it is quality control, personnel, training, that we haven't followed the exact protocol, that we still have a number of performance errors in the system, other than testing, so that we can't rely on them today -- What is the problem?

DR. SAAH: Part of the problem that I have had as a clinician and an epidemiologist has been employing FDA criteria for a Western blot that was essentially licensed to re-enter blood donors into the system. The interpretation of the Western blot is a vital component of the use of these tests.

As Dr. Ascher pointed out, we are in the midst of devising criteria for the interpretation of the Western blot that

should clean up the large group in the middle, which have been called indeterminant; individuals who don't meet FDA criteria for being called seropositive or infected with HIV and individuals who don't meet FDA criteria for being negative, which means having no bands whatsoever on the Western blot.

The Western blot, as it is licensed for the re-entry of blood donors is a highly, highly sensitive test to the extent that in the package insert it says that 15 percent of normal individuals are expected to have a band on the Western blot nonspecifically. These are not individuals who do not --

DR. ASCHER: I think we are getting two messages here and I think you are confused because Dr. Jackson said that we are beyond the problem of false positives. I said I am beyond the problem of false negatives and yet we are hearing about problems with interpretation. What we are saying is the false positives are gone; the false negatives are gone, but what we were left with as the state of affairs until recently was an indeterminant category where they couldn't tell you what you were. And that is in certain situations just like calling someone positive. That has been a problem for about a year.

False positives and false negatives have been gone for a year in my mind. That is old hat. Forget about that. It is the fact that so many people ended indeterminant equal to seroprevalence, so the test was worth a toss of a coin, if you will, and it had no meaning. These new criteria represent a breakthrough in clarifying that problem; false positives, forget it; false negatives; forget it; getting the indeterminants classified and Dr. Jackson -- to clearly answer your question, Dr. Jackson was referring to test interpretation using the new criteria.

DR. SERVAAS: What did Dr. Jackson do with indeterminants?

DR. JACKSON: Okay. I know at our blood center at the St. Paul Regional Red Cross, we tested over that time period 500,000 donations from about 170,000 blood donors. And we came up with about 1,500 repeatedly reactive by EIA. Of those 1,500, 200 were labeled as indeterminant. So, about 1 out of 2,500 in a low risk population were labeled as an indeterminant. Or, in other words, if they were EIA repeatedly reactive, about 12 percent of those were indeterminant.

DR. ASCHER: And the 1,300 were false positive ELISAs but the Western blots are now considered negative.

DR. JACKSON: And out of that 1,500, I think we had 13 that were -- I am sorry -- there were 11 that were Western blot confirmed positive. So, in other words, the risk of a false

positive, being told you really are a positive, when you are not we didn't have -- well, we didn't have any.

DR. SERVAAS: But out of 580,000 blood tests you had not one false positive in a very low risk population?

DR. JACKSON: That is correct.

DR. SERVAAS: And 250,000 different people --

DR. JACKSON: That is correct.

DR. SERVAAS: -- you tested had not one false positive?

DR. JACKSON: Not one false positive. We had some indeterminants in there, a couple hundred indeterminants.

CHAIRMAN WATKINS: Thank you very much. We are going -- we are running late and we would like to be able to ask you any questions that the Commissioners may have by letter and correspond with you and keep the dialogue between us open as the Commission continues its work. Thank you very much for coming today.

The next panel is going to be a panel on testing, counseling, and contact notification as preventive measures. Dr. Thomas M. Vernon, Executive Director, Colorado Department of Health; Jeffrey P. Davis, State Epidemiologist, Chief, Section of Acute and Communicable Disease Epidemiology, Bureau of Community Health and Prevention, Wisconsin State Department of Health and Human Services; William C. Myers, Health Commissioner, Columbus Department of Health, Columbus, Ohio and Dr. H. Hunter Handsfield, Medical Director, Seattle-King County Department of Public Health, Sexually Transmitted Disease Program, Associated Professor, University of Washington Medical School. Welcome to the Commission and we will start with testimony from Dr. Vernon.

DR. VERNON: Thank you, Mr. Chairman. I am Dr. Tom Vernon, the Executive Director of the Colorado Department of Health. I am also Associate Clinical Professor at the University of Colorado Health Sciences Center with appointments in Internal Medicine and Preventive Medicine and I am the President-Elect of the Association of State and Territorial Health Officials.

I am honored to be here today and I am especially honored to testify before my esteemed colleague and very good friend, Kristine Gebbie.

Much attention has been paid to Colorado's program since November 1985, when we became one of the first two states to require the reporting of the serologic tests for HIV. Our program has been described as a model by some; it has been

severely criticized by others, but whether it has been labeled a model or some less flattering term, the fundamental question for us is whether we have found the balance for public health intervention, which appropriately protects both the public's health and the rights and the confidentiality of individuals.

There have been three promulgations in Colorado which have characterized or at least highlighted our program. The first was the State Board of Health regulation in November of 1985, which added the serologic tests for HIV to a long list of reportable communicable diseases.

The second, the city of Denver was the regulation of bath houses and other public places where HIV transmission is potentially facilitated. The third and I believe the most important historically was the legislation passed in Colorado and signed by the governor in June of 1987. I would like to comment briefly on that legislation, which was called House Bill 1177 when it was first introduced.

The primary purpose of that legislation was to protect the confidentiality of the reports which were required to the public health agencies. That legislation contained language developed by the Centers for Disease Control a number of years before for protecting the confidentiality of sexually transmitted disease reports. Our legislation protects the public health records against "subpoena, discovery proceedings, search warrant or otherwise." No testing may be done of any individual without the consent of that individual, with a few very specific and uncommon exceptions; one of which, incidentally, is the testing of unlinked blood specimens as in a newborn testing program, which we are launching in Colorado. There are very stiff penalties in this legislation for an individual who inappropriately releases public health records.

The second purpose of our legislation was to clarify and, in fact, limit the quarantine and isolation authorities, which were given to the Executive Director of the State Health Department back in 1947. This legislation had no explicit due process and no explicit appeals process. I won't dwell on that for lack of time.

Now, the criticisms of what we have done, which I will speak to simplistically for purposes of brevity, have been essentially three. One is that our reporting requirements added additional risk to the confidentiality of individuals and, therefore, added the insult of further discrimination to a homosexual community, already injured by the epidemic itself. Now, not just as an aside, but as a fundamental point, let me note again, that discrimination because of its influence upon our ability to attack this epidemic is a serious public health problem. If only we could deal adequately with the existence of

discrimination (and, of course, the fear of discrimination) we in the public health could be far more effective in dealing with this epidemic.

The second criticism was that gay men would go underground, would not be tested. Then, of course, the third criticism is that there would be no efficacy to this kind of program. In short, there would be risks taken but no benefit from that risk. Our experience to this date is very different from these fears and the concerns of those who criticize our program. I would like to outline a few of our experiences.

I do want to comment that it is early and that final judgment of what we are doing must await a longer perspective than we yet have. But at this point there has been no breach of confidentiality of public health records in Colorado and there is no active discrimination of which we are aware that could be traced to those records or to the recording system itself.

Concerning individuals coming in for testing, in 1986, Colorado tested more individuals per capita than all but 46 other states in a poll we conducted. I would like to refer you to a page, the next to the last page, in the handout. Note the graphic, which compares testing in Colorado and California. It is clear from that graphic, first, that through mid 1987 Colorado consistently tested 20 to 40 percent more individuals per capita than did California and that the variations from month to month appear to be due to factors which are common to both states factors and not due to the factor of anonymous testing versus confidential testing.

So, to this point, nothing in our experience suggests that either there have been increased risks or that individuals have stayed away from testing, at least in large numbers. The area in which I am most pleased to observe in the report is in the results of our program, its efficacy. Let me mention two or three areas. The first concerns the 10 to 15 percent of individuals with positive tests who do not return to the testing sites for their results. We are able to locate about 75 percent of them in the field and to provide the counseling, which is so important, whether or not they choose to learn the actual results of the tests. And, of course, the results are not forced upon them.

The military report to us in Colorado, including the military recruiting stations. Our field staff follow each rejected military applicant with a positive test and provide skilled counseling, in a civilian environment.

The third area (and I am most pleased with this) is the efficacy, at least at this point, of our partner notification program. We are very committed to partner notification (contact

notification). I provided in the last sheet of my handout a graphic which shows you some early data; 282 infected individuals interviewed by our staff revealed 508 individuals who had been partners in unsafe sex or unsafe IV drug use. We were able to locate 414 of those individuals, all of whom were counseled or recounseled. There were 296 individuals, who came to testing for the first time and of those, 45 or a high 15 percent were positive.

Now, in closing, I want to anticipate what I am sure will be one or more of your questions. I have also been asked this question by a congressional staffer, who was interested in what I was going to have to say today. Is this Colorado model as applicable to Newark, New Jersey, as it is to New Castle, Colorado?

Probably not. Should this kind of a program be mandated by federal legislation or by strings attached to federal grants? No. But I would like to elaborate briefly.

We believe that confidential reporting of communicable disease has served us extremely well for virtually a century. We believe that reporting of HIV infection should be much more widely adopted in this country than it has been to this date, but I do not believe that the Federal Government should mandate that reporting anymore than it has mandated other reporting of communicable diseases, particularly by name.

I believe that it should be the state health officers in consultation with their disease control officers and the local health officials of their state, who should be making those decisions.

Lastly, I believe that partner notification becomes a moral imperative. I feel very strongly that we have an obligation to warn unsuspecting partners in unsafe sex or IV drug use.

Now, another question is whether confidences are inappropriately revealed when partner notification occurs. Fortunately, we rarely have to make such a stark choice when we are conducting partner notification programs. The skills that our disease investigators learn in facilitating this process makes it a rare occurrence when there is an inappropriate revelation of a confidence.

I do not believe it is the place of the Federal Government or any government to mandate the notification process and I was pleased to hear the debate with an earlier panel today on that very subject. Just as this process is inherently confidential, it is also inherently voluntary. And I think that the loss of voluntariness in partner notification would undercut

the very basis upon which we make that process work. And as a last sentence, I must say it is a process which needs funding. Thank you.

CHAIRMAN WATKINS: Thank you very much, Dr. Vernon. Dr. Davis.

DR. DAVIS: Thank you very much, Mr. Chairman, Members of the Commission. I will be limiting my comments to the general area of contact notification. I do want to thank you all for the opportunity to provide both verbal and written testimony.

Contact notification historically has been a method for controlling sexually transmitted diseases by locating and referring sexual partners for evaluation and treatment as early as possible to reduce the spread of infection, prevent complications and interrupt the transmission cycle of the infectious agent.

As applied to the prevention and control of HIV infections, critical goals are to interrupt HIV transmission, particularly by those unaware of their HIV infection and risk status, to provide individualized counseling and to facilitate referral to knowledgeable health care providers of those who may require additional medical evaluation and treatment. The primary tools to prevent and control HIV infection are educational programs for the public and health care providers focused on risk reduction and disease prevention and provision of counseling, disease prevention, and HIV antibody testing services.

However, some people, ignorant of their HIV risks, will be missed by mass messages. Others will choose to ignore risk reduction messages, while falsely perceiving their risks to be negligible or non-existent. Thus, no strategy to control HIV spread is complete without a companion activity that delivers a personalized, yet fully objective risk reduction message directly to individuals at maximum risk of HIV infection.

Achieving the goals of interrupting HIV transmission requires HIV infected individuals to participate extensively in the referral of partners. However, such participation will not always be possible. Thus, it is critical to establish a rational plan in each state to provide partner notification and referral services compatible with state laws and resources.

The rationale for initiating such programs is multi-faceted and I have provided a long rationale in the written testimony, but I will provide a few examples. First, learning about a personal potential HIV infection is likely to be an overwhelming event for some. Sexual or needle-sharing partners may be angry, may be hurt or even become violent when confronted with the knowledge that they have been exposed to an HIV-infected

individual. Describing the implications of such exposures and details regarding available counseling and testing may be too complicated for some to grasp, let alone convey to their partners.

Second, due to diversity in training, experience and resources, health care providers are generally not well-equipped to notify sexual and needle-sharing partners likely to be outside of their practices, regarding the HIV risk of those partners. Notification of partners at risk only by providers would result in serious lack of uniformity regarding provision of notification services. Also, potential breaches in patient confidentiality could occur and compromise to the credibility of provider care and public health systems could also occur. Third, the demand for contact notification services is high. Anecdotally, many requests for such services have been made to public health agencies and to counseling and testing site personnel by clients who experience or expect difficulty in notifying some or all of their contacts and also by physicians. In a random survey of Wisconsin physicians, 83 percent of nearly 600 survey respondents thought local or state public health agencies should assume responsibility for partner notification, 12 percent thought the primary physician should be responsible and only 1 percent stated no one should notify partners of HIV-infected persons if the HIV-infected individual is unwilling to do so directly.

