PRESIDENTIAL COMMISSION ON THE HUMAN IMMUNODEFICIENCY VIRUS EPIDEMIC

HEARING ON DISCRIMINATION, ETHICS, AND TESTING

The Hearing was held at the
Vanderbilt University Stadium Club
25th Avenue and Kensington Street
Nashville, Tennessee

Thursday, March 17, 1988

COMMISSION MEMBERS PRESENT:

ADMIRAL JAMES D. WATKINS (Ret.), CHAIRMAN

COLLEEN CONWAY-WELCH, PH.D.

JOHN J. CREEDON

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RICHARD M. DeVOS

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BURTON JAMES LEE, III, M.D.

FRANK LILLY, PH.D.

BENY J. PRIMM, M.D.

PENNY PULLEN, M.D.

CORY SERVAAS, M.D.

POLLY L. GAULT, EXECUTIVE DIRECTOR

COMMISSION MEMBERS NOT ATTENDING:

JOHN CARDINAL O'CONNOR

WILLIAM B. WALSH, M.D.

I-N-D-E-X

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

P R O C E E D I N G S

MS. GAULT: Good morning. Ladies and gentlemen, members of the President's Commission, my name is Polly Gault. I am the designated federal official here today, and in that capacity, it is my pleasure to declare this meeting open. Mr. Chairman?

CHAIRMAN WATKINS: Good morning. Happy St. Patrick's Day to all of you. Yesterday, the Commission heard testimony about the problems of discrimination faced by HIV-infected persons in employment and schools. We heard from persons who themselves suffered discrimination and from those who were attempting to address these problems. We received powerful testimony on the benefits of schools and workplaces developing policies and guidelines prior to facing their first case of AIDS, and our witnesses made some important policy recommendations focused on preventing discrimination. Today we focus our attention on the equally significant matter of ethical decisions relating to persons with AIDS. Our panels today will address the critical questions of health care provider responsibility for persons with AIDS and how the nation's medical resources should best be allocated to achieve the finest health care possible; how decisions are made relating to the ethics of medical research and how decisions about treatment and care are determined.

We will, also, examine the question of medical confidentiality and the decision of health care providers or public health officials to inform third parties of possible exposure to HIV, and to commence this morning, we are pleased to have Dr. A. Gene Copello, Director of Vanderbilt AIDS Project, Vanderbilt University Medical School as our first panelist, and we have cleared with Dr. Copello that he will be able to remain throughout our first panel which will follow him and that we will hold our questions for him then until the follow-on panel completes its testimony.

So, with that welcome, Dr. Copello, please give us your statement?

DR. COPELLO: Mr. Chairman and members of the Commission, my name is A. Gene Copello. I am the assistant professor of medical ethics in the Department of Medicine, Vanderbilt University and Director of the Vanderbilt AIDS Project which is a regional unit of the Federal Department of Health and Human Services, East Central AIDS Training and Education Center. In addition, I am the President-Elect of the International Society for AIDS Education. My work in AIDS began in 1984. My training includes medical ethics, public health and social science. It is an honor to address you today.

Your work is a critical component of the national response to the HIV epidemic. My intent is to provide you with a framework for ethical analysis and recommendations regarding the control of HIV transmission and the management of social ethical problems which attend the epidemic. My testimony is based on the professional literature, my own research and the experiences of various regional and international organizations of which I am a part.

The development of public health policy requires ethical analysis. A general ethical conflict within public health has historically been between protecting the rights and privacy of the individual versus the collective rights of the community. This consideration alone raises a need for ethical analysis during the developmental phases of public health policy. While many professionals, including myself have come to agree with June Osborn of the University of Michigan that in the HIV epidemic this tension is generally in balance, others have not. In almost every public health debate this tension is felt at some level. The HIV epidemic is no different, and this alone calls for ethical analysis.

This analysis concerns the development of socially appropriate solutions to problems. Ethics is the rigorous study of human relationships in the community. It is the discipline which identifies, interprets and plans management solutions to conflicts of value and the behavioral and attitudinal manifestations of such conflicts. Returning to public health, for example, the historical value conflict has been between collectivistic values and individualistic values. The ethical analysis of such value conflicts and the attendant behavioral, social and attitudinal manifestations of that should take into account at least five factors. First, one must probe the underlying assumption of a particular health policy decision. For example, if one wants to criminalize the transmission of HIV, it is the underlying assumption of this position that persons living with HIV infection routinely and purposely infect others. Such an assumption needs to be evaluated. Current behavioral research, for example, strongly suggests that persons living with HIV infection are not prone to such behavior. Related to assumptions is purpose. The HIV epidemic has been highly politicalized by the left and the right of the political spectrum. The first public health agenda, as William Schaffner and I have argued, in terms of HIV is to contain the transmission of the virus. Other agendas or purposes, as nobel or notorious as they may be, are secondary to this primary purpose of public health. I have been involved in too many AIDS debates where both the professional and the lay person become confused as to what the actual purpose of various public health policy strategies should be. One example of this is the confusion between the rights of sexual minorities and the control of HIV transmission. Another is the confusion between AIDS education and preserving virginity among youth. While both protecting the rights of

sexual minorities and preserving the virginity of youth may be considered nobel purposes, depending on where one stands on such issues, they are secondary purposes to the control of HIV transmission. This is not to say that such purposes do not play a role in
the epidemic but to collapse such secondary agendas into the primary one will seriously damage the public health by confusing and polarizing individuals. Such isolationism will not solve the problem of HIV transmission.

Communities need to be drawn together by a language and a policy which can be broadly embraced. Confounding this effort with burdensome ideology will place communities at risk for further social fragmentation.

The third factor of ethical analysis is related to data. Again, as June Osborn writing in February in the New England Journal of Medicine has said, "Ethicists sometimes embark on an approach to thorny issues with the assertion that good data make good ethics." Ethical public health policy must be based on data, and in general the more personally restricted the policy, the higher the ethical demand for sound and consistent data. Ethicists and social scientists rely on both quantitative and qualitative data because quality questions are as important as questions of quantity. It is important to understand the effects of what is being studied as it is, also, important to know the various numerical counts with respective to a particular study. In the HIV epidemic, it is critical that public health policy be based on what is known about modes of transmission, methods of prevention, the natural history of the virus and the social and behavioral contexts of viral transmission.

It is this known body of knowledge studied and evaluated over time that must be considered the foundation of HIV public health policy. I will not review this data base, assuming that you are aware of it.

The fourth factor is appreciation for the social context of disease. Disease is not merely a biological event. Persons who are ill suffer a wide spectrum of psychosocial reactions, such as anger, guilt, abandonment. Disease involving human-to-human transmission, that is infectious disease may magnify some of these reactions, for example, guilt.

In addition, chronic and potentially fatal disease, such as HIV infection, further complicates this context. There is ample data in pediatric chronic illness and adult oncology which demonstrates that disease chronicity compounds attending social and psychological problems, and finally with HIV and AIDS a number of behaviors which are considered unacceptable by many, homosexual acts and drug abuse which is needle based have come to

compound problems of disease-related discrimination, fear and misunderstanding. Social context factors are, also, important considerations in the planning and implementation of AIDS education and prevention programs. Cultural sensitivity is critical. Without appropriate knowledge of the values, language and communication modes of a given population, educators will not be effective. Population-based educational outcome studies have demonstrated the importance of cultural sensitivity in this country and elsewhere.

The final factor I will present as a core element in ethical analysis is the issue of rights. Given the data on the modes of transmission of HIV, essentially that the virus is sexually transmitted and blood borne, it appears to me that the question of community versus individual rights is largely solved. The exception would be the case of intentional transmission. Such cases have been very rare. The mental competence of the index case should be evaluated in such situations. If incompetence or otherwise mental impairment exists, appropriate psychiatric and/or mental health services should be provided. Competent persons who intentionally transmit HIV should be contained, if they are refractory to behavior change. I want to stress that such cases have been extremely rare. Most studies show dramatic changes in behaviors, particularly among groups of individuals who are at higher risk for contracting and/or transmitting HIV.

Another issue to be considered in the ethical analysis of the epidemic in terms of rights is the public right to information. Citizens have a right, I would argue a moral right to information and educational programs which will protect their health. Persons in occupations where this risk is greater than general populations, for example, health care workers have an especially significant right to infection control education.

Finally, in the area of rights, persons who are ill, including those living with HIV infection have a right to health and mental health services. American society has increasingly accommodated the health care needs of its citizens. Persons living with this infection should not be treated differently.

One final comment on rights. They do not exist in a vacuum. Rights exist within human communities. Persons must, also, exercise responsibilities, if the rights of all citizens are to be protected. In terms of HIV infection persons have a responsibility to take control of their own health by learning about HIV and AIDS through practicing preventive methods, for example, safer sex and so on. While policies should make such programs available, it is ultimately the individual who decides to take advantage of such programs.

In other words, having a right to health has something to do with living responsible lives whereby one respects others, as well as him or herself. Such interdependence is community.

I will now turn to a number of specific recommendations regarding transmission, control and management of the social and ethical problems associated with this epidemic, first, transmission control. One, increased funding should be made available for education, counseling and HIV antibody testing programs; funds should, also, be increased for research into these areas. Two, the Federal Government should work with the Global Commission for Quality Assurance in AIDS Education of the International Society for AIDS Education to assure quality in American programs. Three, funding should be made available for both multi-center and population-specific AIDS education and counseling outcome studies. Four, most professional sectors in society should be encouraged to engage in educational activities, including clergy, nurses, physicians, social workers and others. They should work together in educational teams. This will help to reinforce information from different perspectives. Five, terminology related to risk groups should be de-emphasized and risk behavior terminology should be emphasized more. Six, educational and counseling terminology related to drug-taking behavior which increases the risk of HIV transmission should emphasize all forms of needle-based behavior rather than only IV needle behavior. Seven, voluntary HIV test centers should be widely available to the public with options for anonymous as opposed to confidential testing. Eight, seroprevalence studies should be expanded. These studies are generally anonymous. However, I believe persons should be offered the option of obtaining their antibody status results if they so desire. Nine, preventive AIDS education should be mandated in all health care facilities. Ten, preventive education should be strongly encouraged in school and industry settings. Antidiscrimination and confidentiality laws specific to HIV infection should be in place in settings where HIV reporting and/or contact tracing is being implemented. Federal leadership is imperative on this issue.

Following are some specific recommendations regarding management of social-ethical problems arising from HIV. One, discrimination against persons with HIV infection in school, housing, health care and employment settings should be made illegal. When discrimination is proven, sufficient penalty should be incurred by guilty parties.

Two, a special body should be established immediately to study health and life insurance issues related to HIV infection. This body should recommend insurance industry regulation in this area or recommend quality alternatives.

Three, the illegal release of HIV status should be punishable with a penalty sufficient to deter such behavior.

Four, community leaders should have program development plans in community-wide AIDS education made available to them from a national clearinghouse, and five, communities should be encouraged to begin AIDS education early. This may assist in lowering the risk for antisocial behavior toward persons infected with HIV as well as lower the risk of infection.

These recommendations are generally consistent with the recommendations of the World Health Organization Special Program on AIDS, the International Society for AIDS Education and many of our own national, professional and governmental bodies. They are, also, consistent, I believe, with the data base, ethical analysis and my own experience in the area.

I believe the people of the United States will foster the energy, skills and hope to deal with HIV infection in reasonable, humane and scientific ways. As palliative and curative research and vaccine development must continue, our preventive educational efforts must, also. Human intelligence and compassion will overcome HIV.

CHAIRMAN WATKINS: Thank you, Dr. Copello. I would like to move quickly into Panel 1 then. We have today covering the area of Health Care Provider Obligation Dr. M. Roy Schwarz, Assistant Executive Vice President, American Medical Association; Dr. Lorraine Day, Department of Orthopedic Surgery, San Francisco General Hospital; Enid Neidle, DR. Neidle, American Dental Association, Assistant Executive Director, Division of Scientific Affairs; Leonard Lindsey, American Nurses Association, Assistant Professor of Community Health Nursing; Dr. Arthur DeSalvo, Chief, Bureau of Laboratories, South Carolina, Department of Health and Environmental Control, and Dr. Clark Keith, Chief, Bureau of Preventive Health Services, South Carolina Department of Health and Environmental Control.

We would like to lead off with testimony from Dr. M. Roy Schwarz.

DR. SCHWARZ: Good morning, Mr. Chairman. My name is M. Roy Schwarz, and I am the Assistant Executive Vice President of Medical Education and Science for the American Medical Association. Before I give my formal testimony, I would like to, as an individual and on behalf of the AMA congratulate all of you on the Commission for the extremely fine job we think you are doing. As you all know, you entered this fray with some difficulty when it came to credibility. In our opinion your first report went a very, very long way to recover that lost ground. We salute you for working for all of us in this very

difficult arena, and we especially salute your Admiral who was pressed into service unexpectedly as a part of that process.

Last November, the Chairman of the Board of Trustees of the American Medical Association appeared before this Commission to report on AMA activities relating to AIDS. One of the items that he covered was a report of the AMA's Council on Ethical and Judicial Affairs. That report, a copy of which is attached to this statement addressed the question of the physician's ethical obligations toward individuals who are infected with HIV. In a clear pronouncement, the Council stated that a physician may not ethically refuse to treat a patient whose condition is within the physician's current realm of competency solely because the patient is infected with HIV.

This report was presented to the American Medical Association's House of Delegates in December, and I am pleased to say that our house voiced strong support for the report and its contents.

The articulation of this ethical standard draws on a historical principle of medical ethics. The tradition of the AMA, since its organization in 1847, is embodied in the following, and I quote. When an epidemic prevails, a physician must continue his labors without regard to the risk of his own health.

In the current situation, adherence to this historical principle serves two important purposes. First, it serves as an example to the general public that the medical community understands the nature of HIV transmission. When physicians behave in a manner that is consistent with the message that HIV cannot be acquired through casual contact, it enhances the credibility of the public health message.

Second, it serves to ensure that persons with AIDS and those infected with HIV receive appropriate medical care, even though it may pose some occupational exposure to the physician. Physicians have, to a large extent, lived up to the ethical ideal and have not refused to treat patients solely because of HIV infection. Of course, there are exceptions. We are asked occasionally how the AMA enforces its ethical principles among physician members. Our answer is that ethical principles are intended as guides to responsible professional behavior and not as rules of law.

The AMA does not maintain mechanisms for investigation and enforcement. What we have done is to circulate the ethical principles as widely as possible. We have availed ourselves of every opportunity to testify on this issue before Congress and other bodies. We have, I think, for the first time in the history of the two organizations been invited, for example, to

present our views from the floor of the House of Delegates of the American Bar Association. We, also, have encouraged medical schools to place a greater emphasis on teaching medical ethics and discussing this challenging issue.

Going beyond ethical considerations, the AMA is on record very clearly as supporting the enforcement of existing laws and regulations prohibiting discrimination against the handicapped and providing these laws to individuals infected with HIV.

In conclusion, our ethical stand on treatment of patients with HIV infection is clear and unequivocal. The actual behavior of physicians as a whole is something for which the medical profession can be proud.

By accepting the small but very real risk of occupational exposure to HIV, we are meeting our obligations to our patients, providing necessary medical care and benefiting society by example, as well. Thank you, Mr. Chairman.

CHAIRMAN WATKINS: Thank you, Dr. Schwarz. Dr. Lorraine Day?

DR. DAY: I am Dr. Lorraine Day. I am Chief of Orthopedic Surgery at San Francisco General Hospital and an associate professor at the University of California, San Francisco.

AIDS patients must be cared for. At San Francisco General Hospital where approximately 30 percent of our patients are high risk for AIDS, we have been performing all emergency and elective surgical procedures on these patients since the disease was recognized. I probably have operated on as many AIDS patients as any surgeon in the country, but is it unreasonable to consider the risks to the surgeon's life while we perform these procedures? We do not have accurate statistics on our risks to surgeons.

A prospective study on health workers from San Francisco General Hospital reported on 800 accidental needle sticks with AIDS blood with no individuals turning AIDS positive until October 2, 1987, when a woman health worker turned AIDS positive after a single needle stick. She had no other risk factors and had tested negative prior to the needle stick. It was only then that we realized that a single needle stick could transmit the disease to a healthy person.

We are told that our risk as surgeons is low. Compared to what? According to the occupational safety and health regulations, we are not allowed to work with carcinogens if there is any measurable risk of death. For our protection

and the protection of our patients, we must be certified before we are allowed to operate the fluoroscope; yet I know of no physician or patient in the last 40 years who has died or become ill from the use of fluoroscopy in the operating room.

We are told that we must risk death, a risk that varies from 1 in 800 to 1 in 100 per single exposure, and orthopedic surgeons may get many such exposures per year. Non-surgeons tell us to be careful, but most of them have never entered an orthopedic surgery operating room and are completely unaware of the type of surgery that is done.

May I have the lights off, please? I may need more lights off than this for these slides to project well.

We use sharp instruments, including saws, metal screws, rods and nails to realign sharp bony fragments in the depths of bloody wounds. We use drills and reamers that cause blood and the virus to splatter and aerosolize, contaminating the air we breathe in the closed operating room.

This shows a face mask covered with blood that has been spattered from drilling. We are careful and wear as much protective equipment as we can find, including double shoe covers, boots to our knees, reinforced gowns with extra sleeves, goggles, plastic face masks and double gloves. The clothing as shown here on the knee, gets blood soaked. Gloved hands can be punctured by needles, sharp instruments or sharp bone fragments. A surgeon does not have to be clumsy to get stuck during this operation. I may get my gloves and my hands punctured three to four times during this particular procedure.

Lights on, please.

In California, a surgeon may order any test on a patient without his expressed consent, except an AIDS test. If the patient refuses to be tested, the planned treatment cannot be changed even if a non-operative approach would have the same chance of success. Surgery that decreases discomfort but is not necessary to save life or limbs, such as bunions or hip replacement, cannot be refused by a surgeon for an AIDS-positive patient, even though it puts the surgeon's life at risk. And what happens to me if I turn positive? As an employee of the University of California, I will get $896 per month, plus $2000 for my burial.

We are told that it is unwise for us to know who is AIDS positive because we should use universal precautions on every patient regardless of their AIDS status. This is a high-sounding but unrealistic approach. Proper safety equipment may be unavailable or in short supply or it must be used on the patients at highest risk. A high level of

awareness is imperative, but you cannot play the Super Bowl every Sunday.

The consequences of a positive AIDS test are felt to be too serious to allow testing without the patient's knowledge. There is no one who understands the consequences of a positive AIDS test more than a surgeon. Yet, I feel all surgeons should be tested and that a patient has the right to know if his surgeon is HIV positive. I have been tested, and so far I am negative.

If I turn positive, my career and my life are over. Yet there are AIDS-positive surgeons in this country who are operating on patients who are unaware of their surgeon's condition. It is entirely possible that a surgeon could give AIDS to a patient from an accidental needle stick or scalpel cut during an operation. We are told that there are no known cases of this happening. However, the patients of these AIDS-positive surgeons have not been tested. Lack of widespread testing allows many irresponsible statements to be made. The ultimate question is how will we ever control the epidemic if we don't know who has the disease?

I have worked at San Francisco General Hospital for 15 years. We have a regular prison ward and another ward for the criminals who have severe mental illness. I have received death threats from delusional paranoid schizophrenics and from drug addicts who felt that they deserved more narcotics. My medical environment was hazardous long before AIDS appeared. Patients have rights, but don't they, also, have responsibilities? Doctors have responsibilities, but don't they, also, have a right to stay alive?

Routine AIDS testing of all hospital admissions would heighten safety awareness of health care workers, allowing more efficient use of safety equipment that is now becoming more difficult to obtain and could teach us more about the disease. I am not asking for a totally risk-free medical environment, only for a reasonable chance to stay alive. Thank you.

CHAIRMAN WATKINS: Thank you very much, Dr. Day.

DR. CRENSHAW: Dr. Day, thank you for your courage in operating on infected HIV and AIDS patients for all these years and, also, for your courage in speaking up about additional requirements to best ensure the safety of health care workers. If I understand it correctly, there are some studies that you are wanting to have done in the operating room environment that would require a couple of weeks to accomplish and you requested this of the institution where you work. Can you, one, give me some more detail about what happened since that time or how that came about and how you were responded to and, also, what

repercussions have you experienced as a result of having the courage to speak out on this issue?

DR. DAY: I asked for the air in our operating rooms to be tested, since we drill and ream the blood and bone, and apparently the virus, and as you can see, it covers our face mask, and it covers our bodies. I asked for the air to be tested and our gloves to be tested to make sure that the virus didn't go through, even through intact gloves. Of course, there is a very high defect rate in gloves, and then we get stuck all the time, too. I asked for our gowns to be tested. The response to this was to try to have me replaced. The university called me in and said that the medical director, I mean the executive administrator of the hospital was taking action against me to have me replaced.

Now, as I say, I have been at San Francisco General Hospital and with the university for 15 years, and that was their response. I told them that that wasn't going to make any difference. I was still going to speak out. I have to protect not only myself and my staff, but I have to protect all the young doctors that I am training. I have 12 doctors on my service that I am training at all times. I used to be responsible for their medical education which I still am. Now, I am responsible for their lives, and I must know whether this is happening, whether we are breathing in this virus, and whether blood on our skin is bad for us.

When I told them that they would not sway my position, then they went to my chairman at the university and they told him that they would withhold all financial support, university support from his department unless he got me in line. So, he has decided now to fund these studies out of departmental funds because it is obvious the university really doesn't care much for our safety.

My residents, if they turn positive, get nothing. They don't even get carfare. If a medical student turns positive in the line of duty, they, also, get nothing. When I first spoke out for voluntary testing, which was within the law last October, I discussed this with the chiefs of service at my hospital. In private they all agreed, but when it hit the newspapers that I was asking patients with informed consent to be tested in a voluntary way, it got bad publicity in the papers and all of my colleagues went underground. They disowned me. They said that they had never heard about this, and that I was making policy on my own. So, I can tell you that the environment out there is not particularly pleasant. I have been tested. I have encouraged my staff to be tested. As far as I know, we are the only doctors in the hospital that have been routinely tested.

DR. CRENSHAW: Thank you. In what way can the Commission help? What recommendations would you like to see come from this body to improve the situation? As I understand it, you are just asking that all available possible precautions and investigation be done so that you can maximize safety. You are not looking for risk-free guarantees. Would you make a few comments on recent history with regard to the same pattern occurring for the nurses not so many years ago?

DR. DAY: Yes. Several nurses in our hospital a couple of years ago wanted to wear masks and gloves when they were taking care of patients on the AIDS ward. They were refused this because they said that it would bother the psyche of the AIDS patient because the AIDS patient would somehow feel unclean. So they were not allowed to do this. They were brought up actually in a panel and severely penalized for their desires. Since that time, one of those nurses, Norma Watson, came down with the cytomegalovirus and gave birth to a baby with CMV who is deformed and mentally retarded. She is suing the hospital for some unknown amount, a very large amount. So, we have been told all along the line by the quote, unquote, AIDS experts at our hospital that we have really been at very low risk. I wonder how it would be if we had a piece of equipment in the operating room that had a chance of killing us of 1 to 100 or 1 in 800, and they said, "Oh, go ahead and use it. You know, you may drop dead, if you use it, but it is a small chance. It can occur anytime you use it, but your chances are only 1 in 800." But with AIDS, if we turn positive, we look the same, and then over a period of time we go someplace else and die alone. So somehow, it is considered that we aren't at risk. What was your first question, excuse me?

DR. CRENSHAW: It was what recommendations or how can the Commission help you in your efforts to just get the maximum precautions available to health care workers?