A fourth example, many whom are not familiar with contact notification mistakenly believe the process is not compatible with confidentiality. In the United States, thousands of individuals daily are notified by STD workers of exposure to one or more STDs and accept that information even though it is conveyed by persons not previously known to them and the source of the infection is not revealed during the process. The confidentiality of the source is the key to the success of the process. In fact, individuals informing their own partners can provide a greater risk to their own confidentiality if their partners talk to others.

Three principles of partner notification are that the services are voluntary, confidential and accessible. Partner notification programs should generally be voluntary for persons identified and reported to the program. Services must be confidential. All records must be maintained confidentially.

The index patient must not be identified to named partners and partners' names must be used only for the purposes of field investigation and notification. When possible, all identifying partner information should be destroyed upon completion of the investigation and statistical summaries should be used to evaluate program efficacy. Services should be accessible for those persons with validated positive HIV antibody or antigen tests and for persons with AIDS or ARC reported to

health departments. Categories of individuals to be notified include male and female sexual partners and/or needle-sharing partners of HIV-infected persons; children born to women identified as HIV-infected; recipients of blood, semen, body organs or other tissues donated by HIV-infected persons; and, in some states, persons directly exposed to blood or body fluids of an HIV-infected individual through provision of a service, such as emergency medical care.

The Oregon AIDS Task Force has recognized that persons most likely to unknowingly transmit HIV to others are those not perceiving themselves to be at risk of HIV infection. Such persons include children of HIV-infected mothers, female sexual partners of closeted bisexual males, victims of sexual abuse or rape, recipients of blood from HIV-infected persons, sex partners of closeted IV drug users and persons who continually invoke high risk behaviors, but deny they are personally at risk. Contact notification services should provide a special focus on referral of such individuals when other services do not apply.

To date, little cost benefit is available on contact notification programs and some of the novel programs have yet to be fully evaluated. In Virginia, through December of 1987, among 318 sex or needle-sharing partners referred to STD clinics for HIV testing, 72 percent were gay men, 15 percent IV drug users; 40 percent were partner referred and 60 percent were field worker referred; 13.8 percent were HIV seropositive. During the parallel time frame, of over 41,000 pre-counseled non-referred individuals who presented at STD clinics for STD services, nearly 15,000 were tested and 3.2 percent of those tested were seropositive. Thus, in Virginia, the referred partners of known HIV positive individuals are four to five times more likely to be HIV seropositive than non-referred clients presenting for STD services.

Dr. Vernon has summarized the Colorado data and I won't to through those numbers, except to say in talking with his staff, there was an additional figure that I was provided. If you look at their cost data and utilize non-start-up personnel costs, plus the costs of collecting blood specimens in the field, the costs of detecting each previously undetected HIV infection was approximately $530.00, which in relation to a lot of other programs to screen for positive individuals is a very low cost.

Since you have heard about the duty to warn in a previous panel, I will not present further testimony now except to say that duty to warn policies will impact greatly on partner notification programs.

In most states services similar to contact notification have already been provided through blood center look-back

activities involving recipients of blood or blood products obtained from known HIV-infected persons and also through follow-up of no identified risk AIDS patients. So, the expertise is there. There may not be that many people with the experience, but certainly trainable persons and the ability to expand these programs are certainly there.

One additional point I want to make is that when contact notification programs are being developed, it is very critical to develop broad-based support of individuals and groups that are likely to be impacted by such programs. Thank you.

CHAIRMAN WATKINS: Thank you, Dr. Davis. Mr. Myers.

MR. MYERS Admiral Watkins, distinguished Members of the Commission, I am Bill Myers and I have been Health Commissioner in the City of Columbus for the past eight years. I would also like to acknowledge in the chamber today Dr. Teresa Long, who is Medical Director of the Columbus Health Department. Questions could also be addressed to her later if the Commission desires.

Columbus is a low incidence area for AIDS with 132 persons diagnosed and reported in Columbus and Franklin County since our first reported case in June of 1982. Those of us who are fortunate to be local health officers in low incidence cities are awaiting the recommendations of this Commission with great expectancy, for I believe Columbus and other similar cities have the opportunity to avoid a crisis of the magnitude that has afflicted many of our colleagues.

We can stop this epidemic if we can agree on a national strategy based upon scientific evidence, rational and humane thinking and solid public health principles. The plan needs to recognize and foster a public health partnership between the federal, state and local levels, a plan that will build upon the strengths of each level.

Discussing the roles that testing, counseling and partner notification play in the prevention of HIV infection, I want to repeat our basic premise as stated in our written testimony and that is in the absence of a vaccine, a cure and effective treatments, behavior change is our only line of defense for the management and prevention of HIV infection. Our efforts to stop the spread of this disease must focus on eliminating a person's risk behavior. Testing, counseling and partner notification are methods to achieve that end. Because of our obvious time constraints I will highlight only a few of our recommendations in each topic area. I would like to begin with counseling, for it offers, in my judgment, the greatest opportunity at present for interrupting the transmission of this virus.

Quality counseling provides a unique opportunity for intensive, specific and individualized interactions with a person. All counseling programs should be required to have an active quality assurance component. Additional resources need to be provided for community counseling programs and for the hiring and training of AIDS counselors to staff them.

While counseling can stand alone as an intervention strategy, testing cannot. Testing must always be accompanied by appropriate pre and post test counseling, must provide for informed consent and must remain voluntary. I believe we must move toward offering confidential testing, but only after states enact strict confidentiality statutes, with criminal penalties for those who violate them.

We must also enact antidiscrimination statutes to protect the basic rights of those who are HIV positive or have ARC or AIDS. IN my judgment, this cannot be left to the states. The Federal Government should protect these individuals as we have offered protection for all of our citizens against race, sex, age, and other forms of discrimination.

Even as we resolve the obstacles to confidential testing, and we are resolving them, we should maintain support for anonymous counseling and testing sites as alternatives for those individuals who may shun a more structured system. Taking a proactive approach to breaking the chain of HIV infection by allowing those who have been exposed to the virus to have knowledge of that exposure is now a Columbus Health Department priority.

This statement is the essence, I would submit, of partner notification. Partner notification methodologies have been successful as intervention strategies in the control of communicable diseases in this country. Although we are just beginning these partner notification efforts in Ohio, I believe we must accelerate the implementation of formal partner notification programs throughout the country, but we must first resolve the confidentiality and discrimination issues and we must educate the leadership of the at risk communities to support this effective public health approach.

Partner notification can be done in a professional and sensitive manner by first encouraging the person with the HIV infection to notify their own sexual partners. This takes counseling of the infected patient and providing the support needed by that patient to take that difficult step. If the patient is unable to notify their partners, health department services must be available and offered. Clearly, if we are going to offer and aggressively market, if you will, routine counseling and HIV antibody testing in sexually transmitted disease, family

planning, drug treatment clinics and other facilities where high risk behavior individuals are likely to be seen, then additional resources at all levels of government will be needed.

The magnitude of the AIDS epidemic has forced local health departments to rob valuable human and treatment resources from other needed public health programs. Admittedly we can and we have adjusted some priorities, but we cannot afford to ignore other communicable disease, perinatal, nutritional, environmental and a host of other public health programs. If we do, I submit, they will just come back to bite us.

The President's proposed budget, I might submit, is a very positive step toward providing -- at least beginning to provide a realistic level of resources in this country.

We can conquer this epidemic. As I mentioned early in my remarks, we need a national plan. It must be given priority, which includes adequate resources and we must not allow ourselves to be sidetracked from what we know is sound public health practice by spurious and emotional arguments.

Members of the Commission we are here to help you. Local health departments have worked and have demonstrated the fact that we work well with our state and federal counterparts and we would ask that local health departments be included in the formulation of this national strategy and that the plans certainly have allowances for local flexibility and leadership. We are here to help. We ask you to call upon us. Thank you for the opportunity to testify, Mr. Chairman.

CHAIRMAN WATKINS: Thank you very much, Mr. Myers. Dr. Handsfield.

DR. HANDSFIELD: Thank you, Mr. Chairman and Members of the Commission. My name is H. Hunter Handsfield, M.D. I am the Director of the Sexuality Transmitted Disease Control Program for the Seattle-King County Department of Public Health in Seattle and Associate Professor of Medicine and Epidemiology at the University of Washington School of Medicine.

I appreciate the opportunity to articulate my views and those of the Seattle-King County Department of Public Health on the issue of disease control through testing, counseling and partner notification.

I will spend most of my time talking about the partner notification issue because I think that is one that falls directly from some of the principles of testing and counseling that have been discussed at greater length. I will state a philosophy regarding testing and counseling programs and that is that we believe in my department that programs that will

maximize the extent of testing of persons at risk, especially those at risk behaviorally, who have not yet made complete changes to reduce or eliminate their risk, has the highest public health priority.

The issue is how do you maximize that and it is our firm belief that you do not maximize it by mandating it, that the voluntary component is a critical issue to meeting that goal. We also believe, although I endorse Dr. Vernon's statements, we do not currently have a policy of notification by identifiers of simply seropositive individuals in the State of Washington, believing that at least in our environment -- and I endorse Dr. Vernon's comment regarding the inappropriateness of automatically transferring of policies from one state or jurisdiction to another -- we believe in our jurisdiction it would have the effect of reducing the level of cooperation and frequency of testing and counseling, at least in our environment.

The benefits of testing and counseling are dependent on the individual having his or her own results at hand and are not primarily dependent on the authorities tabulating the results of those who are infected and positive. Nevertheless, a certain amount of identifying information is, of course, necessary when you look at the issues of partner notification and I would like to spend some time on that particular issue.

We would submit that there are really two major reasons for partner notification. We prefer that term, by the way, to "contact tracing," which to some has pejorative elements, but the terms are, in my opinion, essentially synonymous at a technical level.

From a public health standpoint, the main purpose and the one that most of us tend to focus on is as a means of controlling disease, by educating people who otherwise would not be educated and inducing them to alter their behavior so as to reduce the total number of new infections that are transmitted.

But there is another reason that goes a little bit beyond that and that gets into the right of a potentially infected person to be aware of the fact that they are at risk even if that person is not himself or herself particularly likely to be a transmitter of disease further. For example, the spouse of an infected person even if she is beyond her childbearing years and not likely to have other sexual partners is not a risk to others beyond herself but, nevertheless, has a right to know there is a risk as it may affect her health care seeking behavior.

There are those who would look at a pure cost effectiveness issue and say that partner notification must prove itself cost effective in terms of reducing ultimate incidence of

disease and that is a very important goal but it is not the sole one because there is this humanitarian issue regarding the exposed individual that may not necessarily be reflected in those kinds of statistics.

Really, informing the partners is in many ways not, in my view, the central issue. There is general agreement, I think, that the persons exposed to risk of HIV infection should be informed of that fact and encouraged to seek counseling and to consider being tested, especially if they are a potential source to spread the virus to others. The relevant issues are not so much whether the partner should be notified, but who should do it; how coercive should the process be; what is the potential disease control yield and at what cost and how shall confidentiality be maintained to maximize the process?

In considering these issues, I endorse what others have said, especially Tom Vernon, that all partner notification is inherently voluntary. If the identity of an exposed partner is unknown or even the existence of an exposed partner is unknown, there rarely are practical means to forcibly obtain this information and attempts at coercion will generally backfire and that has always been the case for partner notification for gonorrhea, syphilis and other diseases.

The ideal method for notification is always for the infected person to be the one to do the notification and this is, in fact, what happens in the majority of cases. When we initiate partner notification procedures, that is our first line and it is what is accepted by the large majority of our patients, be it for gonorrhea or syphilis or HIV. The infected person generally chooses to do that themselves and if they do that, of course, that obviously maximizes the confidentiality issues.

If, in fact, the person wants our assistance or wants us to do it for them, we will certainly meet that need and we will do that regardless of the risk group that the individual comes from. Whether that individual is a gay man or an IV drug user or whatever, if that person agrees that his or her partner should be notified and wants our assistance, it will be given. We think that person is in a better position than we can be to determine what is going to work best for his or her partners, who may have been exposed.

When a person voluntarily participates in behaviors that he or she knows to be risky, that individual shares in the responsibility for the consequences. In other words, the responsibility of health authorities to forcibly or to semi-coercively push this process is lessened if it is clear that the exposed person knowingly and voluntarily participated in risky behaviors. This balance, of course, is influenced by

the potential for secondary spread, especially to innocent parties and especially when there is a risk of transmission to a newborn, of course, the ultimate innocent victim.