DR. DAY: We need routine testing of all hospital admissions. We are asking for patients to be voluntarily tested, and this takes care of a lot of patients. Recently I had an experience where one of my residents, a woman, was stuck with a Steinmann's pin that goes through the leg on a patient who was a very high-risk patient. He refused to be tested. She was stuck with the pin and of course, was very concerned. She is getting married in the fall. She didn't know what she was supposed to do, get married or not get married. He refused to be tested. Now, in a situation like that, I think that the health care worker has, also, some rights. Why does she have to live with this problem month after month after month, maybe years, not knowing what the HIV status of that patient was? So, I think we have to have routine testing and in some cases where a health care worker is at high risk, such as this. I think that that right should override the patient's right not to be tested.

DR. CRENSHAW: Thank you very much.

CHAIRMAN WATKINS: Dr. SerVaas?

DR. SERVAAS: Dr. Day, when I read about you in AMA News, I asked our local orthopedic surgeons about this thing. "Do you get your gloves punctured when you are doing hip replacements?" These men said, "Yes, sometimes it means four times we change gloves. Down deep in the hole we cannot avoid puncturing our gloves or getting needle sticks or sticks with sharp instruments." My question to you is, you mentioned the young residents, if you had a young sister now, these young residents are -- you have already elected to become orthopedic surgeons. Are we driving away, frightening away some of the brightest and best in internship programs and in med schools by not in California having protection for the health workers? Have you noted any decrease in the number of applicants into your specialty or into the infectious disease specialty that would be a result of not taking action now to protect as you are recommending?

DR. DAY: I don't have numbers, but I can tell you absolutely that that is happening. I have talked to many people who are residents right now who are reconsidering their life plans, and I can tell you what my life plans are. If I continue doing what I do in the situation that I am doing it in, with no more safety than I have now, it is only a question of when I turn positive, not if. I am going on sabbatical next fall, and then I will re-evaluate whether I will ever come back to medicine.

DR. SERVAAS: My experience with it is that I think the public needs to know more about the sacrifices that medical students make. We take in a number of black students from Africa who are very vulnerable to TB, and in our class we had two who came down with TB. They were sent back to Mozambique. They had nothing, and they couldn't get back in med school. It was a tremendous battle for them to get reinstated into medical school because they got TB on the job. I think that we need to take a hard look at how we do protect medical students and residents because it seemed to me a very tragic thing to have given so little attention to how we look after the insurance. I don't know what your insurance is, but your premiums for your own life insurance, have they gone up?

DR. DAY: I don't know. I haven't checked that. I have been too busy doing these other things. I don't know.

DR. SERVAAS: Do you think that our Commission should recommend that we do what Tom Vernon has done in public health where they do in that state that some of the other states like Colorado do these things. Would that be your --

DR. DAY: Can you tell me exactly what you are referring to?

DR. SERVAAS: Tom Vernon, the public health officer in Colorado, as Dr. Schwarz explained has kind of proven in his state anyway that we don't drive people underground when we do testing.

DR. DAY: We have to do the things that are necessary to protect the population, not only the health care workers, but everyone else. The people who have the disease have a right to be treated, but the people who don't have the disease have a right to remain free of the disease. So, we have got to stop treating this as a political issue and treat it as a medical issue. We have known for years how to handle an epidemic. Somehow we have forgotten how to handle an epidemic. They talk about polio. First of all, polio was an epidemic that very few people died in. Secondly, everyone was allowed to take whatever precautions were necessary. Thirdly, these patients were put in one area in the hospital or in a special hospital. Everybody knew what they were dealing with. Fourthly, surgeons didn't operate on polio patients while they were contagious. Rarely did that happen, and if that happened, everyone knew of the person's status. This was not secret information withheld from the health care worker. What a patient says to me is, "You must take care of me. I demand that you take care of me. You must give me your skill, your knowledge, your empathy, your time, day or night, but I have this loaded gun under my coat which may go off at any time and kill you, and I am not going to tell you." Somehow that puts a breach in the patient-doctor relationship.

DR. SERVAAS: Thank you.

DR. PRIMM: Dr. Day, first let me offer you some solace. I am from New York, and at Harlem Hospital Center, which is in the addiction capital of the world, there are a number of intravenous drug users admitted on a daily basis for traumatic injury who have to go to the emergency surgery. The surgeons in that institution, and the psychiatrist in that institution, have talked to me, and have said that they, too, are in favor of routine testing of every hospital admission to that institution because of the high incidence and prevalence of intravenous drug use and in the great numbers of people in New York who happen to be positive for the HIV antibody. I also know surgeons who have stopped doing surgery in the Harlem community because of the very fear that you have.

I, last week, was on a panel with Dr. Gerbedy. Do you know Dr. Gerbedy from San Francisco General Hospital?

DR. DAY: Yes.

DR. PRIMM: She talked about the number of needle sticks that have occurred in our country and the number of people who have tested positive after these needle sticks. She said that 2500 people have been reported to have been stuck with the needles, and only four out of all of those were positive. There were some 14 documented cases of nurses, and 12 people who had some splashing of blood and body fluids, etc.

She, also, talked about the danger of hepatitis B and non-A non-B. People have a greater perception, have a perception of being stuck and being exposed and then being infected which is far greater than the actual sticks themselves in terms of being exposed. She compared this to hepatitis. What would you do with the results, number one of that test? Would you refuse to operate? Would you send this patient somewhere else? What would be your response? That is one question.

Two, your great concern about HIV infection, how do you compare that with a concern about hepatitis B or hepatitis non-A non-B? That is another question. For you, Dr. Schwarz, you had spoken about leaving these things up to the local level: The decision of whether to make a decision. When you talk about the local level, are you talking about the state or are you talking about the county, the city or the hospital where in certain hospitals in certain cities, the incidence and prevalence is great, greater than others? So, I mean if the State of Tennessee, for example, put out a mandate that there would be no routine testing at Hubbard Hospital here in Nashville, and there was a high incidence of infectivity among patients and etc.... What do you feel about that in terms of the AMA? So, either one of you can begin to respond.

DR. DAY: I can tell you about what my response would be to the information of the patient's HIV status. First of all, I don't have that information, nor will I probably ever on emergency cases. I try to get that information after the fact, after I have operated on them and taken care of them, because I think we need to know that, if for nothing else, for demographic data. But if I know ahead of time, in fact, right now, I am getting that information before any elective patient is scheduled for surgery.

Now, the one patient that caused the newspaper headlines back in October or so was a patient who had an ankle fracture. Now, in our hospital we generally operate on ankle fractures because our patients have a low rate of compliance for follow-up, and we figure if we fix them when they are there, that if they don't happen to come back (they are unreliable) we at least have it fixed. Now, if a patient is HIV positive and that fracture can be treated just as well in a cast with the same

outcome, but the patient might have a little bit more inconvenience because they would have to be in a long-leg cast, rather than a short-leg cast, I think that that is a reasonable alternative. It saves the risk for all the health care workers, and the patient's care is not compromised.

DR. PRIMM: You would do a closed reduction. That is what you are saying?

DR. DAY: Correct, and I did that on this patient. He went to the newspapers saying that he had been withheld a very important operation that was necessary for his health care.

Now, I was called on the carpet because I, quote, unquote, changed the treatment because of the patient's HIV status. Now, I think that that is quite reasonable. I think we, also, ought to discuss whether a patient who is on crutches and has discomfort in their hip, particularly now since we don't know about aerosolization of the virus, if we ream for a total hip replacement just to get that patient a little more comfort but we are putting five or six health care workers in jeopardy for their lives, it must be discussed. I am not saying that we should withhold that. I am saying that we should discuss it. It is not even a discussable item at the present time.

DR. PRIMM: Okay, what about hepatitis B?

DR. DAY: We are all concerned about hepatitis B, but for the time that we had the hepatitis vaccine which was made from potentially AIDS positive blood, we didn't want to take it then. So, we took our risks because not nearly as many people die for exposure of hepatitis than die for exposure of AIDS as far as turning hepatitis positive or HIV positive, but I am now in my --

DR. PRIMM: You don't mean die from exposure.

DR. DAY: I am talking about turning positive; the ones who turn positive from AIDS die. If you get hepatitis, there is a --

DR. PRIMM: That is not necessarily so. I think a couple of reports have said that they all go on, from the San Francisco report recently, that 100 percent will go on to develop full-blown AIDS, but lots of reports indicate that only 30 to 40 percent of those seropositives, antibody positives, will go on to develop full-blown AIDS or opportunistic infections.

DR. DAY: In our hospital, I can tell you that all the AIDS experts say privately that if you turn HIV positive --

DR. PRIMM: Why don't you tell us about it?

DR. DAY: All right. If you turn HIV positive, you will die. That is what they all say privately, but then they say, "But we won't say that publicly."

DR. PRIMM: I am glad you are saying that to us, Dr. Day, so that we can have the right information from an institution that really has probably the most experience of any institution in this nation concerning this virus.

DR. DAY: When Julie Gerberding and I were on a television talk show together discussing this, I said that it was 100 percent fatal, and she argued with me on television. She said, "You cannot say that." The person next to me was from the Alameda Department of Public Health, and he said, "We prefer to say that it may shorten your life span." I said, "Yes, by about 40 years probably," and Julie Gerberding said, "No, only about 40 percent that turn positive will get AIDS and die," and I said, "Julie, that is because the whole group of people hasn't lived long enough to die," and she adamantly refused to listen to anything else on television. Then after the program was over, we sat around and talked for about an hour, and I said, "Julie, you know that if you get AIDS, if you get HIV positive, you know what is going to happen." She said, "Yes, I know, but I cannot say that publicly because I am taking care of a health worker at our hospital who turned positive, and if I say that publicly, I will destroy all her hope.

DR. PRIMM: Dr. Schwarz?

DR. SCHWARZ: May I comment on that last question? I think it is fair to say that to the best of our knowledge there has never been a diagnosed reported case of AIDS that has not ended in a fatality. Clearly, however, our understanding of what constitutes AIDS is broadening as the data come in. There is a much broader spectrum of clinical expression than many of us know as we sit here. There is the data that is rolling in now about tuberculosis, coccidiomycosis, toxoplasmosis and all these diseases that come up that are really secondary to the underlying defect which is the HIV infection. It is also clear as Dr. Day has said, that the percentage of people who convert from seropositivity to AIDS continues to go up as the time lengthens over which a cohort of patients is observed. It is true that CDC started out saying, "ten to 15 percent." Then the IOM study came and said, "well, maybe 25," and now, CDC is saying, "thirty to 40," and the San Francisco report of last week is 75. There is a cohort in West Germany that is now over 90. All this evidence suggests that if you are seropositive you will convert and you will die over a period of time. Life expectancy now on an average is about 15 months. The longest that I am aware of is just under 9 years, and AZT doesn't seem

to do anything but extend it by a couple of months. So, I think for public health purposes, you have to plant this fact in your cerebral cortex and use it as a guideline when you are developing policies. I pray to God that there are seropositive patients who will as in syphilis, cure themselves in some yet-to-be discovered way. I pray to God there are people who get AIDS who do not go on to die, but I think it is misleading to the public and to people who are making policy if they don't accept that at this moment in time all the data we have says that if you are infected it is just a matter of time, and therefore our efforts have to be mounted in such a massive way to prevent spread.

I think that most people who are familiar with the disorder would agree with that. I have never been challenged on what I have just told you in any of the settings I have been a part of.

Now, with regard to your question about local, I think when we said that, we were thinking about individual hospitals, individual group practices, maybe a small HMO, an area where you have some uniform data and the maximum data that applies. It doesn't make any sense for us nationally to say that every hospitalized patient must be tested. In my own town in rural Idaho, I don't know for sure, with no disrespect to my family, etc., that are still there that they know how to spell AIDS. They just haven't seen it yet. I think it will come, but they haven't seen it. For them it doesn't make as much sense to do it as it does in San Francisco, New York, Chicago, etc.

There is, however, one other reason that you might consider it and that is as everybody knows, we don't know how widespread this virus is, and we don't know how it is changing over time, and that is a fundamental question. If we knew that there are only 300,000 people infected, and it is spreading at the rate of 1/10 of 1 percent per year, we would respond in public policy quite differently than if we knew it was 8 million and increasing at 5 to 10 percent a year. So, any piece of data we can get about the prevalence of the infection, I think would be very helpful to us. That is purely epidemiological justification. It has nothing to do with protection or anything, but until you know that, you don't know what you are dealing with, and that is why the CDC plan of 30 cities taking data from every source they can get will be helpful. We ultimately have to find out how widespread it is and how it changes over time.

CHAIRMAN WATKINS: Mr. DeVos?

MR. DEVOS: Some of you ought to be feeling a little left out today because Dr. Day seems to be getting all of our attention. I guess we are finally enjoying the primary issue here which has to do with testing, and we always have talked a

lot about testing and the dangers of testing, and maybe all of you could comment to it. I listened to the ABA, AMA and the ANA here all give us typical, it could be corporate world nice policy statements, and in contrast to that we deal with a doctor who is on the frontlines. My experience in our hospitals at home is that the organizations that they belong to have nice statements, but the guys who are in the frontlines have very differing views and are showing a great devisiveness.

I guess my concerns have to do with what we are talking about as something between doctors' rights and the patients' rights. Now, I am going to make an assumption that confidentiality is handled and taken care of. Now, that may not be correct. I make an assumption that we are making progress on discrimination as general education gets known about the disease and the fear of it and the spread of it. I have a great deal of sympathy towards the concern on your end, and so to you, Dr. Day, or to the rest of you, if it is important to do that to a hospital patient coming in or selected patients coming in for elective surgery, doesn't any doctor have a right to know on any patient they are treating for any disease or refuse them treatment? If I go in and have a bad cough, and I say that I don't want a chest x-ray because I might find out what I have, I understand the discriminatory issues that scare them from that, but how can a doctor intelligently treat a patient if he doesn't have access to the data that is available to him? I am just frustrated. How can he do that?

DR. SCHWARZ: Were you looking at me?

MR. DEVOS: I am looking at any of you.

DR. SCHWARZ: I would be pleased to respond.

DR. DAY: I can, also, tell you that you are absolutely right. The people who are writing the rules are not the ones who are at high risk, and we are being told, and we have been told all sorts of misinformation along the way, and that is why we are not only frustrated, but we are rather angry. I was told for many years that needle sticks could not give us AIDS, and they would say out of one corner of their mouth, "Low risk," and on the other hand, "Cover up, low-risk cover-up," and then when the person got AIDS or turned HIV positive, they said, "Well, we told you always to cover up," but we don't have the equipment. I can tell you what happens in our hospital. Just a few weeks ago, I was on call for a weekend. We get all the trauma in San Francisco. We had an HIV patient who had fallen five stories and had multiple injuries and had bilateral heel fractures that were treated in casts. He had a hip fracture that was treated operatively, and he had heel fractures that were treated non-operatively, which is the standard of treatment. When he went home from the hospital, he had his cast removed, but

he had a very tiny superficial pressure sore on his heel, just superficial. Three weeks later he came back. He had a wound that was 3 inches wide, 6 inches around his foot and it tunneled all the way down to his toes under the plantar surface of his foot, and that was the beginning of his AIDS. He had been HIV positive, but apparently the trauma brought on his AIDS. We had to take him to the operating room to debride this foot, to clean it up and we used a surgilog to irrigate, as well as the scalpel for debridement. The surgilog is like a water-pik, and it irrigates with antibiotics down deep into the wound, but it also sprays. We have little splash shields that are like umbrellas that go over the end of the surgilog. I asked for them, and they said, "They are not available. They are on back order." I said, "That is not an answer. I have to have this in order to take care of patients. I am not going to use this instrument unless I have some protection."

"Well, we don't have any." I said, "Then you go borrow them from another hospital." So, they went and borrowed them from another hospital, and they brought me back five, and I said, "I am going to have 30 patients come in over the weekend that have open fractures and various other things. I am supposed to use these on everybody. You only gave me five," and they said, "Well, you are going to have to use them on the highest-risk patients then." I said, "But I cannot know who the highest risk patients are." Now, they can have all sorts of high-sounding phrases about using universal precautions. "Use the same thing on everybody." But I can tell you that that is not how life is in the trenches. It is different.

DR. SCHWARZ: I would like to respond, if I could. That is too good a question to let it go by. First, with regard to how AMA policy is established, you should understand that the report YY which Dr. Nelson talked to you about was crafted essentially in the proposal state by myself and our general counsel. I happen to be an immunologist by training. I have had an interest in lymphocytes and their function for some time. Our general counsel has no expertise beyond the fact that he is a lawyer, but that --

[Laughter.]

DR. SCHWARZ: No medical expertise. That went through our Board of Trustees members of which are all practicing physicians, about 40 percent of which are surgeons, most of whom are cardiovascular and thoracic surgeons. Secondly, it went from them onto the floor of the House of Delegates which is 450-odd people, about 30 percent of which are practicing surgeons. To suggest that the position paper that was ultimately passed was passed as a clean, sanitized statement without input from people in the trenches is an unfortunate choice of words in the least. It clearly was not the case.

Secondly, does a physician have a right to know? I as an individual personally believe that I do, that I would, especially if I had reason to believe that the individual was in the high-risk category. Let us assume, therefore, that I guess the question is enjoined, however, as to what you do with it when you know, and that is the question that they always ask Dr. Day. So, if you test everybody, and you find out that they are seropositive, is this going to be an excuse to deny treatment, and you have heard a response to it, and I suspect if I were doing surgery, my response would be the same, but let us assume that the patient refuses to be tested and that you have a personal policy that you won't provide service; are you ethically justified in not providing it? On the basis of our statement, I think that you could read it either way. Clearly if this is an emergency case, you have no alternative but to provide care with or without the knowledge the test brings. If it is a non-emergency case, you have the option of referring that patient to someone who will care for them, but you don't have the option of abandonment. That is a fundamental ethical precept, and therefore, I think if the patient refused to be tested and you felt that was morally justified, then you would have the options of either going ahead and treating the patient or in a non-emergency situation referring them to someone who would. You cannot abandon them because if there isn't anyone who will accept the patient, then the emergency rules apply.

DR. DAY: I don't have anyone to refer them to. I am the last resort. So, I don't have anyone to refer them to. They get referred to me when other people don't want to do it. So, I cannot cop out in that way. I have to make the decision, and so, I have a larger and larger number of patients being referred to me because other people don't want to do it, and I have no place to send them. So, I have to make those decisions.

MR. DEVOS: I understand the procedure and that there is a lot of input. I just wanted to say that I guess I am hearing what Dr. Day is saying and the people I know who have to deal with it. Somehow here are our guidelines, and there is going to be all sorts of damage on this, and you, yourselves leave it out. So, it is local option. You know, that is like a lot of government policies, local option, and somehow the hospital can do it, but the doctor cannot do it.

DR. SCHWARZ: We haven't said that.

MR. DEVOS: You are saying that each hospital sets its own policy.

DR. SCHWARZ: When most people interpret local, they are thinking at the local level, hospital, group practice, small HMO's.

MR. DEVOS: I am not denying that the profession isn't dedicated to serving these people, but when that gets interpreted out, if I am a doctor, I surely have got a right to know if the patient has got it, if I can deal with him intelligently and treat him well. I do in every other disease. That is all I am saying.

DR. SCHWARZ: I don't argue with that.

DR. COPELLO: May I make a couple of points? First, I think the whole issue of testing, particularly in hospitals, routine testing becomes less controversial as antidiscrimination and confidentiality guarantees can be put in place. I think the issue with confidentiality isn't so much necessarily with the physicians, but there are all sorts of people who read medical charts in hospitals, and word gets out, and I think without those guarantees, particularly legal guarantees, there are problems -- even outside of hospital settings.

For example, in Colorado, the experience sounds very positive. The South Carolina experience is the opposite. That data will be presented in Sweden at the Fourth International Conference. The School of Public Health in South Carolina at the University has demonstrated a 57 percent decline in people coming in to get tested even last year since the institution of HIV reporting and contact tracing. They have not recovered from that net loss. In that state those guarantees are not in place, and they are assuming that they have driven under some persons who would have come in for testing. I don't know what the antidiscrimination/confidentiality status is in Colorado. That may have made a difference, I don't know.

MR. LINDSAY: I think in nursing we have two camps. In one camp we have nurses who are wearing spacesuits trying to take care of patients, and on the other hand, we have nurses who are not using precautions at all. I think the American Nurses Association strongly endorses CDC recommendations, and we are concerned because there aren't the supplies in the health care setting to implement those universal precautions.

CHAIRMAN WATKINS: Dr. Conway-Welch?

DR. CONWAY-WELCH: I have several interrelated questions, and I would invite any of you to comment on them. This may appear to be very simplistic, but if a patient, other than an emergency patient presents and refuses to become involved in some kind of testing, voluntary testing, whatever, and still wants care from that health care provider, other than university situations, is it not sufficient to simply assume that that patient is HIV positive and proceed with care, rather than dealing with the issue of whether they will or will not be

tested? Is it not logical to simply assume that they are positive and go from there?

DR. DAY: That is what we try to do. We are. Talk about spacesuits -- you can see how we dress up -- and we are getting more to cover our necks. I get blood all over my neck when we are reaming and drilling. Now I have an alarm clock in the operating room. First of all, if I get blood anyplace on me -- it is like that resident had blood that went through the knee of his trousers -- I just sat him there for an instant to take a picture. Then I sent him out to change his clothes and have his leg scrubbed. When I get blood on my neck, I stop and have them scrub my neck. Now, I set an alarm clock in the operating room. Every hour, we inspect ourselves and our gloves, and if our gloves get contaminated in between that time, naturally we change them. Now we are trying to inspect ourselves all the time. It is taking an enormous time to do an operation. If there are a lot of people who refuse to be tested -- and there are a significant number -- you go through this. It is very stressful to be put in the situation where you cannot know.

DR. CONWAY-WELCH: So, your point is that the time and the stress is different.

DR. DAY: The time and the stress and the -- just like this one resident who got stuck. She has a right to know that. I mean it just is common sense that she should have that right to know it. So, that is what we are doing now, but I can tell you that isn't satisfactory.

DR. CONWAY-WELCH: That follows on a second question then.

CHAIRMAN WATKINS: Could I have just a quick follow-up. I don't really understand, because had you known, Dr. Day, that they were positive in all those same cases, and now, I have to assume they are positive, wouldn't you have the stress and all the changes and the blood mopping and so forth? So, would that change that set of circumstances? You would know to do it, and you would plan to do it, but you would still have to do it.

DR. DAY: We don't necessarily have to do it. As I pointed out with the patient with the ankle fracture, there are other ways of treating injuries. We treated femoral shaft fractures, thigh bone fractures, for a long time in traction. Now, that increases the hospital time, and it increases the cost. The patients have very good results. Patients have very good results. The morbidity from lying around in bed is slightly increased, but not very much. The main reason we do it is that the patient gets out of bed more rapidly, can return to their job and don't have to stay in the hospital as long. So, it

is economic in most cases. We could, in certain instances, treat these patients non-operatively, and in fact, in certain instances we are finding that for patients that have operations, they may bring on clinical AIDS, if they are HIV positive.

CHAIRMAN WATKINS: Is it possible, is there a finite number of circumstances in which that nearly equal alternative would be the answer if the person refuses to voluntarily be tested? You said that you must then go through another procedure which we would prefer not to do, but we have no choice under these circumstances -- what about medically sound alternate procedures that are not as intrusive?

DR. DAY: But I am not allowed to do that now.

CHAIRMAN WATKINS: But I mean is that a possible theoretical alternative?

DR. DAY: Yes.