Our department's policy has been based on the foregoing principles and a copy of that policy, which includes an outline of the specific procedures, is appended to three of the copies, the ones that are bound in plastic, of the written longer version of my testimony, if you would care to review it. And actually it is with thanks to Kristine Gebbie and the Oregon State Health Department that gave us a rough outline of what was going on in her jurisdiction, that we then used as a framework for building our policy.

In the interest of time, I will not review that in detail except suffice to say that the extent to which we imply coercion or basically tell someone that in our opinion they must notify their partners and if we know who the partner is, (we will do it if they do not say so), relates largely to the extent to which we believe that exposed individual is unlikely to be aware that such a risk existed.

So, for example, we would assume that in the IV drug abuse setting, in the heterosexual setting, that the majority of people out there have not yet been impacted by the educational messages that have been so prominent, for example, among the gay communities, at least in urban areas. We don't make a distinction on whether someone is gay or straight, simply on how likely it is that the partner is going to know there was a risk and what is the impact likely to be.

You are all aware of the fact that a very large number of exposed individuals had their peak exposures years ago with large numbers of unidentifiable or unlocatable partners and, obviously, intensive efforts in that milieu are not going to be especially cost effective.

Two notes about procedure and then I will close. We never divulge the name of the infected person to the exposed partner. This principle has been applied throughout the history of partner notification for gonorrhea, syphilis and other STDs. If person A names person B as a contact, B is told only that someone with HIV infection or another STD as it applies has named him or her as a contact. If person B has several sexual or needle-sharing contacts, the identity of person A is protected.

Obviously, if B has only one partner, he or she will know A's identity, but the principle is upheld that we do not divulge identifying information.

Secondly, permanent records of identifying information are not necessary and are not kept. After all exposed partners

have been informed and counseled -- and Dr. Davis described a similar situation in his jurisdiction -- all identifying information is purged from the records and they are also purged once it becomes clear that the named partner cannot be located and we always do that as a matter of policy within six months.

Thank you, again, for the opportunity to meet with you. I am available for any questions you may have.

CHAIRMAN WATKINS: Thank you, Dr. Handsfield. We will commence the questioning with the Commissioners on my right. Dr. SerVaas.

DR. SERVAAS: Could we come back to me?

CHAIRMAN WATKINS: Sure. Dr. Crenshaw.

DR. CRENSHAW: I just want to thank you for your comments and, correct me if I am wrong, but I understand that all of you basically said that contact notification is by definition voluntary, that it isn't a coercive event, and so you need to have rapport with individuals in order to bring that about.

If I understood what you were saying, it is even more anonymous sometimes if the public health department intervenes in the event that the person doesn't want the partner to know that it happened to be them who was infected. Is that correct?

DR. HANDSFIELD: Yes.

DR. CRENSHAW: So, you can serve a function of even preserving more anonymity under certain circumstances?

DR. HANDSFIELD: Yes. If I may comment, you can certainly preserve anonymity. The other issue and the reason why even with anonymity, I think it may in some circumstances be a mistake to do it against the wishes of the individual concerns the issue of whether the exposed partner has the right to not know that they were exposed, especially -- or potentially infected -- especially if they, from here on out, are likely to not be participating in behaviors that will transmit further. But, I agree, that on balance in the majority of cases it is better if that person knows.

DR. CRENSHAW: I might just anecdotally share that a few days I was giving a talk to the American Psychological Association on duty to warn on a panel and asked a rather large audience of therapists how many of them would like to know or like to be told if they were in a sexual relationship with someone who was infected and they all raised their hands. But then ensued a debate on how many would warn.

MR. MYERS Dr. Crenshaw, I think there might be even a practical comment that I may make about this, too. Even though -- and I agree with Dr. Handsfield and others that probably the best thing to do is to have the index case, (the patient) contact his or her sexual partners -- it is probably good from the standpoint, too, of resources. If, in fact local health departments had to take on the burden of doing 100 percent of the partner notification, we simply would not be able to do it at this time without significant increases in resources. At the present time, it may be preferable for the patient to make that contact because of limited resources in local health departments.

DR. CRENSHAW: Another short point. If the patient says that they will tell their contact, do you have a follow-up so that you know that, indeed, the circle was completed? What is the system?

DR. HANDSFIELD: We certainly do. We strongly encourage the partner notification. Once we know who the partner is, and in some cases we may know because it was a spouse, for example, our -- again, in a non-coercive tone -- our discussion focuses on developing an informal contract that will set up a time frame. At the end of that time frame, we will directly contact the partner and bring that person in.

The infected individual has up until that time to do the notification themselves. That also gives an opportunity if the relationship between the two is such that this is an acceptable way to do it, for the two of them to come in together and for us to then provide additional counseling regarding the issues of safe behavior from here on out. We find the system works well.
Again, there are specific individuals where we have to modify that and where we end up doing the notification ourselves.

MR. MYERS Dr. Crenshaw, I wish to offer a comment on the question of follow-up because in Ohio we are just beginning the partner notification program. We have performed confidential partner notification with other sexually transmitted diseases for years but we are beginning a process with HIV patients that I consider to be much weaker than what has been talked about today.

We are essentially going to implement an anonymous partner notification process and from a public health standpoint, in my judgment, it will not be as effective as the process that has been discussed today. The Ohio Department of Health, as a condition of funding, will require that local counseling and testing sites begin anonymous partner notification programs later this spring. Because there will be no written link between the index case and the partner, we will really not know if a partner comes in to our center, for example, unless we see an increase in

the aggregate data. We will ask an individual who comes in to the CTS on the initial contact form, why they came to the counseling and testing site.

If they tell us that they were I was a partner of someone who told them to come in, then we will have that data, but our process clearly won't be as effective, in my judgment, as the other processes that have been discussed today.

CHAIRMAN WATKINS: Mr. Creedon.

MR. CREEDON: I have a question for Dr. Vernon. I believe you indicated that you did not think that the process that you were following would be appropriate in New York or New Jersey.

DR. VERNON: I am cautious to say that I, first, believe very much in the process in our environment and, to the extent that I understand disease control environments in other states and other cities, believe that it should be used much more widely than it is.

On the other hand, I do not know Newark, New Jersey, which has some 60 to 70 percent of currently reported AIDS cases in an IV drug using community, while the comparable number in Colorado is 4 1/2 percent. So, indeed, it is a very different milieu and I simply want to express that I can't say with conviction that reportability of HIV serologies is appropriate for Manhattan or Newark, New Jersey.

MR. CREEDON: While you can't say, you don't know of any reason why it couldn't happen. I guess what I am really trying to get at is to me, at least, the idea of reporting IV infections and trying to maintain some surveillance of those cases makes sense from a public health standpoint and I just wonder whether you think, from the standpoint of the Commission, recognizing that there will be differences in different states and localities, that we should encourage reporting and maintaining the type of system, subject to whatever variances are appropriate, that you are pursuing.

DR. VERNON: Unequivocally yes. In fact, the Association of State and Territorial Health Officers addressed the issue of reporting and the long range appropriateness of this in AIDS control. But I would harken back to the comments that Dr. Handsfield made, where he who knows the community there certainly better than I, with all that knowledge, has drawn the conclusion that the institution of reportability at this time would detract from the use of the test by at least the gay community there. We were afraid of that, too, and it has not turned out to be the case, at least not in large numbers and I would like to believe that were Seattle to try our model, they

would find the same results, But I cannot replace his judgment with my own.

MR. CREEDON: Well, I commend you for being courageous because I think some steps such as what you have taken are necessary to find out whether some of the fears that people have are real fears or whether we can break through them and --

DR. VERNON: It is important to know that historically in syphilis work and others sexually transmitted diseases we have never required proof of identity of those individuals who come to our clinics to be tested or to receive treatment. We do not require proof of identity in our HIV testing sites either and we know that a number -- we don't know exactly what proportion of those individuals, especially those who are from the gay community, do use pseudonyms when they come. The advantage we see is that in the pre-test counseling, in the discussions that occur, an individual who will, nevertheless, use a pseudonym will often provide the correct home address and/or phone number and our experience has been that we have been able to locate the majority of such individuals when we have done field follow-up.

MR. CREEDON: Now, the process that you describe as shown in the final page of your report suggests that when someone does identify a partner or contact or whatever, you follow up, I take it, and eventually you wound up identifying 45 of those who were positive. Is that correct?

DR. VERNON: Yes. Indeed, Dr. Handsfield again discussed the unwritten contract that is drawn up between a field investigator and the individual in terms of -- if you are returning to the issue of whether the individual informs his own partner but --

MR. CREEDON: Well, either you inform or they inform, I take it?

DR. VERNON: Yes, and to emphasize -- and I believe this is the take-off from your point -- that all of those individuals, who are located in the field receive the counseling. Whether or not they have previously been tested positive, they are recounseled. If they have not been tested positive but refuse to be tested, they are counseled and received that educational message, which we have all emphasized is so critical.

MR. CREEDON: You recommend voluntary testing --

DR. VERNON: Very much so. And, as you can see, from the 296 people who were tested for the first time, 15 percent is a distressingly high positivity rate.

MR. CREEDON: It certainly is. Thank you very much.

CHAIRMAN WATKINS: Ms. Gebbie.

MRS. GEBBIE: A couple of questions.

One is just a request for some data from Dr. Vernon. In the figures you used comparing California and Colorado experiences, a number of states experienced large increases in testing in about those same months that you illustrate. That was triggered by things, such as publicity about blood banks, and drew in large numbers of people to be tested from low risk, relatively -- often from uninfected groups -- and that might mask drops or shifts in numbers of persons seeking testing from highest risk groups, particularly the gay community. Can you provide some detail on that?

DR. VERNON: An important question. I would draw your attention to the testing data on that bar graph for 1987. You all know of the "heterosexual scare" which occurred in most of our news media in January and February of 1987. And, indeed, the numbers you see there, at least in Colorado, and we believe in California, as well, were due to the very large numbers of very low risk heterosexuals, who came in for testing at that time. And, indeed, our positivity rates dropped at that time. The question comes to whether or not there has been a decline in the number of gay men who are coming in for testing.

Throughout this period of time, charting on a monthly basis, the number of gay men has remained quite stable, even through those periods when the controversies in the State Board of Health and in the State Legislature over the legislation were most prominent in the local media. So, while we have not had a rising rate of testing among men who were willing to state their sexual preference at the clinic, it has not dropped.

MRS. GEBBIE: Thank you.

DR. DAVIS: I can provide some additional information as well. In Wisconsin we have a dual system. We have anonymous testing and confidential testing and from December

1985 through November 1987, there were almost 12,000 people tested confidentially with identifiers and a little over 10,000 people tested anonymously without identifiers. So, the majority of people that are tested in our state, given a dual system, still are tested with identifiers.

In 1986, the seropositivity among those tested with identifiers overall -- and I don't have it broken down by risk group -- was 4.7 percent and in 1987, it was 2.3 percent. So, we had data similar to what Dr. Vernon just described, a similar drop there.

Similarly, with our HIV counseling and testing sites, in 1986, our overall seroprevalence was 6.7 percent and in 1987, it was 3.6 percent. We tested over 6,500 people at counseling and testing sites in 1987 and only a little over 2,300 people, in '86.

By risk category, our overall seroprevalence among homosexual/bisexual men coming to our counseling and testing sites in 1987 is 8.4 percent and looking at the last three months of 1987 it was 8.9 percent. We did see a significant increase in seroprevalence in people that fall into an undetermined risk category; in the last three months of 1987 we tested 146 people in an undetermined risk category 12.3 percent of those were positive. There might be a little bit of ambiguity in terms of how people identify with risk groups. The main thing is that we have a system that accommodates that.

MRS. GEBBIE: If those numbers aren't attached to materials we have received it if you would supply those.

DR. DAVIS: Yes. I will be happy to supply that.

MRS. GEBBIE: My other question is one that is directed at all four of you and it is one that may not be answerable sitting here today. We have really been talking about four program elements that can be separated, although they are often intertwined. One is the issue of reportability for one reason or another. Another is the issue of contact identification or follow-up for one reason or another. Another is the issue of counseling of people, who come into you, either because you went and found them or because they walked in the door. The fourth is the issue of testing, the technological thing that gives you some information about people.

As we hear those four elements put together in different ways in different places and decisions made about their investment of resources in doing them, I would be very interested in your observations about the relative importance of those four elements. Do you see them as separate and if you can only pick one or two, which ones would you pick?

But, in addition, your comments on the relative importance of those elements as contrasted with education, outreach and education, which is the subject of our next two days, because I know that in most places decisions about public health investment are not made with an empty checkbook. They are usually made against a very finite set of resources. So, either comments on those right now or some written comments back about that point.

DR. HANDSFIELD: Maybe I could start, comment. First, as you are well aware, the public education versus individual education, which is really what counseling, testing, and reporting are all about, are not mutually exclusive and clearly they are complementary. Neither one alone will do the job. I agree with Mr. Myers' comment that the single most effective approach for changing an individual's behavior is one-on-one counseling. Whether that is cost effective in terms of the personnel that you have to handle it is the issue.

Among those particular issues, I suspect we would all agree up front, although I don't want to put words in other's mouths, but the counseling, the one-on-one counseling is the single most important component of those. Now, I think we would all agree that counseling around a test result is probably a more effective way of counseling than counseling in a vacuum without a test result. So, I would rank the testing very high.

I am not sure that the follow-up doesn't sort of cross all the lines because the follow-up is a very individualized thing, depending on the need to get a hold of partners and that sort of thing. My view, and I think the view of our Department of Public Health in Seattle, would be that reporting is far and away the least important of those. The behavior modification that people are going to go through is not dependent on, as I said before, tabulating who is positive and who isn't and it isn't even dependent on knowing how many. I think everyone on the panel would agree that the utility of the data on prevalence and disease trends, from a required reporting system is probably going to be only modest. Although we have used that for years for gonorrhea and syphilis and newly in some jurisdictions for chlamydia, I think we would all agree that had we had the means in those days to do a blinded randomized prevalence survey, that we would have leaned on those data far more than we ever did on the reporting data, which was the best we could do.

With HIV infection, we probably will have the means and do have the means to do blinded seroprevalence surveys to get at a more accurate estimate of the prevalence of infection in various segments of society and I would submit that that would give you better data than anything you can generate with a reporting system. I know that there is some, perhaps, difference in tone of that philosophy from Colorado, so perhaps Tom wants to comment.

DR. VERNON: On Hunter's last point -- I know he came in after Jim Mason testified earlier today, but you heard Jim Mason state that the benefit of the data, which are tabulated solely for determining seroprevalence in populations, is very limited and Dr. Handsfield has just repeated that. We agree with that. That is not a prime purpose; though we believe the quality of our data are distinctly better, we are not that much further

along toward understanding prevalences in various populations than the rest of the nation and I think we must admit that.

However, we should not be thinking of reporting of communicable diseases generally as benefiting us primarily, certainly not solely from our ability to tabulate those numbers. It has been very important to the control of the sexually transmitted diseases, in our opinion, that we have had laboratory reporting regulations over the years, which give us access to a population of infected persons for bringing them to treatment, to whom we would not otherwise have had access. I think that is a benefit from reportability that is well beyond the tabulation of numbers.

DR. DAVIS: In terms of breaking down some of these things, looking at reportability, contact notification, counseling, testing, and if you were to try to break them out programmatically, if I was to divide a budget into 20 parts, looking at some of those elements and what it would take to have some of those elements workable, perhaps 10 parts would be the actual counseling and testing services, which would be anonymous counseling and testing, which would be available to all comers. Maybe 2 parts would be contact notification, which could be expanded, based on demonstrating efficacy of the program and a greater need. Perhaps 5 parts would be additional health education and risk reduction activities.

One part would be public information to try to generate the system and 2 parts would go in focusing on minority issues to try to make sure that some of the resources are adequately targeted. It could vary from state to state. In a state like ours, that would probably be the way ours would break down. So, you could multiply that by a million or two million or however much the budget would be.

The other thing that one has to consider is the other resources that can impinge on this. For example, if state medical societies have a different activity, a different area of focus, you need to take that into account so that you could maximize your HIV dollar. One thing I wanted to mention also and the point was made earlier by one of the panelists was that we must not ignore other communicable diseases. This is very key. If we have a population that is susceptible by virtue of being immunocompromised, some of the other diseases that we are going to be working with can only become more complex in that regard. So, I think it is very critical that we not lose sight of the need for resources to continually work with other communicable diseases. The other thing, too, in terms of working with STDs is that we are dealing with the likelihood of infection by multiple agents that we need to understand potentially as co-factors and we also have to work very aggressively with those other STDs.

MR. MYERS Ms. Gebbie, I certainly agree with you that all of these program elements are intertwined and it is difficult to isolate one element as the most effective approach to control this infection; but I am going to try to do that anyway.

At the local level, I think the best thing we can do is to be very aggressive in our outreach to the at-risk community. Once we identify those individuals, the next best thing we can do to provide a very intensive counseling. It is going to be costly because it is individualized but in my judgment, counseling is the most effective method we can use at this point in time in the absence of other control measures.

I would certainly agree with Dr. Handsfield that individual education -- in effect that is what counseling is -- is most effective when coupled with testing. Testing is a catalyst that can be used to bring individuals into us.

Going on from there, I would propose partner notification, if you will, as the next priority. And, clearly, as I think the rest of the panelists may agree, I would put reporting last. This does not mean that it is not important but I would certainly place our limit, if we have limited resources in those other categories first.

CHAIRMAN WATKINS: Dr. Lilly.

DR. LILLY: My main question has to do with syphilis. For areas of the country in which there has been contact notification with respect to other sexually transmitted diseases, I am wondering have you not experienced the increase in syphilis that has been seen in the country as a whole over the last couple of years? In other words, has that contact notification policy with respect to syphilis, has that paid off with respect to controlling the incidence of the disease?

DR. HANDSFIELD: I think you raise a point that actually goes much beyond syphilis and that is the whole issue of how effective partner notification is to control any disease. The extent to which that has had its impact on other sexually transmitted diseases is not well-documented. There is a lot of belief and intuition that for syphilis in particular it is a very important control measure and that is because you have a period of time after disease acquisition of several weeks before the person becomes infective for others, so you have enough time to begin to impact it.

For gonorrhea that period of time is essentially zero from the acquisition until someone is infective for others and the effect of partner notification for controlling gonorrhea has never been documented in any kind of well-fashioned study.

As far as syphilis is concerned, I think we all agree it probably is very effective. We have certainly seen an upsurge of syphilis and also of gonorrhea in inner city, primarily black (although the ethnic background is only incidental) populations in the Seattle area that we believe is linked with drug use and especially with sex in and around crack houses.

Syphilis is probably being driven by the same forces. I don't think the fact that it is rising necessarily means, however, that partner notification isn't working to limit what that rise otherwise would have been because we really can't know that.

That is another way of saying that the patient is not the sole or main issue that is having an effect on the current upsurge of syphilis, I don't believe.

DR. VERNON: I agree, Dr. Lilly. While our syphilis rates for 1987 did not rise in line with the national rates, I could not prove that our decrease has to do with the program we have in the field. Partner notification for syphilis exists to my knowledge to this day in all 50 states. Ironically, we can call other states in the Union, 49 of them, with identifiers for an individual who is exposed to a syphilis index case in Colorado and have an expected response; that is, an attempt to locate that individual in that state. If that individual were infected instead with the HIV, such a response would occur in the minority of those states.

CHAIRMAN WATKINS: Ms. Pullen.

MS. PULLEN: I would like to express appreciation to all of you for your efforts, not only in informing us in detail, but also your efforts to do something about this epidemic.

Dr. Davis, you indicated that in Wisconsin, I believe, you have a coexistence of anonymous testing and confidential testing. Where is the confidential testing done? Is it done by the Department of Public Health?

DR. DAVIS: The confidential testing with identifiers is primarily done by physicians. Most all of the testing in the state is conducted are at the State Lab of Hygiene, which is our centralized laboratory, our public health laboratory. Physicians have access to the public health laboratory and requisition their testing with identifiers. The only fully anonymous testing that is done in the state is done through the counseling and testing sites and we have 45 counseling and testing sites throughout our state.

MS. PULLEN: How does the contact notification or partner notification go forward procedurally in the confidential testing in your state? Is a contact location team triggered by the report from the State Lab going to the contact social workers or is it triggered by the report from the physician going to the contact workers or how does that begin?

DR. DAVIS: Procedurally, the tests done with identifiers would be reportable to the State Epidemiologist, myself, and then we would work through a designated program and then --

MS. PULLEN: What do you do with anonymous testing where the person who does come in and get his results is asked to talk to his contacts and, of course, there isn't any reporting --

DR. DAVIS: It can be done either way. Regardless of whether a person is tested confidentially or anonymously, notification can take place. A person, for example, who would want to initiate contact notification by a third party, would have to demonstrate that they have a validated test. In other words, we don't want a person who says that he or she is positive, but cannot assure us if that fact provide us with a list of individuals who are going to be notified that they have been exposed to somebody who is HIV positive. So, one of the things that is important in terms of accessibility to our system, whether persons are tested with identifiers or anonymously, is that there be some means of validating that these people are, indeed, infected. Beyond that, they would be able to provide names of individuals for the purposes of notification.

MS. PULLEN: When the person is tested anonymously and comes in for his results, is it at that point that he is asked are you willing to contact your own contacts or do you want us to do it for you and then they give the list of names if they wish you to do it or does someone hand them your business card and say if you want Dr. Davis to do this for you, send him the list or how does that work?

DR. DAVIS: Our program immediately has to start very small. Our goal is ultimately to develop a system where a small group of individuals that are thoroughly trained and supervised a lead worker will ultimately train more people so more people are qualified to do this. Not just anybody can do contact notification. It has to be done in a very sensitive way with fully trained individuals that know how to handle information confidentially and are very careful to provide a fully objective piece of information when conveying a piece of bad news, in essence.

So, ultimately, there could be perhaps more direct involvement with individual programs that are not centralized, but right now, by virtue of the small nature of the program, things have to be centralized. Then I anticipate with proven efficacy of the program, which would have to be proven down the line because we really don't have a clear idea yet of how effective these programs are going to be, local facilitation can take place.

MS. PULLEN: So, the partner names come to your office whether or not -- in a confidential manner, whether or not --

DR. DAVIS: No. The only person that would actually have the partner name would be the individual who is working with that person. In other words, centrally, we don't need to have the name of the partner; only the case worker who is dealing with the individual who is infected would need to have the names of that person's contacts and once all the investigations are completed, that list is destroyed. There is no need to retain those names.

MS. PULLEN: That is what I thought but I thought I heard you say that it needs to be centralized a minute ago.

DR. DAVIS: We have a need for a centralized program by virtue of the fact that it is very small and there is room for growth, but only through evaluation of the program to demonstrate what the further needs are, the further needs. Clearly, more and more local public health agencies are going to want to become involved, but the individuals employed at local public health agencies who will do the contact notification would have to be trained before they would be allowed to do that. But in terms of individuals who are infected, the only person provided with the contact's names is the one worker who is working closely with that person.

MS. PULLEN: Do you have any kind of data on how many people come to testing sites or get tested, who say I was told by my partner that I should --

DR. DAVIS: No. I don't have that right now and that is a question that we are working into our counseling and testing site anonymous questionnaire. We will have that data and I am sure by the end of the year we should have a fair amount of data.

DR. HANDSFIELD: It is not infrequent and it is increasing, at least in our jurisdiction, where more and more people are coming in and stating that reason, but we also don't have specific data. I think it is a common phenomenon.

MS. PULLEN: If any of you have that data, I would appreciate receiving that.

CHAIRMAN WATKINS: Dr. SerVaas has a follow-up question here.

DR. SERVAAS: I am addressing my question to Dr. Vernon. I congratulate you on your courageous and excellent program and your excellent presentation. It would appear that you lead the nation in proving that to date you haven't caused any discrimination or driven high risk persons underground with your program.

My question is, I believe your state had the first post-1985 blood bank screening AIDS case from a high risk person donating in the window period. Even though your blood supply is probably safer than that in California or New York, have you thought of reaching out to aggressively test all your prior to 1985 blood transfusion recipients? Isn't this an overlooked risk group, given that these people don't require expensive counseling to change their life style and possibly it would be cost effective to go and take care of this group, who really don't need to change a life style.

So many cases have come to our attention where a blood recipient has gone from pillar to post to try to find out why they are not getting well or why they are sick and it seems that we should be trying to help find and identify -- I think they estimate 12,000 in the country -- who are probably infected with HIV from blood transfusions. We really don't know how accurate that 12,000 is probably. Could you tell me what Colorado might have up your sleeve to do something there?

DR. VERNON: Well, thank you for your comments. I really cannot add to your data base on the blood transfusion population prior to 1985. We have generally followed the guidelines of the Centers for Disease Control. I think we have essentially done what virtually all other states have done in that respect.

We have worked very closely with the blood bank community in Colorado relative to that follow-up, but I don't believe I can point to anything that is above and beyond what I am sure Jeff or Ms. Gebbie and others have done in their jurisdictions.