CHAIRMAN WATKINS: And is it medically sound?

DR. DAY: Yes.

CHAIRMAN WATKINS: And is that something that the American Medical Association would consider as an alternative and has the American Medical Association addressed that in that context?

DR. SCHWARZ: No, but I am sure if we did, we would leave it up to the judgment of the physician.

CHAIRMAN WATKINS: Let us say that that were a new policy at San Francisco General, would that be within the ethical rules that you have established? Would that be for the local hospital or would you suggest that that be one means for doctors to allay some of the apprehensions of picking the most intrusive procedure?

DR. SCHWARZ: The AMA has never developed a cookbook of how to treat patients on any subject on any condition. We leave that to the judgment of the individual physicians or group of physicians.

CHAIRMAN WATKINS: But I am talking, Dr. Schwarz, just on a broad policy issue.

DR. SCHWARZ: As a broad policy, we would have no objections to that.

CHAIRMAN WATKINS: Is there a reconciliation then on that issue that warrants some follow-up on the part, say, of the

American Medical Association? Along those lines, it doesn't have to be specific procedure, but it could be a general principle, it seems to me, to at least be reviewed with your peers to determine whether or not that gives some reasonable options that don't seem to interfere with anybody's rights or the public health?

DR. SCHWARZ: Yes, that would be appropriate. We are right now in the midst of reviewing our report with an eye to updating it based on the information that is available. I will keep that issue in that review process.

DR. CONWAY-WELCH: The second question I have relates to the issue of testing and the fact that at the current time the state of the art is to test antibodies. We, hopefully, are having antigen testing on a variety of them, but currently, because of the window of time, every patient coming into a local hospital here in town to be tested may, in fact, identify some folks who are seropositive but may, in fact, miss other people because their window of time between infectivity and antibody formation is longer than others. My question then is do we not, at least with current technology available, do we not run the risk, if we require routine testing, would we not run the risk of lulling people into false reassurance that a patient tested negative when, in fact, we simply may have been on the early side of that window?

DR. DAY: We are not easy to lull, I can tell you that. We have our guard up as high as we can all the time. However, let me give a short example of the way you can function in life. You go home from your job, and you will drive carefully. You obey the rules. You are a good driver, but tonight I tell you that a small child will run out in front of your car sometime on your way home. Now, you will drive differently tonight than you normally drive, although you normally drive as a good driver. You cannot drive like you will drive tonight for the rest of your life. So, we need to have as much information as is available in order to take care of these patients, but we gown up; we glove; we put the alarm clock on; we do all of those things on every single patient, but you do have a heightened awareness if you know.

DR. CONWAY-WELCH: I agree with you, but my point is that because of the fact that there are varying periods of time before people become antibody positive, with our current technology and testing, you wouldn't know possibly that the child is going to run out in front of the car because you would have a false negative on that person.

DR. DAY: History has shown us that we have never gotten smarter with less information.

DR. CONWAY-WELCH: Does anyone else?

DR. NEIDLE: Yes, I would think you are absolutely right. That window of time does restrict the value of testing. It doesn't totally invalidate the testing, but you will not know about some proportion of people who have been infected and have not converted to positive antibody or antigen status at the time of the test. I would like to comment, of course, that we have not talked at all about dentistry, and I can understand these are more dramatic examples, but the dentist is constantly, daily and in practically every procedure exposed to blood and saliva. Now, saliva is not a vector for transmission according to current data, but blood certainly is, and in two very excellent films which I originally considered bringing to you, one called "If Saliva Were Red," the dentist carries out a series of procedures, standard procedures in the office, with a red fluid which is a substitute for saliva, and, at the end of the film, the dentist is covered. The chair is covered. The cabinets are covered. Shoes are covered, and the assistant is covered. So, they are exposed to very real and continuing risk.

The ADA policy with respect to testing, and I think it is relevant to bring it in at this time, is that if the dentist believes on oral examination that he sees something that is suggestive of HIV infection, and it is important for this Commission to know that the dentist is very often the first person to see the signs of HIV infection any place in the body, he should refer the patient to his or her physician, and the physician can then call for testing. The policy statement recommends that the physician share with the dentist, the referring dentist, the results of that test, but we have not gone any further with advocating general testing for all dental patients. One final comment, I believe you may hear this on this very afternoon from Ms. Wolf from the Hastings Center, but I believe she is the one who has done a study of the efficacy of confidentiality, and she tracked the number of people who handled a single medical record in the hospital in New York, and the number was 76. So, there is, in effect, according to her finding, no confidentiality at all, and I would differ with Dr. Copello that it is possible through legal restrictions to guarantee that to any patient.

DR. SCHWARZ: Dr. Conway-Welch, let me respond to your antibody window question. You are absolutely right. There is a window as everybody knows where a person is infected yet seronegative, and hence can go undetected. However, I think that the question is not whether there is or isn't. It is a question of how big of an exception it represents, and I think it would be misleading to leave the impression that it is a very large window and that a sizeable percentage of infected people slip through it.

The best evidence that I have seen on incubation, length of incubation comes from transfusion studies where you know when the exposure occurred, and those studies have indicated if you are less than 4 years old, the average incubation period is 1.9 years. If you are 5 to 60, it is 8.8, and if you are over 60, it is about 5.5 years. Let us assume that the average incubation period of all ages is somewhere around 7 years. You set that, and you assume that patients are distributed across that time period in an equal fashion. Then the percentage of time in that average incubation that any infected person would be in that antibody window -- and let us assume it is a maximum of 12 weeks -- is very small compared to the long incubation period. Therefore, the percentage of people that should slip through in this window-based on the data we currently have would be very small.

Secondly, I would tell you that the antigen tests are coming along, that there isn't any absolute certainty that antigen is present throughout that period. It may be present for a period and then disappear as it is taken up by macrophages, etc. There are other tests that are coming on to test a different class of antibody, however. There are two major classes, IgM and IgG, ELISA, Western blot test, IgG, IgM comes up much quicker and falls off more rapidly, and now the tests are looking to see if you can get the IgM as a valid testing endpoint. So, I think it is a small window in terms of the percentage of people you miss and that we have some exciting things on the horizon that may help us reduce that window even more.

DR. CONWAY-WELCH: I think one of the challenges to the Commission in terms of policy recommendations that we make is that we need to be relevant to what the technology is doing at the same time, and that is a dilemma that we are going to continually have to face, regarding the testing issue, the window, the antigen, antibody, etc.

One quick last question, and I guess this goes to Dr. Day. Dr. Mitchell, several hearings ago, raised the issue of what do you do after you are pricked, if you personally are a physician, and you have a needle injury from an infected patient. What actually are your recourses? What can you do? Some folks have raised the issue of whether a protocol or not, they would get their hands on AZT and start taking it immediately. Other, somewhat more bizarre suggestions have been made. I wonder what happens at San Francisco General Hospital?

DR. DAY: When someone gets stuck? First we swear, and then we pray, and then we are sent to the occupational health clinic to get a test, and then we wait, and that is all that happens.

DR. CONWAY-WELCH: Is there something; is there a, and perhaps this is a rhetorical question, but is there some recommendation, perhaps that we should be considering regarding the institution of some kind of medication?

DR. DAY: I would not take AZT -- I can tell you that -- if I got stuck with a known AIDS patient. I wouldn't take AZT because I see too many patients with too many side effects from AZT. I would not do that until there were some real benefit shown, and at the present time, I don't see that happening. So, I would not, but I can tell you that it is a long wait after you get stuck.

DR. CONWAY-WELCH: Do you have any idea of what your staff or whether surgeons at San Francisco General Hospital, do they informally talk about what measures they would take if they --

DR. DAY: Nobody would take AZT. We have talked about using Clorox, and then if you use Clorox, first of all you don't know that it will get into the cut, and secondly, then you have skin that is now compromised. It is abraded and it is rough, and then that puts us at higher risk. So, no, we just have to sit and wait.

CHAIRMAN WATKINS: Mrs. Gebbie?

MRS. GEBBIE: I am struck by several things in the course of this morning's discussion. My understanding from talking with a lot of folks who work with patients is that all things under public debate being silent, by and large, in an individual caring interaction between a patient and a physician, a nurse and a patient, whoever and the patient, that given adequate information about what is going on, people consent to testing. Given adequate understanding of what is involved with care, people consent to having that information appropriately shared, and that what is going on is the fact that we are almost unable to have that kind of quiet and typical interaction because people are, also, trapped in the broader public policy debate and are trapped in part by policy decisions that have been made for a variety of reasons or public stances that have been taken for a variety of reasons. I give this long introduction to my question to put it in some context.

Yesterday we were struggling with the issue of the nice paradigm we could draw up for the town that has never yet heard of AIDS that suddenly hears of it and has to write policies for schools and workplaces sort of de novo with what we know now and how engaging and positive that could become. But how difficult it is in a town where battle lines are already drawn and you have to back out. I think for health care workers, particularly as I see it in states which got into this epidemic

very early and policy lines or statutes were put in place very early, it is really hard to start backing out and having nice, quiet little discussions of how you would write policy for your hospital, all things being equal. Given that as a background -- that we are struggling to develop the best policies in all of these contexts -- I think another piece of the interplay is the fact that dentists and doctors and nurses and everybody else don't just sit in ivory towers and read the American Journal of Nursing or the Journal of the American Medical Association but read Newsweek and watch the 6 o'clock news and see the headlines in the National Enquirer in the supermarket and seem to be at least as influenced by the popular press as they are by their professional press.

My question then to the association people particularly, but to any member of the panel, is how do you think we can best give our professional discipline a heavier dose of the scientific information they need as opposed to some of the popular press information, and help them become real partners in communities in backing out of what appear to be perhaps some wrong decisions, backing into really good policies that can be supported by thoughtful patients, by thoughtful providers, etc?

DR. NEIDLE: Mrs. Gebbie, I am glad you asked that question. I have given you some examples of what the American Dental Association has been doing for the profession. We continue to provide them with streams of information, and that is the only vehicle we have to lure them from the supermarket magazines and Newsweek which did that wonderful piece on Masters and Johnson. The problem, I have to tell you frankly, is that that well will run dry. The infection control piece that you have, with the poster that is meant to be hung on the wall and is meant to reassure the patient and to remind the dentist what he or she is supposed to do is very, very expensive. We have spent hundreds of thousands of dollars in the last couple of years just on print materials and tapes and so on for the practicing dentist, but that is the only way to go, and that was the substance, in effect, of my recommendation: that we need help on this. Our journal, by the way, is also full of articles, and I think Dr. Schwarz will probably comment very legitimately that you cannot pick up a journal of the American Medical Association without encountering masses of wonderful information and reports on AIDS. It is the best I think we can do at this time.

DR. SCHWARZ: Maybe I would respond in this way. AMA has an AIDS action plan. It is built on the premise that we must first educate physicians and make them educators of the public and that we must start at the national level, work down to the state and county level to get to the individual physicians using specialty societies where it is appropriate. The way we have done it to date is that we publish manuscripts at periodic

times, both in JAMA as articles but, also, in booklet form, the latest information on issues of current concern. We have one on testing which is in its final stages being developed right now. We have then distributed these through American Medical News which goes to about 385,000 physicians. It is the most rapid way to get information out that I know of in this country. We have had regional conferences. We continue to publish on a weekly basis multiple stories in AM News. We take major articles in JAMA and we make video news releases. We put them up over satellites. They are picked up on an average by 360 major newspapers, TV stations, etc., a week, and that is a mechanism. We go to national television stations and ask them to pick up public service announcements that talk not only to the public, but, also, to others. We have some dedicated time on a lifetime television show where, again, AIDS is highlighted, and finally we have conferences. I think none of it is absolute. None of it is the magic bullet. All of it together, over time, I think is the best way to proceed. It is interesting. Admiral Watkins and I were on a program for the American Medical Association's Leadership Conference a couple of weeks ago, at the end of which they were allowed to ask questions, and just for fun, we took all those questions, and we collated them, and I think it is fair to say that we were surprised in the extreme by some of the questions which came forward: bedbug questions, mosquito questions, things of that nature which suggests to me that we still have, in spite of our efforts to date, a very long way to go before we get all physicians up to a reasonable level. I don't know how else to do that. Medical students are taking it on. On Saturday we had representatives from 127 medical schools at a conference in Washington, DC, looking at what three schools have done and pledging themselves to develop programs not only to educate themselves but to develop outreach programs to communities as well as to the profession from their medical schools, run by medical students. Never have I see a conference where there was that level of enthusiasm. So, that sort of thing is going to be ongoing and I think over time will pay off.