DR. SERVAAS: Does it occur to any of the members of the panel that these 12,000 people, maybe that it wouldn't cost so much to identify the 12,000 people who are believed to be infected from blood transfusions? Even though it is not where all the action is, that is a lot of people who don't know they are HIV positive and they are probably exposing their spouses.

DR. HANDSFIELD: Perhaps someone in the audience may have better data. It was my impression that the estimate from CDC was that 12,000 may have become infected, and I believe it is a majority of those people will already have succumbed. You have to look at why people have blood transfusions and if you take people who have blood transfusions, a large proportion are dead within a year because of whatever the underlying problem was that led to the blood transfusion to begin with, be it an accident or cancer chemotherapy or whatever.

So, I believe that the 12,000 was the number that were infected but not the number currently existing. Whatever number is currently existing will have been reduced substantially, it seems to me, by a large proportion of those, who will have already sought testing spontaneously because of media attention and the like.

Then on top of that, the people who received only one or two units of blood statistically are going to have an extremely low risk of infection and you can ask what would be the bang for your buck in terms of finding them, given their low rate of infection.

My belief is, but I defer to anyone who has better data, that the number of people who are likely to benefit and the disease control impact -- an all-out effort to find them all and test them might not be very great. They will be diffused throughout the country and so on. Jeff, do you have any comments on that?

DR. DAVIS: I feel that is a very accurate assessment at this point in time.

MR. MYERS Dr. SerVaas, I think there is one thing we can and have done at the local level -- I believe that is to support when the recommendations from CDC that recommends a conferencing, if you will, between physicians and their patients regarding blood transfusion and the potential transmission risk to that patient. We have encouraged and educated our local medical community to follow those guidelines and I think that is something we should all do at the local level. I am not convinced that these individuals ought to enter into our discussion of the public health magnitude of this epidemic.

CHAIRMAN WATKINS: Dr. Lee.

DR. LEE: I want to make sure I have got these numbers right, so correct me if I am wrong.

Dr. Davis, you said 530 bucks it costs you for one --

DR. DAVIS: That wasn't ours. I can go through this --

DR. LEE: Don't go through the whole thing. How much does it cost you for a positive finding?

DR. DAVIS: I couldn't tell you that in our state. The data that I was able to -- the most comprehensive experience is in Colorado and I can go through the -- Tom could also, clearly, because it is in his state, but this was done very well --

DR. LEE: What was that $530.00?

DR. DAVIS: I will explain. I had data from one of Dr. Vernon's associates on the first 265 individuals, who were HIV positive. At that time, there were 465 partners identified; 376 of those 465 were actually notified. Of those notified, 11 percent had previously tested positive; 19 percent declined testing, but were counseled and 70 percent or 264 agreed to be tested. Of those newly tested, 16 percent at that time or 42 were seropositive. Utilizing the data on non-start-up personnel costs plus costs of collecting blood specimens in the field, the costs of detecting each previously undetected HIV infection was approximately $530.00. If you look at the non-start-up costs in that program, plus costs of collecting blood specimens in the field --

DR. LEE: Okay, but I thought -- I am getting to Dr. Vernon, but I thought that 530 was your figure.

DR. DAVIS: No, no. I am sorry.

DR. LEE: Okay. Then my second is question answered. That is your figure for the cost of --

DR. VERNON: It is a figure Jeff obtained from calling his colleague, Dr. Richard Hoffman, who is our State Epidemiologist in Colorado.

I asked our staff, oh, perhaps two months ago to give me some estimates. They have given those to me. I have looked at them and felt that perhaps the estimations of investment and of benefits were not conservative enough and, meanwhile, had not reported my opinions back to my own staff. So, Jeff got the old figures.

One has to be very careful in such a situation. How many of those people found to be infected would have gone on to infect others? If so, how many others? So, one has to make an assumption then that an infected person if not detected and counseled about his behavior would have infected one other person in the next ten years, use that as a conservative assumption. For that one other person, what would be the likelihood of his going on to full scale AIDS with the costs of

a full scale case of AIDS? One uses perhaps 20 percent or 25 percent, but even placing very conservative assumptions upon the data from our staff, I find that the cost of investment to the cost of benefit in our program would be $1.00 to $6.00. Thus, a 6 to 1 savings from a partner notification program with quite conservative inputs.

DR. LEE: At least 6 to 1. Now, there is another figure that I haven't been able to get at. Maybe with your intensive little screen there, you have some idea. How many of the prior unknown positive contacts were positive because of a bisexual male?

DR. VERNON: Unfortunately, I don't have those data at the tips of my fingers. Early in our program, there was a fair contingent among our small IV drug using community, but unfortunately I can't give you the data. I can tell you that all risk groups in Colorado are represented in our partner notification data. I just cannot give you the proportions or the --

DR. LEE: It is hard to get at a figure of what the risk women have --

DR. VERNON: Yes.

DR. LEE: -- you know, if they are not having sex with drug abusers.

DR. VERNON: Yes.

DR. LEE: One other thing. Dr. Mason showed -- this is the last graph on his book that he handed out and this was the decrease in syphilis in homosexual males. So, to answer Frank Lilly's question, it would seem to me that behavioral change and education has a tremendous effect on sexually transmitted disease. On this graph, when it is going up all over the rest of the country --

DR. VERNON: We are absolutely convinced of that and the data from Denver show precisely that kind of a plummeting incidence rate of acute anal gonorrhea, of syphilis among the homosexual male population, but we do not see the decreases occurring in groups outside of that population. And I am very disturbed by the data we heard about Miami this morning where homosexuality is predominantly in the Hispanic and black communities, where there has not been that decrease. That is a very important message for all of us.

DR. DAVIS: I have one question to ask Hunter, one additional -- I don't want to get complex into antibiotic

therapy, but do you think the Spectinomycin -- the use of Spectinomycin to treat penicillinase-resistant gonorrhea has any effect since that wouldn't get at incubating syphilis in some patients?

DR. HANDSFIELD: In a nutshell, no, I don't think that is the major influence. I think that not very many of the syphilis cases are occurring in people who were incubating at the time they got -- incubating at the time they were recently treated for gonorrhea, if they were at all. I don't think that is a major influence.

CHAIRMAN WATKINS: Dr. Crenshaw, do you have another question.

DR. CRENSHAW: The varying testing centers across the United States generally report two figures: the numbers who come in to get tested and the numbers who actually get tested. Could you tell me in your respective states approximately how many come in and don't get tested or what percentage?

DR. HANDSFIELD: I can't tell you for the State of Washington, but in the Seattle-King County Department of Public Health, about 92 or 94 percent, a very large majority of the people attending our AIDS prevention project and who had originally come in, get tested, as well as counseled. In our sexually transmitted disease clinic it is even higher but there are some differences in how persons select themselves for attending that project.

MR. MYERS Our data from Columbus would confirm that. We have had contact with over 9,000 individuals at our counseling and testing sites since 1985. Of that number, over 7,800 have elected to take the test and the post test counseling. We have found an overall positivity rate of 8 percent. Similar to the previous comments that percentage has dropped. We were running about 20 percent positive in 1985 when most of our patients were in high risk behavior groups; it dropped to about 14 percent in 1986 and about 8 percent in 1987.

So, we are having success in of getting a high percentage of those who initially come to the clinic to remain, after the pre-test counseling, for the test, and then to come back for post-test counseling. In fact, 75+ percent of our people who take the test then come back for post-test counseling. I would be curious to find out how this figure compares with other counseling and testing sites. Also, 95+ percent of the people who test positive at our site indicate that they are from one of the identified at risk groups. So, we feel, at least at this point in time very good about the fact that we appear to be reaching the at-risk community in Columbus.

DR. CRENSHAW: Do I understand 1,200 who come in intending to be tested don't get tested?

MR. MYERS That is correct.

DR. CRENSHAW: That is really my focus of interest and as you answer the question what I am getting at is that I am an advocate of counseling for obvious reasons. That is the direction that my bias goes, but it does appear that in some of the programs, and many of the other programs have far wider disparity in the numbers than what I am hearing here today, the pre-test counseling seems somehow to discourage pursuit of the test. It takes a lot of courage to walk through those doors and venture forward to get tested. So, I would be interested in any insights on how to capture that margin a little more effectively. I think 1,200 is a lot of people.

DR. VERNON: Let me respond. I admire Dr. Handsfield because he had the exact percentage on the tips of his fingers. I don't have the exact figure but I am quite sure it is on that order. We believe in the test. We believe the test should be utilized. We believe the test is a trigger, which makes the all-important counseling more effective than it would otherwise be. So, we not only encourage the test for those who have come to the site, but we believe that returning for the counseling, whether the result is positive or negative, is extremely important.

Dr. Myers has suggested that 25 percent do not return. We believe that 10 to 15 percent of our persons tested, of our positive persons, do not return. But therein lies, we believe, an important element of our program. We follow those people. We believe that finding them in the field and providing the counseling to them, whether or not they choose to learn the result of the test (and it is their choice) is an important element of our program. Yes, we believe in the test and more than that we believe in the counseling which is associated with that test.

DR. DAVIS: I will provide our data in writing because I don't have the numbers of people counseled but not tested at counseling and testing sites.

One other thing, though, people may tend to pre-screen themselves by calling hotlines and asking appropriate questions regarding whether they should be tested. So, in large part, you may have a high proportion of people testing at counseling and testing sites because they come in with the expectation of being tested possibly because they have already spoken to other people about it.

MR. MYERS Dr. Crenshaw, I would also suggest that there are many reasons why 1,200 may not choose to be tested and some of the reasons may be very valid. I think the important thing to understand, though, is the fact that all of those 9,000 people received counseling. If we are talking about changing behavior, I think we are reaching a portion of the population that we need to reach with preventive counseling. I think the other thing to understand is that after the counseling -- I don't have the exact figures -- but many of those people should not get tested because there are no risk factors involved.

So, I don't think you can just look at that 1,200 number and come to the conclusion that it is either a high or a low number. Actually, we feel quite comfortable that the vast majority of folks that we need to reach are being tested and returning for the post-test counseling.

CHAIRMAN WATKINS: Ms. Gebbie.

MRS. GEBBIE: We heard some discussion earlier today of this issue called duty to warn, which implies that an individual practitioner of medicine or some other healing discipline ought to be the one who carries out an obligation to warn a potentially infected person if he or she has knowledge of it. I think it was Dr. Davis' testimony that indicated that that might not always be the best idea because maybe there are individual physicians, practitioners, who don't have the skills in the sensitive process of alerting an unsuspecting sexual partner of their infection, which sort of goes contrary then to that idea of the individual duty to warn. I would be interested in some more discussion -- I don't think they are necessarily contrary, but --

DR. DAVIS: I don't disagree with the duty to warn. In fact, I think the position in Oregon is a very good one. There may be confusion. What we have tried to do, for example, in Wisconsin is send a clinician's guide regarding AIDS and HIV to every physician in the state or virtually every physician. A large portion of that is focused very specifically on how they can counsel and provide a service, which would facilitate a very accurate and objective message with the sensitivity needed to provide good counseling.

I think the issue regarding duty to warn isn't fully clear among all physicians practicing medicine in this country and one of the real positive aspects of the Commission is to provide a very clear message regarding what that means to physicians throughout the country. The AMA position, I think, is very consistent with the position that you all have in Oregon, if I am not mistaken.

The main thing is consistency. We are concerned that if physicians or other health care providers are not consistent

about how counseling of patients and how contact notification might take place, that perhaps in that setting that the public health system should become involved. But I am not saying that the duty to warn should be fully passed on. If a physician is competent to do that, by all means, I think it is important that the individual get information that is very accurate and that appropriate actions can be taken by the physician to facilitate good care of that individual, plus facilitate notifying those people that need to know. Whatever system works best within a state should be utilized. If there aren't adequate resources to have the public health system warn literally everybody that needs to know, certainly that wouldn't be the best system. There has to be a mix, I think, to make the overall system work. I am sorry if I was a little bit confusing in terms of my comment.

DR. HANDSFIELD: We also believe the duty to warn is an important one and that many physicians are not equipped to do that. The philosophy we have tried to inculcate among Seattle area physicians is that they can discharge that duty by calling the Department of Health. That does not constitute reporting in the sense that we don't keep permanent records of that, but if a physician has a setting in which he believes, and his patient believes, that a partner should be notified and they together want the assistance or the physician requests our assistance, we will take steps to assist in that process.

We are actually considering an approach to the State Board of Health to formalize that, to get some sort of codification of the principle that the doctor may either inform directly or may discharge that responsibility by telling the local health department and then putting the load on our shoulders as to how to handle that particular case.