MR. LINDSAY: The American Nurses Association has really undertaken education of its members as a priority. The example that you have probably heard about is known as the California Nurses Association Training Program where they have trained over 30,000 health care workers in California. A little bit closer to home the Tennessee Nurses Association, while we are trying to duplicate effort like that, we find the problem that most health educators do when trying to talk about AIDS is lack of resources. We go out in the evening and educate wherever we can gather in a group, particularly nurses and other health care workers, but there just aren't enough resources for us to do the work. There are are not enough bodies. There is not enough money to actually mount the effort that is needed to educate health care workers.

DR. COPELLO: I think that satellites and conferences have a role to play in professional education, but I think that it is, also, very important that there be local business leadership within the professions developed. We have found in some of our studies here that those are some of the most effective ways to educate professionals or lay. We have just finished conducting a study in Tennessee of physican and nurse knowledge through the East Central AIDS Training Center, and the level of knowledge is in preliminary results far below what it should be, and I had not really seen that much physician or nurse education activities on AIDS going around in Tennessee, particularly in Middle Tennessee, the Nashville area. So, I am not sure how much of the information, if you will, is trickling down, particularly in developing local programs, and that is a concern I have for the professions.

CHAIRMAN WATKINS: Dr. Lee?

DR. LEE: First, of all, Dr. Schwarz, let me return the favor. You started off with a comment about our Commission, but there is nobody who has been more helpful, who has contributed more to our Commission than you and the AMA, and if we end up with any credit, you deserve a big piece of it. I hope that other organizations will follow the lead of the AMA. We are trying to enlist the ABA on several projects, and if organizations like that will help us as you have, our final report is going to have tremendous impact.

I have to get back to Dr. Day. You and I share something in common. We both are starting to look older than our stated age.

DR. DAY: You are a real gentleman.

DR. LEE: I am 35. Let me tell you with Beny Primm that help is on the way. Mr. DeVos made a very good point. The people on the lines are getting us there fast. I have always felt that testing is going to reach the proper level very rapidly through necessity. Now, at Memorial Hospital where I work, the people in the higher echelons decided that it was not kosher to test everybody on a quote, routine basis, end quotes. The chief of surgery, however, who is a very bright, very capable man said that that was not the way he was going to run his department of surgery, and if they didn't like it, they could fire him, and everybody who goes into the OR at Memorial Hospital, with very, very, very few exceptions gets a test for HIV. On my lymphoma service, everybody gets the test for HIV. Now, why? The reason doctors order tests is because the results of the test help them with their treatment plan. Now, you brought up the long-leg cast, but as anyone knows, if you are HIV positive, if you put a foreign body in the bone, you want to avoid that. If anyone is going to get an infection, it is going to be them. In the

lymphoma game, as I guess we will hear later this afternoon from Dr. Levine, there are a million reasons that that test is very vital to us. So, it is medically important. You cannot operate the way you are. A lot of the fun is going out of medicine for you, and my last plea to you is do not leave medicine. Take your sabbatical. Leave San Francisco. Come to me, and we will hire you.

Do you have anything to say, like, "Thank you"?

DR. DAY: Thank you.

MS. PULLEN: Mr. Lindsay, a couple of weeks ago, we heard from a public health official in Rhode Island that there was consideration of legislation there, and I understand it is part of the written informed consent law already in Colorado, that would remove the opportunity for a patient to withhold consent if there is an exposure to a health care worker, to blood or bodily fluids that could transmit the virus. Does the ANA have a position on that or do you, personally have a position on it?

MR. LINDSAY: The ANA position is that it should be written informed consent, and I think in my testimony I did state that if the patient does not give informed consent within the rules and regulations that the nurse could probably not perform the test.

MS. PULLEN: So, is it your position that written informed consent should be required in all cases, regardless of whether a health care worker has been exposed?

MR. LINDSAY: That is my understanding of Association policy.

MS. PULLEN: That is an interesting policy. Thank you.

CHAIRMAN WATKINS: Dr. Walsh?

DR. WALSH: I was interested in hearing voiced on the panel some things which were encouraging. Dr. Copello, you did speak of individual responsibility which is something we rarely have heard on this panel, meaning individual responsibility of the patient, of the individual who may be in a high-risk group. Yet, you, also, persist in saying that this is a public health problem as many witnesses do when it is obviously a societal problem, as well as a public health problem. If we treated it purely as a public health problem, this would be a reportable communicable disease. You spoke of emotion. Where have all the emotional arguments been made? They have been made by the HIV susceptible population. That is where the emotionalism has

affected policy. You have public health people abandoning the very principles of public health and of preventing the spread of disease to those who are not infected on an emotional basis. We hear the citation of "76 people look at hospital records." I am surprised it is only 76 that look at hospital records, but confidentiality, as Dr. Schwarz has said, has certainly been a part of medicine for 8000 years, and we have always had 76 people looking at hospital records. To me these kinds of arguments are specious and foolish and do nothing to help us in combatting the spread of this disease. I wholly endorse Dr. Day and others their right to know, and that the obligation of the patient who is seeking care to his own health, as Dr. Lee has just pointed out, that the choice of treatment, he is not doing the doctor a favor. He or she is doing himself a favor. So, I would beg those of you who say that this is a public health problem to start practicing public health and let us rather have an appeal for more routine testing, for more reportability, for more of the fact that it is a communicable disease and face it as such, instead of being always concerned about the emotionalism, about wanting the Federal Government to pass some bright new set of laws that will somehow achieve the impossible of protecting the public and protecting this nebulous thing called confidentiality and so on.

Now, I bring this up because I am very concerned. We, in very good faith in our interim report have, for example, recommended a major expenditure for treatment on demand for IV drug use. We are not a drug commission. We are an AIDS commission. The reason we are recommending that is to prevent the spread of AIDS through IV drug abuse and because of the preponderance of heterosexual spread that occurs in this group. When they come for treatment on demand, do you, as an ethicist feel that they should be routinely tested for HIV because that is the reason that we are setting up the program or should we have to have written consent that they would have the test to see if they are going to agree to stop spreading the disease because if they get treatment on demand, they theoretically are educable which is what you are talking about.

Now, isn't it important that we may as a Commission or should we as a Commission (I shouldn't say, "We may") should we as a Commission consider this? While I realize the South Carolina problem, as opposed to the Colorado problem, frequently that is the technique that is used by the individuals in mounting the contact tracing, but it just would seem to me that if we are going to contain this disease, we have got to begin to take steps that are public health steps, and that people like Dr. Day should not be put in a position of guessing on treatment because the day will come that she will be sued because she has put a pin in an AIDS patient, and somebody will say to her, "You should have recognized that this individual was in a high-risk group".

This business on incubation period and so on, Roy, that you talked about, many of these patients that come in, is there any penalty that you are asking for, for a patient who is a known HIV positive to refuse to give the information? Isn't there some obligation on the part of that patient, personal responsibility to say, "I know I am HIV positive, and if this is going to affect what you are going to do for me, you ought to know because it may change your treatment"? That is for his or her protection. Now, where does the ethicist and the public health physician and the health care worker come down on that?

DR. COPELLO: You have asked several questions. I will try to take a couple of them anyway. In terms of drug abuse that is needle based, and I say, "needle based" because drugs are injected in more ways than IV, and I think that is a problem we have had with our language. I think that if it is part of treatment that there is routine HIV testing and that is known, then I think that there is an ethical basis for that because in routine testing there is the option to opt out as opposed to mandatory. I think that routine testing should occur among persons in those drug clinics, but with their awareness that there is routine testing.

There are hospitals now that have, for example, as part of the admission criteria, a statement to the effect that if there is an occupational injury that they will be routinely tested. The patient is aware of that in the admission process. So, I think that in the technical definition of routine, I don't think we are disagreeing on routine testing.

In terms of the public health consensus, I think that I am not sure there is a consensus. I think that the public health community is somewhat divided about how to handle this epidemic, but if one looks into public health history, there has not been always consensus in a lot of other epidemics, also, and I think that we need to look at, for example, Alan Roth, recently in the Journal of Science. I think it was in the January issue that he wrote an article comparing the syphilis model with HIV and concluded that there really wasn't a whole lot he would apply from that model to the HIV situation. So, I think when we look back historically over public health, we need to look at some of the unique characteristics of this epidemic. Again, HIV reporting and contact tracing become less controversial, I believe, when we can have some protection in place for people. I do believe that patients have obligations to share with their physicians their conditions, whatever they are, but we want to reinforce that relationship in a positive way. If that information is shared, whether it is with a physician or a school official or whatever, and then there is some terrible kind of discrimination that occurs, as we saw with the young boy

yesterday, in the school setting, what is that reinforcing? It is probably reinforcing people not to share that information. So, I agree that there is an obligation, but the obligation needs to be in the context of some sort of protection.

DR. WALSH: Again, I think that on the, where there is some disagreement in the public health approach, I think that this is part of what Dr. Gebbie pointed out, that in those areas where there have been drastic emotional and political influences exerted because of high concentrations in cases and political forces of certain communities, that it is much more difficult for the public health official to modify principles that have been held. We saw in the New York State Legislature an excellent presentation, as you know, by Tarkey Lombardy and Senator Dunn up there of what should be done or what could be done, but nobody will do it because it accepts basic public health principle, and we see people moving around, as I think Burt has said, to more frequent testing where you are seeing people who have health commissioner posts who have been known to be very liberal in their thinking are now changing their mind about the validity of testing because they are being overwhelmed by the occurrence of disease. We have had witness after witness talk about these public health principles, and to me a disease like AIDS is a reportable communicable disease. Why in New York State is it still reportable and not communicable? The reason is that the physician could quarantine or could do whatever he wished if he were dumb enough to do that. He could discriminate, if he were foolish enough to do it, but certainly they have become sufficiently sophisticated now and knowledgeable about the disease, thanks to the educational programs carried out, to not do that. I don't feel that we can ask health care workers to continue to take that risk when we say, "only 4 in 2500." I would not want to be one of the four, and I question the validity of some of those statistics, but, Roy, I see you have a feeling.

DR. SCHWARZ: May I comment? Clearly what we are trying to find is a difficult road. Through that is a balance between the right of an individual to confidentiality and protection versus the right of an individual to protection from being infected versus the right of society to protect itself. You don't have to read very far in medical history to know from past examples of typhoid, syphilis, polio and tuberculosis exactly how society before has come down on that issue, and you can find tremendous parallels that we are moving in the same direction today with AIDS. As you watch the public attitude, survey polls or specifically if you watch the physician attitude survey polls, you will see a dramatic shift occurring.

I have a summary that I will leave with the Chairman called An AIDS Update. It is a report from the San Francisco Medical Society survey of attitudes of physicians. Among other things, 74 percent said that they will treat AIDS patients, and 64 percent said that they would treat more patients than they are treating now. Specifically with regard to attitudes on how you approach this disease, there are two groups. They have a total group and their impressions, and then they have data from a group of physicians whom they call "AIDS intensive," the people who have spent a great deal of time treating these patients. Remember, this is from one of the AIDS capitals of the United States and the world. Of the entire group, 52 percent favored allowing HIV tests without informed consent. Of those who spent a lot of time with HIV patients, only one-quarter favored that; 53 percent, however, of the AIDS intensive group favored deleting the requirement for written consent, 53 percent, over one-half, versus 66 percent of the total sample. Forty-five percent of the AIDS people thought that HIV infection should be reportable versus 72 percent of the total group, a very high percentage, 72 percent is the largest I have seen. Fifty percent felt that physicians should be able to notify endangered third parties. These are the AIDS doctors, versus 73 percent of the total group. Fifty-six percent of the AIDS doctors favored contact tracing programs versus 79 percent of the total doctors in the survey, and 22 percent of the AIDS doctors felt that isolation and quarantine had some potential as versus 39 percent of the total group.

These are dramatic figures. They are mirrored in a confidential survey done at the Oregon State Medical Association which, Admiral, is still draft. So, I cannot give it to you, but your staff may want to contact them. Some of these figures are essentially the same there, and we have a survey we have done which isn't ready for presentation yet, but which will mirror these findings concerning physician attitudes. So, we are seeing a fundamental shift in attitudes in the profession which probably will antedate the shift in attitudes of the public. My guess is that we will come out in the way we handle this disorder pretty much like we have in all previous infectious epidemics.

DR. WALSH: I have one last question, a very brief one. Has there been any effort, particularly say in your situation, Dr. Day, in San Francisco or do any of you know of any efforts to educate the high-risk behavior groups to the fact that sharing knowledge with their physicians or with those who care for them is vitally important to their own well-being? I mean have we tried to educate those groups who have spent most of the last 5 years trying to educate us to leave them alone?

DR. COPELLO: To speak for Tennessee, in Tennessee our education programs for high-risk groups, particularly gay men, that is done routinely, and if you look at some of the

brochures available, for example, from the American Red Cross, there are statements to that effect in those sorts of materials.

DR. DAY: I don't know of any. There may be some attempts going on in the communities in San Francisco, but I can tell you from the gay population, I have not seen that. There are many people in the gay population in my hospital who really set their jaw, look at me and say, "You have to take care of me, and I am not going to tell you anything." In the drug addict population, it is a little bit different. It depends on what they have been on last and how they are feeling about things as to how much they want to tell, but I have one patient that I operated on 22 hours straight who had a hyperdermic needle tattooed in his antecubital fossa. So, he was ready at any moment for an injection, and he said, "Sure, you ought to check me and check us all," because he said, "A lot of us are going to be positive." So, there are varying degrees. I would say that probably 10 percent of the highest risk groups are refusing to be tested. I don't have those figures. I have got someone working on those figures, but
that is my gut feeling.

DR. WALSH: Thank you.

CHAIRMAN WATKINS: Mrs. Gebbie, you had a quick follow-up?

MRS. GEBBIE: Just a quick one, more comment than question. Dr. Copello did part of the clarifying. No rule in New York State can stop this from being a communicable disease. I think it is absolutely critical when we are having discussions like this to be exquisitely careful with our terminology and understand that the debate about routine testing or extraordinary testing, whatever the opposite of routine is is a separate discussion from the debate about consent, informed consent, documented informed consent and written informed consent, and we need to be really careful to understand those as two different discussions and have both of them as we proceed. Thank you.

DR. WALSH: But, Kris, it is a law in New York State that it is not classified as a communicable disease. It is the law.

MRS. GEBBIE: I cannot be accountable for New York. Public health people try to be clear on that.

DR. PRIMM: Dr. Schwarz, did you have this information or did the AMA have this information before the things went before the House of Delegates to vote on for whatever recommendations you made to the larger body of AMA?

DR. SCHWARZ: The survey?

DR. PRIMM: The survey you just did?

DR. SCHWARZ: No, the survey I just reported on is from San Francisco, and I just received it a week ago.

DR. PRIMM: Because I think that had they had that survey that indeed, well, let me ask you, what do you think they would have done had they had that survey that you have there now in terms of recomendation to the larger body?

DR. SCHWARZ: I think some of the recommendations would have been different.

DR. PRIMM: I do, too.

DR. SCHWARZ: That is why we are reviewing those recommendations right now. In a year's time a horrendous amount of information has been acquired. On my desk is summaries totaling 3 feet of papers, received in the last 6 months. It is not surprising, therefore, that we might want to change some policy statement that seemed reasonable a year ago but which may need revising now. Report YY was not a static target. It is moving.

DR. PRIMM: Thank you very much.

CHAIRMAN WATKINS: Do you have a quick one, Dr. SerVaas? We have to really close out the panel. We are getting pressed on time.

DR. SERVAAS: I just have one comment to the panel, and that is in making your recommendations, in my professional group we advertised for medical writers, and over the last weekend we have never had so many clinicians who have never been medical writers wanting to become medical writers, and I am very fearful that doctors, if we don't make amends to take care of the Dr. Day's in these high-risk areas, that we will lose some very good men, and if we aren't careful, about the legal problems when it comes to referring patients and being worried of being sued because the cost of malpractice is so very high, and when you get into the legal conversations I hear about that I think we should definitely consider the problem
of the malpractice and the time that doctors spend already with lawyers. Is that something anybody wants to comment on?

DR. SCHWARZ: It is a very, very serious thing. As you know, the applicant pool in medicine has dropped 34 percent in 10 years, with the last 3 years at 8, 9, 8 percent. It was held up for a long time by virtue of the fact that young women were coming into the profession. But that has changed. In the last 3 years there has been a 12 percent drop in the number of

women applying to medical school. There is a 49 percent drop in white males, and now we are seeing tailing off of minorities. If you project that forward, and if it is simply a lag in birth rate which some people think is a big component, we will not have hit the bottom until 1997. We are now down to 1.7 applicants per entering slot which is the lowest in modern history. That is what it was when they let me in, and we have never seen anything like it before, and it is going to go further. The profession is frankly not very attractive. People who are in it, are unhappy. I talked to a neurosurgeon over the weekend in Fort Collins, Colorado, who said, "Roy, I invested 15 years of my life getting ready to practice, and I would do anything to get out. I ethically cannot practice under these conditions."

AIDS is coming along. I am very interested in seeing what impact it has on the number of applicants.

This is not, however, a phenomenon that is unique to us. The nurses can tell you a dramatic story, also. The dentists can tell you an even more dramatic story. In contrast, the physical therapists are doing well; the pharmacists are doing well, but I have some very serious reservations about what is going to happen to the supply of health care workers, especially physicians, between now and the year 2015.

CHAIRMAN WATKINS: Thank you. We are going to close out the panel now with just one more question that I will give to Dr. Schwarz initially and then anyone can chime in. We heard compelling evidence yesterday on discrimination as being a major obstacle, either anticipating what they might be facing were they to declare themselves HIV positive or I would like to know what the AMA's position on discrimination is, particularly as it relates to the possible outcome of any testing policies that might be developed. Is it the necessary issue to address as a precursor before you can legitimately face the testing issue, and if so, what is the AMA position on that and then any other, either from the ethical point of view from Dr. Copello or any of the other panel members who could answer that question. It is important to get this on the record. It can either be in writing to us or perhaps we need both and certainly we want a general picture here in the shortest time that you could give it, Dr. Schwarz?

DR. SCHWARZ: Thank you, I would be happy to. I think our impression is that there is an ethical triangle, three points on the triangle with testing in the center. At one point is discrimination; another is confidentiality; and the third is contact tracing. You cannot move on any one of the points without involving the other two, plus testing. You cannot move on testing, without facing discrimination, confidentiality, contact tracing. You are going to have to

treat this as an infectious disease which it is, a sexually transmitted infectious disease. As such, we will have to apply public health principles and these demand contact tracing to protect people against spread. It isn't that you are going to say that you cannot have sex with somebody who is seropositive. You just give them the choice with the knowledge.

So, the AMA's posture is that you must tighten the antidiscrimination statute. If you cannot do that, you will forever and on a continual basis face the wrath of those who feel that discrimination, and nobody who is even conscious can deny that the grossest form of discrimination hasn't occurred in this country based on seropositivity or AIDS, and I could quote you 100 cases without even thinking. So, we have got to tighten that. Secondly, we have had egregious examples of contradictions of confidentiality. That does not mean that it is going to absolutely happen in every case. Whether it happens on a routine and customary basis in point of fact, I don't think it does. So, we are in favor of tightening that, and in fact, we have drafted a model bill for states to consider on confidentiality. We are considering very strongly recommending contact tracing, but we have not come to any permanent decision on that. I think, however, that all of these impact on testing. We addressed part of that in the AMA report (YY). I think you can be pretty much assured that you will hear us comment again on these issues at our annual meeting in June.

CHAIRMAN WATKINS: Dr. Copello?

DR. COPELLO: I have thoroughly read the AMA document on the points of antidiscrimination and confidentiality and concur with it. It is a very reasonable statement, and I concur with what Dr. Schwarz has said.

CHAIRMAN WATKINS: Dr. Neidle, to finish up, we had some, I thought rather conflicting testimony from some of your predecessors. I thought yours was a clear expression of the logic train that the American Dental Association went through on the policy. On the other hand, there are still some serious questions in my own mind. For example, if a person comes to a dentist under your ethical policy who is HIV positive, asymptomatic and so says to the dentist, what is the referral option that the dentist then has? Nothing in the mouth that is particularly awkward relative to disease and clearly a statement that I am HIV positive?

DR. NEIDLE: As you are aware, the policy does not specifically address that ethical issue in so many words. We are hopeful that by the next meeting in the House of Delegates it will be there unassailably clear, but our message, and I emphasize that message takes the dentist through a series of logical steps which should make it clear that if there are no

oral manifestations or physical reasons why that dentist feels incapable of treating that patient, he should treat the patient, whether he has HIV-positive status or not.

CHAIRMAN WATKINS: So, if the medical replication of any mouth lesions or whatever took place 2 months later, and the patient were then referred back to that same dentist, that same dentist would have to care for the, in this case the AIDS patient?

DR. NEIDLE: We would --

CHAIRMAN WATKINS: By ethical policy?

DR. NEIDLE: We would hope that he would do so. We would hope that the patient presented no problem so special that he was now taken out of the realm of general dental practice.

CHAIRMAN WATKINS: We were given other rationale for the policy, such as many dentists feel they are personally and professionally not qualified to deal with infectious disease which brought some questions from the doctors on the Commission. We, also, were told that there was a survey run in which four out of five dentists would not deal with an AIDS patient and that the reason was not only fear of infection itself but just as important fear of losing other patients. The question is do you consider that in your ethical policy of dealing with that ancillary issue, the health issue?

DR. NEIDLE: I think you have asked two questions or maybe more. With respect to the preparation of the dentists or their capability of treating patients in a safe and proper way, we absolutely disagree with that statement. Dentists have the same basic science training as medical students, very often in the same classrooms. The problem occurs when they leave those basic sciences and enter the clinic. When the medical student enters the hospital, he interacts with physicians. He faces very ill patients, and the basic sciences are reinforced in that setting. The dental student enters the clinic where for two years he concentrates on the acquisition of technical skills, and the microbiology, the immunology and pharmacology that he acquired earlier is shoved aside.

I think that is going to change in the dental curriculum, and I think dental schools have been very responsive to the AIDS crisis in instituting major curriculum changes.

In any case there is no dentist alive today who cannot practice effective infection control procedures and protect himself and his patient.

With respect to the loss of patients, that is a very difficult and contentious issue. In the present public climate there is every evidence; there is some evidence, some good evidence that if a dentist appears to be providing care to many AIDS patients, he creates alarm among his regular patients, and many of his patients may leave him, and the question is what kind of economic liability should the dentist face after having built up a practice over many, many years through his treatment of HIV-infected patients. We believe that they should continue to treat them, but they have a real problem with this, and that is one of the reasons we are recommending a large-scale public information program that makes it clear to patients that they are not at risk of getting AIDS if they are treated by someone who is treating other AIDS patients.