DR. VERNON: At the time I was surprised but when our legislation was before our general assembly last winter, it was organized medicine which requested the insertion of the provision that fulfillment of the reporting requirement fulfilled the duty to warn by a physician. Now, I am somewhat ambivalent about that because it sounds like doctors are passing the buck, but I wholeheartedly agree with the comments that have been made here, that in this very often difficult and certainly delicate process of partner notification, physicians do not do it very well. They don't have the time, the inclination and, above all, the training.

MRS. GEBBIE: It is my impression that not all local health departments or state health departments are wholly delighted at having that responsibility pushed back to them in that process and that it is clearly something that needs to be debated further.

DR. DAVIS: I think you raise a good point there, Kris. I believe within each state there has to be understanding how duty to warn will work.

MR. MYERS I might comment, too, on that. It is a curious phenomenon that particularly within the past six months in Columbus many physicians and HIV positive and AIDS patients are asking us to do partner notification. This is a very positive statement about how far we have come in the past 6 to 12 months in gaining the trust of the at-risk population. However, we still have a way to go.

CHAIRMAN WATKINS: Dr. Lilly.

DR. LILLY: Just a very quick question.

Dr. Vernon, you said a couple of times that you don't think that your reportability requirements and so forth have scared off the gay community. I am just wondering, how do you know that?

DR. VERNON: Well, you know, I have some humility about that question. We have tried to examine it from all angles. We have compared our testing rates. We have compared, as I have showed you, the experience with California, which has quite the opposite requirements concerning reporting from our own.

DR. LILLY: What do you mean by "compared" testing rates with California?

DR. VERNON: With the best denominator we have, which is a weak one, which is the active population, and the best numerator we have, which is the number of individuals who have been tested --

DR. LILLY: This is in the population at large, but my question has to do with gay men.

DR. VERNON: Yes, and, Dr. Lilly, Ms. Gebbie was getting at that question earlier when she inquired about that increase -- those increases in testing and to what extent were we simply looking at a heterosexual population. The best data I have are those which I presented and that is, during this entire period the number of gay men being tested as evidenced by the questionnaire at the testing site has been stable.

DR. LILLY: And that is a fraction of the total tested. Is that what you are saying?

DR. VERNON: No, the absolute number. During a time when the total number of people being tested ascended quite rapidly early in 1987 and, incidentally, a time when the

legislation was receiving a lot of publicity in the media, the number of gay men tested each month was quite stable. Yes, fluctuations, clearly; 10 to 15 percent up or down each month, but there has not been a substantial decrease during the most publicized times.

Again, accept my humility about data bases. We can't use as a denominator the number of gay men in our community anymore than any other community. The data simply are not available. So, we use the best we can.

CHAIRMAN WATKINS: I will close out the panel asking just a couple of questions.

Dr. Vernon, you got my attention when you said that you and the State of Colorado are very conscious of the turn down of the potential enlistees into the military, those who were turned down for HIV positive test results, and you provide a counseling transition for them.

Would you tell me more about that? I have heard some rather severe criticism from a variety of witnesses and people who have written and so forth, that, in fact, it is a very callous process. The HIV positivity is determined. The person is given a slip of paper to the nearest place that perhaps can provide some counseling and is sent on his way, his or her way.

So, I would like to know a little bit more about how that baton is passed smoothly and sensitively onto the proper counseling agency and how do you do that in Colorado?

DR. VERNON: I wish Ms. Gebbie were sitting here beside me because two years ago the two of us and a couple of our colleagues went to the military entrancing processing headquarters in Chicago to discuss their process and to inquire specifically about what follow-up process was going to be available for these young men, who were escorted home to their doorstep, having been given some level of counseling; we felt it was rudimentary. And, indeed, we considered this to be a significant problem to be addressed to all of our colleagues in the 50 states.

We in Colorado then made it very clear not only to the processing stations, but to our military facilities that we had the same expectations about reportability, once we had our reporting regulation in place, that we had always had about rubella or salmonella or whatever else. There has been no problem. Because of preexisting military policy, when the local or state jurisdiction has a requirement for reporting, they will abide by that requirement. We, therefore, receive those reports and have followed up on each individual who has been found to be positive. There are only about 15 enlistees in Colorado to this

point but, indeed, we found one by the initial testing was apparently a false positive. So, that was a useful follow-up, when we did not find a history of risk behavior, to retest such an individual.

CHAIRMAN WATKINS: Dr. Handsfield, in your state, do you have a problem there with those that fail entry because of being HIV positive, that then seem to flounder and are sent back to society without possibly a smooth transition in the proper counseling facilities?

DR. HANDSFIELD: Our rate of seropositivity in the military recruits is smaller than in most of the nation and the number of positives that have come to our attention is a very small number and we have not seen any obvious problems with acute psychological decompensation or other issues. That is not to say there isn't any --

CHAIRMAN WATKINS: Any of the other witnesses have any --

MR. MYERS Same experience.

DR. DAVIS: We have 13 of 28,156 military recruits that were positive and to my knowledge those people were referred to counseling and testing sites for --

CHAIRMAN WATKINS: So, it has not been an issue with any of you? Now, these were from the states that are most heavily impacted and I assume it is just another problem of available resources to do the job properly and with the proper follow-up.

I would also like to know and you were touching on it, I think, a little bit earlier -- of the number of people that come back after anonymous testing, do you have any way of determining that? Who comes back to really find out what their own personal status is and seek the counseling? Do you have a number? Maybe you gave me a number. I wasn't sure that we were talking about that particular piece of information.

DR. DAVIS: I don't have that number here.

CHAIRMAN WATKINS: I can't believe that being anonymous wouldn't allow some to want to come back and determine their status.

DR. DAVIS: I will try to get those numbers from Wisconsin and provide those for you. I don't have those with me. But people that don't return --

CHAIRMAN WATKINS: Do you have that information? Is it provided from the data that you obtain when the person comes in for follow-up counseling?

DR. HANDSFIELD: I don't have figures with me but we have an anonymous testing system that has the patient -- we still create an identifier that we can determine whether someone has returned or not. We ask each patient -- we use such things as mother's maiden name, father's first name, name of the town someone was born in. By using this, and we ask people to take the first two or three letters from those various things, you can build a personal identifier that only the individual can recreate and that you don't keep a record of.

My code would have been HUHUWECHI43. That is all based on names and things that only I could know, but by doing that, when people return, they give us that same code. Then you have to remember, because all we have to do is say what are the first two letters of your father's name, what are the first two letters of the time you were born -- so, they recreate the code and we can then determine whether someone with that code has, in fact, returned.

So, our anonymous track does allow us to determine what our return rates are. I don't remember off the top of my head what they are because those are --

CHAIRMAN WATKINS: Is it a significant number?

DR. HANDSFIELD: -- if the proportion returning is no different in our anonymous track compared with our confidence non-anonymous track.

CHAIRMAN WATKINS: Is it a significant number?

DR. HANDSFIELD: Among those who are seropositive, in the range of 80 to 90 percent do return and it is no different among the confidential versus the anonymous ones. The difference is that for the anonymous ones who don't return, we cannot field visit them as they would be able to do in Colorado, in order to bring them back in, but the number is small.

DR. DAVIS: We have the same problem, of course, in Wisconsin.

DR. VERNON: Between 10 and 15 percent of positive, antibody positive, individuals do not return and they are, of course, a target of an intervention.

CHAIRMAN WATKINS: I want to thank this panel very much. You have been a very informative panel, very helpful to the Commission. We will keep our dialogue with you open if that

is all right with each of you and there may be follow-on questions for you. Thank you very much for coming today.

DR. HANDSFIELD: Mr. Chairman, it may be presumptuous but may I make a very brief observation?

CHAIRMAN WATKINS: Certainly.

DR. HANDSFIELD: I hope what you have seen today is a display of rampant pragmatism. Those of us in public health are criticized commonly for not handling this epidemic in the way we have handled other epidemics. In one sense that is true, but the way it is false is that for past epidemics, for gonorrhea, syphilis or anything else, we have devised our disease control policies in the context of the social, political, medical climate. The fact is, for reasons that we may be upset about, we may decry the fact that this test is special and this disease is special and affects population groups that are special, but you can't deny the reality of it.

I hope that you have had the sense that regardless of perhaps differing philosophies and so on, that it really comes down to a track record that is almost unassailable, of public health officials making their policies on the basis of what they think is going to work best and if things are different, it is because we live in a different context and different times and that we can't turn back the clock. Thank you.

CHAIRMAN WATKINS: Thank you, all.

The final panel today is a panel on the subject of sexually transmitted disease and AIDS. We have three panelists: Dr. Michael Rosenberg, Executive Director, American Social Health Association; Dr. Willard Cates, Director, Division of Sexually Transmitted Disease, Centers for Disease Control and Wendy Wertheimer, Director, Public and Government Affairs, American Social Health Association. We would like to hear first from Dr. Michael Rosenberg.

DR. ROSENBERG: Thank you.

I am the Executive Director of the American Social Health Association, as well as a practicing physician and a researcher in the field of reproductive health and sexually transmitted diseases.

The American Social Health Association is the country's only national nonprofit organization dedicated to controlling sexually transmitted diseases. The organization has existed for 75 years, and the fact that our mission is still unaccomplished has immediate implications for the current HIV epidemic.

ASHA's largest program is the National AIDS HOtline. Since we began operation of the Hotline over a year ago, we have provided more than a million Americans with information about AIDS and appropriate referrals. This year we expect to handle more than 3 million calls as part of the Hotline.

We also act as technical advisors to Ogilvy and Mather as part of the National AIDS Information Program. Some of our other programs include the National Sexually Transmitted Diseases Hotline, Herpes Resource Center and a variety of school and work place-based educational programs.

I am here today to discuss the relationship between AIDS and other STDs and I will begin by telling my conclusion. It is that certain STDs, notably those which break the skin, are emerging as the strongest risk factors for acquiring HIV infection. The direct implication of this is that better control of STDs may be on one of the most immediate and practical control measures for the HIV epidemic.

From the beginning, certain differences emerged in a pattern of HIV infection in Africa and the United States. In Africa, AIDS has been and continues to be a heterosexual disease; in the U.S., it is not. An explanation for this difference may be in the high prevalence of STDs in Africa. For example, the rate of syphilis in the U.S. is presently 31 cases per 100,000 people, while in Africa, the rate is between 100 and 300 hundred times higher. Early studies from africa have also been consistent in finding a markedly increased risk of HIV infection among persons with ulcerative STDs. The risk calculated in early studies from Africa are substantial with STDs increasing risk by three-fold or more. Studies conducted in the United States also consistently support a causal relationship between HIV infection and syphilis, gonorrhea and ulcerative STDs.

Two recent studies, both published within the last two months, are worthy of particular note, because each represents the strongest evidence to date of the relationship. The first investigated mainly heterosexual patients at a large urban STD clinic in Baltimore. Each STD investigated, syphilis, gonorrhea, hepatitis, genital herpes and genital warts, increased the risk of acquiring HIV infection. Among men the most important risk factor was past infection with syphilis, which doubled the risk of HIV infection. In women, genital warts were the most important risk factor and also doubled the risk of HIV infection.

The second study looked at genital herpes among gay men in San Francisco. This study is the clearest evidence we have that preceding infection with genital herpes increases the risk of HIV infection; in this case by one and a half times.

In summary then, the literature is remarkably consistent, demonstrating that STDs which cause skin ulceration markedly enhance the risk of becoming infected with HIV. The ulcerative STDs of concern are syphilis, genital herpes, chancroid and genital warts. These four diseases will afflict about 40 million Americans this year and herpes and warts, which are caused by viruses, are incurable. Underscoring the importance of these numbers is the fact that each is becoming more common in this country.

All this means basically one thing and that is that individuals with ulcerative STDs are at heightened risk for HIV infection. Therefore, better control of STDs means fewer cases of HIV infection. This fact also has crucial implications for the heterosexuals in the United States.

Studies show that this segment of the population considers itself safe from the AIDs epidemic and has not changed its behavior. The presence of an ulcerative STD in any individual enhances the risk of HIV infection and should be seen as a warning signal that the threat of HIV is quite real.

My recommendation, then, is fairly simple, and that is to better control STDs. Historically, increased spending on STD control has had a measurable impact on prevalence. Given the problem today, a thorough control effort must involve spending several times the 65 million dollars we currently spend each year.

There are two control components which I think are worthy of emphasis. First, we need to integrate discussion of other STDs into prevention messages, which are being developed as part of the AIDS prevention program; indeed, to separate the two is illogical.

Secondly, there is an urgent need for further research on the relationship of STDs and AIDs and to better provide the tools to help control STDs. Better controls of STDs could prove to be the most effective means of decreasing HIV infection in the next few years and may well prove to be one of the most cost effective measures that this panel could recommend. I thank you for the opportunity of expressing those views and would be happy to answer your questions.

CHAIRMAN WATKINS: Thank you very much, Dr. Rosenberg. Dr. Cates.

DR. CATES: Thank you, Mr. Chairman, Commissioners. Turning to syphilis as the most easily trackable general ulcer condition in this country basically good news with regard to males, a decrease in this country during the 1980s. However, in

1987, in both genders, we saw an increase. Looking at the percent change by three key groups; heterosexual males, females and homosexual males and then by three racial and ethnic groups.

For both heterosexual males and females, the percent change was positive among all of the racial and ethnic groups. Among white homosexual males, there was continued decrease in syphilis, just like that last graph that Dr. Mason showed you in your handout today. In absolute numbers, of syphilis cases the syphilis increase in this country is occurring in inner city minority heterosexual populations.

What are the implications? Because the increase is occurring in the heterosexual population it indicates that they have not yet assimilated the types of prevention messages that we have seen occur in the white, gay male community. Just as importantly from the etiology studies that Dr. Rosenberg has talked to you about, these are possible determinants of both either transmission or acquisition of HIV. That is the scary part.

We have also talked about another genital ulcer, chancroid; smaller in terms of the numbers. There are about 35,000 cases of primary and secondary syphilis in '87 and this is now about 3,500 of chancroid in 1987, about 1/10th that number. In the developed countries, genital herpes is 15 fold higher in terms of symptomatic coming to private physicians' offices. The trend in resources directed to STD over the 20 years, 1966 through 1986 is shown next.

In 1966, all of our STD dollars were directed toward syphilis. By 1972, we had syphilis, gonorrhea and, "the other STDs." Through the next ten years, we had syphilis, gonorrhea, PID, chlamydia, herpes and the "other STDs," but by 1988, we have HIV and the "other STDs." The other STDs, in fact, offer us a unique opportunity to try and control the spread of HIV in exactly the same populations that unfortunately, because of their drug using patterns, have also high seroprevalence of HIV.

What can we do about it? You often hear the line, that education is our only tool. Education is <u>not</u> our only tool. This particular Commission, in my view, was heroic in terms of addressing a key issue; namely, the provision of treatment facilities for drug users -- a way of controlling the spread of HIV. Controlling the spread of genital ulcer disease is another tool beyond education available to you. Eliminating the ulcers can avoid spread in the powder keg situation of the inner city, minority, heterosexual population with high HIV prevalence, increasing genital ulcer prevalence and, unfortunately, decreasing resources that have been directed to the traditional STDs.

CHAIRMAN WATKINS: Thank you very much, Dr. Cates. Ms. Wertheimer.

MS. WERTHEIMER: I would like to commend the Commission for recognizing what very few others have, the importance of sexually transmitted diseases in the epidemic of AIDS.

The other STDs, which have never taken their appropriate place among the nation's health priorities, have been overshadowed by AIDS. We now know, as you have heard, that these diseases are more dangerous than ever as an important risk factor in AIDS. Yet, we continue to address AIDS to the exclusion of, and more importantly, at the expense of research and control of the other STDs.

The STD program at the CDC, as Dr. Cates has told you, has been forced for many years to make difficult tradeoffs and has been stretched well beyond its means. STD programs have been confronted with outbreaks of antibiotic resistant strains of gonorrhea, the need to prevent pelvic inflammatory disease, the rise in viral diseases, such as herpes and human papilloma virus, the recognition of chlamydia and the importance of these diseases in fertility and reproduction. It has been like trying to contain a four alarm fire with a few buckets of water. First slide, please.

Funding for STD programs at the CDC and for research at NIH have had no growth since 1982. That little purple worm that goes along the bottom of the slide is STD funding. You can take that line back well before 1982 and you would see virtually no fluctuation. In fact, 1943 was the year of the greatest federal support for STD control. Adjusting for inflation, we would now have to spend $250 million to equal the federal effort in 1943, when the program consisted only of syphilis control.

Today, the entire federal program to control STDs receives only one-quarter that amount, $65 million, and that is to control all sexually transmitted diseases.

Since 1981, the STD control program of CDC has been subjected to two proposed block grants, reprogramming of funds, cuts in funds, the Gramm-Rudman-Hollings sequestration, a hiring freeze and the direct diversion of funds and personnel to AIDS activities. The President's budget for fiscal year 1988 requested a $4 million cut in funds for the program and the budget just presented to Congress for fiscal year 1989 would freeze the level of funding available to STDs.

At the beginning of the AIDS epidemic, resources and manpower were mobilized to meet the need of this important epidemic. This was appropriate; however, in the years that have passed, if you will show the next slide, these resources have not

been restored. In fact, quite the opposite has happened. The STD control program has continued to make sacrifices to AIDS. Millions of dollars have been diverted from STD programs to AIDS activities. With no new dollars and a continual drain of existing funds, the STD program has suffered severely. The diversion of trained, experienced STD personnel, both headquarters staff and federal assignees, won't appear on that chart. The brain drain has been severe and constant.

In 1981, four STD division members were assigned to investigate AIDS. In 1982, eight members of the division were detailed. In 1983, five headquarters staff and ten field staff left STDs to work on AIDS. In 1984, three headquarters staff and twenty field staff were diverted.

In 1985, the Director of the Division of STDs was actually detailed to AIDS for a portion of the year and thirty positions were detailed away from STDs to AIDS. In 1986, forty-five positions from STD control were diverted and in 1987, those positions were permanently reassigned to AIDS.

Budget sheets and FTE allocations also won't reveal the fact that the people who remain in the STD control program actually spend a substantial amount of their time and energy working on AIDS. A recent study shows that only six of the more than ninety total STD staff actually devote all of their time to STD activities. Twenty-nine said they spent up to 49 percent of their time on AIDS; 23 spent 50 to 70 percent of their time on AIDS and 38 members of the STD staff actually spend between 70 and 100 percent of their time working on AIDS.

Research has also been affected as researchers, who previously have been investigating STDs have now turned their attention and their laboratories to AIDS activities. A major obstacle to the control of STDs, particularly the viral diseases, is the lack of diagnostic and treatment methods. Lacking resources, personnel and in some cases, cost-effective diagnosis or treatment, the STD program of CDC has been forced to make difficult choices. Its resources have been almost exclusively devoted, as you have seen from Dr. Cates' slides, to the control of syphilis and gonorrhea.

Herpes, a viral STD from which 30 million Americans suffer, is now implicated as a risk factor in AIDS; yet, genital herpes receives almost no resources through STD control programs. The resources and manpower simply do not exist to deal effectively with them. Next slide, please.

There is a clear history that increased federal funding for STDs translates to fewer cases of disease. Conversely, reduced spending is probably a main contributor to increases in STDs, such as we see today. And that slide shows what Dr. Cates

showed; the increase in syphilis versus dropping dollars available for syphilis control over the last ten years.

CDC estimates that more than 13 million Americans each year acquire an STD and more that 2.5 million of those are teenagers. These diseases are important in their own right but we now know that infection places these millions of Americans at increased risk of acquiring HIV.

My recommendations to this Commission are really quite simple and fairly echo everyone else's. Funding and trained personnel are urgently needed for the research and control of STDs as an important method of preventing HIV. More specifically, I would include increasing federal spending for STD research, including investigation on the role of STDs as a risk factor in AIDS and on prevention measures, such as contraceptive methods, which could be beneficial in the control of the diseases.

Secondly, to increase allocations for STD research training fellowships. These investigators are an investment in the future.

Thirdly, to increase personnel for STD programs and to increase the training available to them. The program cannot continue to function with part time staff.

And, lastly, to provide a massive increase in funding to provide a viable and stable STD prevention and control program nationwide. Funding should be provided to adequately address the tremendous epidemics of these diseases, particularly the ulcerative ones.

I can think of no recommendation you could make, which would be more cost effective and have a more positive impact on the prevention of HIV infection.

CHAIRMAN WATKINS: Thank you very much, Ms. Wertheimer. I would like to start the questioning with Dr. Crenshaw.

DR. CRENSHAW: Thank you very much for your comments. The thing that strikes me as the most distressing and what I hear all of you say is it seems that AIDS, which is a sexually transmitted disease, has somehow gotten out of your hands a bit in many respects, financially. In terms of the expertise required to deal with this epidemic it is certainly parallel to the expertise you already have in dealing with other sexually transmitted diseases. It seems there has been a separation of church and state here that really isn't quite appropriate and that a lot of cost effectiveness could occur if we used the same ammunition to deal with the multiplicity of sexually transmitted diseases.

Can you identify some specific problems that interfere with this possibility and that are pulling AIDS people away from you or taking your experts into AIDS rather than bringing them to you and incorporating AIDS as one of the many STDs that we battle? It seems that this ought to be a team effort.

DR. CATES: The problem that you put your finger right on is that we initially robbed Peter to pay Paul. What has happened is we have diluted out our efforts that had been concentrated in the early years on one traditional genital ulcer disease, syphilis, that had over time been effective in greatly reducing syphilis levels.

We have diluted that to a point where it no longer was effective in stemming the tide. What we were hoping was that behavioral changes would occur as a result of the general education messages for AIDS and directing counseling messages one-on-one to those at risk of sexually transmitted diseases.

To date we have seen that in the gay male community. We have not seen it in the heterosexual community and since we have taken the resources away from the traditional tools of screening, partner notification, outreach type activities for syphilis in particular, we have seen increases in that particular disease.

That is a simplistic way of representing it. At a time when we have had <u>some</u> population at risk increases, probably related to the sex for drugs concerns where we have identified without concomitant resources to plow back into syphilis intervention activities, an exponential growth of this particular genital ulcer disease occurs..

DR. CRENSHAW: It also seems to me that whether it is genital ulcer or chlamydia or any of the sexually transmitted diseases, that you are dealing with the identical population that is sexually active and perhaps with multiple partners, that is at highest risk for AIDS, whether they have ulcer disease or not.

The other thing I would really appreciate your comments on, and then I do have a few other questions, but I will wait and see if there is time at the end of the panel, is my perception of the AIDS virus is that it is a very democratic virus and that it doesn't discriminate too much between homosexual or heterosexual people and I particularly am gravely concerned about our teenage kids. I think that figures of sexually transmitted diseases that we have among our teenagers are just a preview of what we might expect with HIV if we aren't proactive in these regards.

Could you comment a little bit about the various diseases and teenagers and what you think we can do to help prevent the incurable HIV infection from making inroads?

MS. WERTHEIMER: I think especially chlamydia is extremely high among teenagers. In some college health units it is one of the most commonly seen infections. Unfortunately, a lot of the combination of messages, as you have heard, hasn't worked. Teenagers pretty much perceive themselves as invincible, I am concerned that a lot of the school education programs are going to focus so much on AIDS and perhaps not tell teenagers that there are probably close to three million teenagers, who are going to get an STD this year. This may not seem too important to a teenager until you say that this means you are now at risk for AIDS, that it puts you at greater risk. Other than that, I think Dr. Cates can probably --

DR. CATES: But the answer to your question is "yes." The only reason teenagers are a set-up for sexually transmitted disease is because of behavioral patterns. We are fortunate that the HIV infection has not reached levels in that teenage population which, given their behaviors, you would see an exponential growth in this particular virus.

But, again, just like the inner city minority populations, teenagers are a potential powder keg if the seroprevalence gets to that particular threshold level, at which time the model begins its exponential rise.

CHAIRMAN WATKINS: Dr. Cates, I am going to step out of turn here because I don't really understand how the budget lines can go like that when there is certain authority within the Centers for Disease Control to take doubling of dollars and rapped up dollars in '89, the Presidential budget, and not get yourself more in balance.

It seems to me that if you all believe very strongly that the co-factor or the risk factor linkage here is so predominantly in the middle of the HIV epidemic spread potential, it seems to me that you would find a more rigid coupling and disallow the Peter to pay Paul because it seems to me that they should move -- the funding should move in some sort of linkage with itself.

Have you not defined it in some sufficiently strong way, either epidemiologically or otherwise to define this thing and say, look, you can't rob Peter to pay Paul. It is all the same. They have got to move together.

We found the same thing in the FDA. How can you fund one line like this that is going to drive all the products through one agency and then fund the agency like this? So, it

seems to me we have a similar kind of an expose' here. I didn't realize that you all felt so strongly and, yet, somehow we haven't put it into -- who is putting pressure on you to keep your line level with the others going up? CDC can certainly reallocate and pound the table wherever necessary to bring those more into balance.

DR. CATES: Well, basically, we have two categorical programs. To the extent that the AIDS prevention monies could be reprogrammed into STD, we would probably have to go to Congress to get the okay for that.

CHAIRMAN WATKINS: But has Congress been made aware of the depth of your analysis and the study of linkage and the close correlation? We have seen pictures of STD densities in New York, for example, that coincide directly with other data on the AIDS epidemic and it seems to me that -- and we have heard enough testimony now, and certainly from you today, very compelling testimony, it just seems to me that it is time to review the bidding. Can we separate these one from the other at this point or do they need to at least stay partially linked together?

DR. CATES: Well, we are certainly pushing for a consideration. Over the years the STD funds have been the "slush fund" for starting off many of the state-based AIDS prevention activities. It looks like it may be time to see the arrow pointing the other direction, but at the same time everything needs more. It is not as if we have enough money at the state level to provide for the myriad of activities that we have been discussing just in the last two hours.

CHAIRMAN WATKINS: Have you made a proposal within the Centers for Disease Control and your linkage with the states to say what the funding should be if properly coupled with the HIV epidemic that we should be putting into it and keep the two much more in parallel than so significantly separated?

DR. CATES: That would be preferable in order not to have one disease always -- or one infection always -- command center stage to the detriment of all of the others. Kris, I don't know if you have a comment on this from Oregon's standpoint.

MRS. GEBBIE: Maybe there is something I can say more easily than Dr. Cates can say. I think there has been immense pressure from the Administration on the CDC to not show overall growth and, therefore, to move things among categories and it was easier to do it with the STD program because at least those people were trained in many of the issues that were common to AIDS as opposed to robbing them from the immunization program, which was equally vulnerable.

CHAIRMAN WATKINS: Let me ask a question, though, Ms. Gebbie. Is this because of the feeling that was reflected earlier that there would be a magical spinoff and if we put the dollars over here, we would see the spinoff over here in STDs, as was presented here? And if so, and that hasn't taken place, and that was one of these budgetary myths that floats around periodically to cut dollars and we have to review that now, is this something the Commission should get into?

MRS. GEBBIE: I don't think it was that logical at all. I think it was simply AIDS is new. People are yelling louder about AIDS. Let's go for AIDS. I know that the testimony was given to Congress. I know that the testimony was given to the Administration by people in the field, saying the same things we have heard here and it simply did not prevail.

I think a fundamental issue underlying this process that may bear examination and it may be one of those wedges that this Commission cannot get into, is that funding for prevention services in this country are rejustified each year from zero, as opposed to funding for illness treatment, which is entitled through the Medicare program and is allowed to grow on the basis of demand from the states.

But each of these prevention programs comes in year after year with no entitled base and re-argues for a budget separately and that leads to this kind of very tight budgeting and this terrible trade-off process. Somehow there is a mythical assumption that communicable diseases or other diseases will vanish and don't need maintenance. People are always looking for which one can we cross off now. And I think this illustrates very well that most of these diseases don't vanish, don't evaporate and need sustained funding.

CHAIRMAN WATKINS: I think we are going to need quite a bit more. I think we have found one of these rocks that I have got to keep turning over. It just seems to me that this is an area -- you are obviously a very competent group of witnesses here and all telling us the same thing and it just seems to me that we have to know a lot more. I really would want maybe to work with Kristine here, and perhaps you, and do something more definitive in this area, and work with Jim Mason to really take a hard look at this thing and see what recommendations we should be making because I think you have given us a rather compelling and somewhat frightening presentation here today.

We may be giving Peter a heck of a problem when we have robbed him to the extent we have. I really think that we have got a real problem here that we need to iron out and sit down with you and get the proper projection on what you feel the linkage should be, how it should be focused.

We have said in many other aspects of our recommendations that there are certain aspects of this particular infectious disease that must be additive. We simply cannot rob the other side because to do that puts many other things at risk and we don't know what we are doing to compound our problems and amplify the disease itself. I don't know if you have figures to that extent or if you can take this kind of data and extrapolate to what it is really doing, particularly in high density areas, such as New York and Miami and the other areas. It seems to me we are really compounding our own serious problems here.

DR. ROSENBERG: I think there is one thing that is in the CDC's defense to some degree, worthy of note, and that is the fact that most of the data that I cited has become available over the last year or two; in other words, longer than the budgeting cycle.

I think the other point that you raise is the degree to which sexually transmitted diseases that we have been talking about may be responsible for HIV. Part of what I did is looked at some quantitative estimates of the study from Baltimore, for example. The STDs that they investigated, were responsible for about a quarter of the cases of HIV that were detected.

CHAIRMAN WATKINS: Well, I would like Ms. Gebbie and the three of you and me to talk about this some more and I would like you to help us ask you the right questions and we would like to send those questions to you at the Centers for Disease Control, so we can get more to the bottom of this aspect of it.

I think that we have found another one of these very important areas we need to know a lot more about. I think we can do some things in our recommendations and we need to be more sensitive to it. Do you agree, Kristine?

MRS. GEBBIE: Yes, I do, and, while I would be happy to share some of these little assignments with other Commissioners, I am also pleased to help wind some of this work up.

DR. CRENSHAW: I would be glad to help.

CHAIRMAN WATKINS: We will share it with Dr. Crenshaw. This group up here will work with you, but I really do feel that you have given us very special insights into this aspect of it, which has been a dilemma. I mean, people are asking a lot of questions. Why is this going on? We have heard presentations to us about what it is doing in the San Francisco area among the gay men and the decline is significant. So, there are lots of things that I think this is going to tell us as we look at education and what we may be doing. I would hope that the Centers for Disease Control national campaign to prevent the spread -- we have the pamphlets going out to 45 million households. The question is is

there anything there? Is there any message inside that regarding STDs? I would hope there would be.

DR. ROSENBERG: Yes, there is.

CHAIRMAN WATKINS: Because that is going to be critical. So, perhaps that then needs some substance to back up the rhetoric from the federal level. Anyway, I bring that up. Now, I will open the floor to other questions from the other Commissioners, but it just came to mind as I heard all this and I had to get it off my chest. Ms. Gebbie.

MRS. GEBBIE: In view of the hour, I think I will put my questions in writing, but just to alert you, I think it would be very helpful if you could provide us with some comments, one, on the degree to which we have good evaluative data on what has and hasn't worked with these other diseases, not just hunches and not just numbers of cases, but evaluation of techniques. That would be helpful.

And, second, this whole issue of teasing programs apart by diseases or grouping them by a transmission method, the question of whether AIDS programming should be managed separately or should be part of an integrated STD approach is an intriguing one and has pluses and minuses and I think it would be helpful to all of us to get the observations from your perspectives, the three of you. We will look to see that later on, rather than I think a long discussion of it now.

CHAIRMAN WATKINS: Dr. Lee.

DR. LEE: I have just come back from Africa and there was one -- somebody had submitted some material on Zambia. Which one of you is --

DR. CATES: Zimbabwe, yes, you are right.

DR. ROSENBERG: That table, I think, is mine.

DR. LEE: Zambia is one of the places I was and a British doctor told me, and he said he had been responsible for the testing himself, that 90 percent of the Zambian army was HIV positive. This has certain immigration overtones to it. I mean, I assume that he had sleeping sickness or something. Can you confirm anything like that? I have never read any statistics in that area.

DR. ROSENBERG: I have not heard of that but I would be very surprised.

DR. CATES: I haven't heard of it.

CHAIRMAN WATKINS: Dr. Crenshaw, do you have a follow-up question?

DR. CRENSHAW: I guess I would only add that I would really appreciate help in two areas. One is that in dealing with sexually transmitted diseases and the behavioral aspects, one of the areas that once you get out of gynecology or urology that I have noticed in medicine is often physicians aren't as aware of the extent of sexually transmitted diseases as they could be and we could do more some in education. They will give two prescriptions and not ask if there are any additional partners, by way of example. You know, it is a habit and often the individual won't volunteer the other seven.

The other thing that would be helpful, I heard a comment from the previous panel that 1,200 or so people who came in protesting that perhaps many of them really didn't need it or weren't in a high risk group and one of the concepts I find very difficult to get across is that most sexual partners don't know the full scope of activity of their sexual partners and it is very hard to tell from the historical report of one person through a crystal ball, whether they are the worried well or need to get tested. If you could comment a little bit on how little you can tell from one person's report on the scope of sexual behavior that they may have been subjected to? You would be the best to comment on it because of your experience of what really does go on in terms of shared genital membrane disease.

DR. CATES: I agree with your comments on both counts. Number one, I think physicians are inadequately trained to deal with most matters of sexuality, especially the difficult question of asking about sexual partners.

With regard to how much one partner knows about other partners' activities. It is not infrequent that when you tell one partner that they have been exposed, their first comment is, "Don't tell my spouse." So, we have a multiplier effect. This is the reason that STDs are more than just a simple communicable disease in today's world, because you are dealing with the whole issue of sexuality.

DR. CRENSHAW: Thank you.

CHAIRMAN WATKINS: I will ask you one more question. In gonorrhea and chlamydia data, do we see any growth in that particular sexually transmitted disease among adolescents? I am talking about, let's say, secondary school and, if so, what is it doing? Do you have it broken out that way?

One of the things we have heard from Dr. Karen Hine from Einstein Medical School, who is an expert in the area of pediatric AIDS and so forth, is significant personal concern

about the HIV in adolescents and so the question is if we are seeing growth in a number of sexually transmitted diseases in adolescents.

Doesn't that give us some considerable concern about what the future may be there in the HIV seroprevalence among adolescents, the potential for that? You talked to that point that you reach when the modeling is going to tell you you are going to see something. Maybe it is two years from now; maybe three years from now. At any rate, do you have that data? Do you have it broken out by age group, we will say, so to speak?

DR. CATES: We do for gonorrhea. In teenagers the gonorrhea rate has not gone down to the same extent that it has in older individuals. Relative to the decrease in the older ages, gonorrhea in teenagers has remained remarkably stable.

We don't have consistent trend data for chlamydia in country. In places that have been collecting data on a regular basis -- once we started moving resources from syphilis and gonorrhea to chlamydia, we started having an impact on trends. Seattle and Indianapolis are the two places with this experience. Teenagers are at higher risk than older women of having chlamydia for combinations of behavioral and biological reasons.

DR. CRENSHAW: Correct me if these figures are not as current as you may have, but it is estimated that 30 percent of sexually active teenagers have chlamydia, which is just a huge number, if you think about it, and the answers we got back from CDC on gonorrhea in teenagers in the 15 to 19 year age group, were approximately 250,000 cases of gonorrhea reported and that was estimated to be 50 percent underreporting, which means 500,000 nationwide of gonorrhea alone. So, that gives some idea of what the potential is should they get seeded with HIV.

CHAIRMAN WATKINS: Could you give us whatever data you have on the break-out in adolescents of sexually transmitted diseases, anything you have along those lines. If you don't have it -- if you know some states that have data that is perhaps broken down in a more useful fashion to do some analysis, I would like very much to get a hold of that.

The data we had and is contained in my recommendation to the Commissioners for our interim report, show that about one-third of the seniors in our high schools today are involved in drug usage that is more serious than marijuana. The marijuana numbers are higher than that, but that is the data coming out of -- I don't know if it is the National Institute of Justice, but we have the data in the Commission office. And you put those combinations, the potential IV drug abuse linkage in adolescents, to sexually transmitted disease growth, and you have all of the

ingredients for serious concern. This is why I am asking the question. I was struck by Dr. Hine's concern because she is doing the work for CDC on pediatric AIDS, I understand, at the Albert Einstein College of Medicine. So, it is related to that. I am trying to put my arms around something right in that particular area, only in a balanced way looking at STDs, as well as the potential for getting HIV seroprevalence information.

You remember, Dr. Koop made a statement publicly about getting information out of a number of high schools. Whether that will take place, we are not sure from this morning's testimony, but certainly packaging up something like that in a way that would really be useful in order to do an analysis of what is really going on, we would be informative.

Thank you very much for coming before the Commission. We will keep the lines of communication with all of you open. Ms. Gebbie and I would just like to chat with you briefly for a minute and see if we can cement a little task force effort on our joint parts and maybe Dr. Crenshaw would be willing to join us just to chat briefly on how we might proceed from here.

We appreciate you staying this long and staying with us on this important issue and we will commence our hearings again tomorrow for the Commissioners at 9 o'clock here in the Interstate Commerce Commission building. So, we will stand adjourned until tomorrow morning at 9:00.

(Whereupon, at 6:07 p.m., the meeting was recessed, to be reconvened at 9:00 a.m., the following morning, Wednesday, March 2, 1988.)