CHAIRMAN WATKINS: Thank you, Dr. Neidle. Thank you very much, panelists, for being a very informative panel, and we will proceed now with Panel No. 2 on Resource Allocation Decisions. The panel includes Dr. Ralph Crawshaw, Clinical Professor of Psychiatry, University of Oregon Health Sciences Center; Dr. Robert H. Blank, Professor of Political Science, Northern Illinois University and Dr. Dan Beauchamp, Professor of Health Policy and Administration, School of Public Health, University of North Carolina at Chapel Hill.

I want to welcome all of you this morning. We are going to try to adhere to the schedule. So, we are compressing a little bit to make sure that we are ready for our follow-on panel with Congressman Dannemeyer. So, I would like to proceed right away then with Dr. Crawshaw's presentation, please?

DR. CRAWSHAW: Thank you, sir. It is a privilege to appear before this Commission, and I would just like to set the stage of who I am. I am a private practitioner, a clinical professor of psychiatry, clinical professor of environmental health at Oregon Health Sciences University. I am the former president of the County Medical Society, trustee of the Oregon Medical Association and a member of the National Academy of Sciences, Institute of Medicine.

In searching for ethical responses to the impact of AIDS on society, the Oregon experience in withdrawing Medicaid funding for organ transplants may bring an increment of candor, definition and insight, as well as direction to the present situation surrounding the AIDS epidemic.

The problem in Oregon. In the spring of 1987, Oregon's state legislature withdrew Medicaid funding for heart, liver, lung, pancreas and bone marrow transplants. Instead, those funds were dedicated to the care of 2500 children and pregnant women who were otherwise without nutritional support, high-risk pregnancy or prenatal care. On December 3, 1987,

after the denial of Medicaid funding for a bone marrow transplant, Cobey Howard, the 7-year-old son of a single parent on welfare died of leukemia when the family was unable to raise the upfront money of $100,000. They only could raise $70,000 asked for by a medical center. Oregonians have experienced severe ethical problems with the death of Cobey Howard. Some citizens are outraged at a death resulting from bureaucratic bungling or heartless legislators. However, the public is awakening to the real dimensions of our health resources allocation problem, an awareness AIDS will make indelible.

Since physicians are the primary providers of care, their role in the developments around the medically indigent may well apply to patients suffering from AIDS. Traditionally, physicians are ethically dedicated to seeking what is best for the patient. However, for Cobey Howard and other impoverished patients, the physician's ethical role in Oregon is changing from doing the most good for the patient to doing the least harm to the community. Despite a full knowledge of possible life-saving treatments, the physician's role shifts from curative to palliative, seeking what can be done to make tolerable the indigent patient's position outside an unavailable medical delivery system.

Covertly Oregon has had this medical care allocation problem for many years. One-half of our indigent, chronically mentally ill lack access to either public or private mental health services. Consequently the admitting physicians at our mental health institutions have a built-in job requirement to protect their institution from being overwhelmed by the population in need. Unlike the traditional role of acting in the best interest of the patient, the admitting physicians at our state hospitals follow state policy. They use political triage rather than medical ethics to determine that among those clamoring for help who will be admitted. The political decision despite possible irreversible harm to the patient is to turn away those who are least likely to threaten the society with property damage, homicide or suicide. Today, Oregon physicians admitting patients in need of organ transplants make similar politically determined decisions, and the state now agrees that medical centers are not to be overwhelmed. It follows that tomorrow, this social ethic may be applied to AIDS patients as well.

Replacing the traditional medical ethic of most effective and compassionate care for the individual with least harm and cost for the community represents a profound shift in philosophy from individually-oriented bioethics to a political belief, biovaluation, where biovaluation is defined as the political decision-making process for establishing community health services priorities relative to all other social needs. Consequently, it is the public process of allocating public resources for health care. Political triage is replacing

medical triage. The sharpest historical example of biovaluation is selective service. When the nation decided which individuals, that is the class of people who were male, 18 to 26 would be put at risk of their death in the service of the least harm to the community.

The combined pressures of a burgeoning medical technology, the exponential demand for care by the elderly and the unrestrained plague of AIDS may well destroy the government's ability to make rational decisions in allocating limited health care resources. If in the present medical care crisis the process of biovaluation is ignored or denied, governmental bankruptcy or even political chaos may be predicted.

Solutions. In anticipation of the potential civic disruption posed by limited health care allocation, a small group of concerned citizens founded Oregon Health Decisions, a non-profit organization intended to raise the citizens' awareness to the bioethical and biovaluation issues. Oregon Health Decisions took the first step in biovaluation by seeking local consensus on the hard choices of health care allocation. In 1984, a cadre of trained facilitators took the bioethical issues implicit in comprehensive health policy to 5000 citizens in 300 Town Hall meetings across the state to locally, openly and equitably discuss what should be done. A broad health policy for Oregon evolved in a summarizing Citizen's Health Care Parliament.

More recently under pressure from state legislators asking for emergency town hall meetings in their districts to discuss the Oregon transplant issue, Oregon Health Decisions returns for another round of public policy building entitled Oregon's Health Priorities in the 1990's. Two town hall meetings have taken place as the process moves towards another statewide citizens health care parliament in September. The goal is building a state consensus on how Oregon's limited health dollars should be spent. Town hall meetings are not left for unstructured, inchoate passion to prevail but seek consensus by presenting the citizens with a series of sophisticated choices which range demographics against state medical programs, that is they choose among infant, child, adult and elderly populations against critical short-term, long-term care and prevention programs. While conflicts are open there has been no demogoguery by zealots nor scapegoating of providers. Concerned citizens become profoundly serious when directly confronted with life and death decisions. The result of the recent round are not yet clear enough to report, but in 6 months the citizen's parliament will offer explicit recommendations to the legislature in determining basic adequate care for Oregonians.

Nor is the health decision process restricted to Oregon. Thirteen states have followed our lead in going directly to the citizens for education and for direction in state health policy. New Jersey and Oregon are working on a joint computer model to correlate and explicate the developing consensus. Here is a civic instrument. It is available, offering AIDS policy makers a means of educating the public to the health policy implications of that dread disease while, also, educating civil leaders to the expectation and the resolve of the citizens.

Conclusions. National health policy makers may well learn from the success of selected service during both world wars that life and death decisions resulting from national policy are best left at the local level for full disclosure, open discussion, minimal bureaucracy, maximum personal attention, equitable judgment and functional community consensus on who is going to be sacrificed for the greatest good.

In approaching the medical care crisis the health decisions process has uncovered a severe contradiction, if not a rift manifested on the provider side by a refusal to care for the medically indigent including for AIDS patients and on the public side by a disinclination, if not inability to fund care for the indigent, and profound dissatisfaction with health care providers. Incidentally coming here this morning from the hotel, in the cab, I had a real exposure to this kind of feeling. The cab driver when he learned where I was coming said, "Oh, you are going out to that AIDS panel where they have all that AIDS shit. You know, it never changes. Last year it was something to do with herpes. This year it is AIDS. Those doctors are just in it to make more and more money." This is just one segment of how the public is unprepared to look at these grave problems that we have.

If this philosophical gap between bioethics and biovaluation is not openly addressed within the health professions and between the professions and the public, the consequent explosion of frustration will place needful patients at increased risk.

Citizens need precise information, statistics of incidence and projected incidence of AIDS, cost of treating AIDS, as well as alternative sources of funding. Most important, citizens need to be consulted as directly as possible in resolving the ethical conflicts developing from the nation's limited ability to fully treat everybody. At the national level, an American health process is needed to bring compassionate yardsticks to bear on a national consensus on what shall and shall not be done for individual AIDS patients within the moral beliefs which ensure us as a nation of caring citizens.

CHAIRMAN WATKINS: Thank you very much, Dr. Crawshaw. Dr. Blank?

DR. BLANK: You have my written testimony. I won't go over most of it. In it I basically argue that I consider it very important that we look at the value context within which AIDS policy and discussion takes place. I discuss very briefly individual self-determination with the emphasis on rights -- a subject which has come up often this morning already -- and the unrealistic dependence on technology. I conclude that AIDS is one disease where technology has failed to provide us with a solution and, therefore, forces us to look at prevention, a fact which is very difficult to face within our value context. I also look carefully at the question of individual responsibility -- the need to incorporate a model of individual responsibility into our more traditional social responsibility model -- and I provide background in that area.

What I would like to do is summarize several of the policy recommendations from my written testimony. The first is that it is important that we integrate the AIDS problem into the broader context of the health care crisis in general. I think the previous testimony about the Oregon program points out that we are dealing here with allocation problems that are, for many reasons, becoming more complex--AIDS certainly has frustrated and aggravated these problems.

The current approach to AIDS that tends to isolate it from the broader health care context will be self-defeating in the long run. I think that if we continue to put exclusive attention on AIDS in terms of an allocation issue, that, in addition to stigmatizing those people with AIDS and focusing attention on them, we are really misdirecting the public. If we are spending one-half of 1 percent of our health care dollars on AIDS today, it is certainly not reflected in the public's knowledge. Anecdotally, I have asked 10 people at the university how much they think we are spending on AIDS now and how much they think the estimate is for 1991, and the figures were between 5 and 25 percent. Certainly, that is a critical exaggeration, and I think it puts AIDS in a much more difficult policy context than it necessarily should be. Also, by placing such heavy emphasis on AIDS and insulating it from the broader health care crisis, I think we are going to see, indeed we are already seeing, a backlash from other areas of health care and from the public which sees the money flowing into AIDS programs. AIDS then becomes a natural scapegoat for frustration over the broader health care crisis. By the way, I support the interim report of your Commission and the $2 billion increased funding, particularly in the preventive
area, but I think that you will be seeing and already are seeing this backlash.

This morning other resources than money were mentioned--the scarce resources in the blood supply, scarce resources in skilled, highly trained personnel, and physicians. All of these are setting up AIDS as a scapegoat down the line because we have exaggerated the extent to which it is a contribution to our health care crisis. As a result, it will take the brunt of most of the criticism when, in fact, it should be, I think, downplayed in its overall impact on the health care system. Given the present political atmosphere, I would not come in here and say that we should spend less on AIDS nor would many policymakers. Although you might have a few individuals express that view, the current political atmosphere is not bent in that direction. However, I think that down the road as we see the accumulation of AIDS patients and direct competition for funds with organ transplants, intensive care, neonatal intensive care, and so forth, we are going to see the pressures developing. I think we have to
set ourselves up for that and should anticipate that kind of problem.

Although I hesitate to say that AIDS has had any positive aspects, I believe it has in the sense that it is giving us a crucial lesson that we cannot expect technology to solve all of our problems. Because no technological fix has been forthcoming, we have to put emphasis on prevention--on attempts to change behavior. I know this is a very sensitive issue, but by isolating AIDS, we make it seem like AIDS is the only health care area where individual behavior has an impact on the disease, and that is certainly not true. Whatever the estimates -- 60 percent, 80 percent -- a large proportion of our disease is caused to some extent by individual lifestyle and behavior. This fact has to be emphasized. Again, by focusing on AIDS we are setting AIDS up as the fall guy for everything else that is happening in health care.

Finally I would like to emphasize that the AIDS epidemic does force us to look at the need for some type of national coordination. Of course, the Presidential Commission is temporarily serving in that capacity. When I look around and see some of the things that are happening in the states and some of the definitions of communicable diseases that states are using, I think that the need for a national policy or coordination is very, very clear. We need to have some national priorities set. We have to take into account the broader context and we have to, in some cases, use funding levers or whatever else to get states not to waste money on AIDS policies that are motivated simply to be doing something on AIDS. The pre-marriage testing in Illinois, for instance, has done little to identify cases. I believe three cases have been identified so far. It is certainly not targeted at a high-risk audience. It has, in fact, become an anti-family legislation in that many couples apparently are foregoing getting married and getting marriage licenses,

particularly those poor, less affluent individuals and couples who are unwilling or unable to spend the two to three hundred dollars that is now being charged in many areas for the premarriage screening test. This, in turn, raises a question as to why it is that expensive; who is making money on these tests?

So, I think we have to look at our AIDS policy in a much broader sense. We have to take the context of individual responsibility, of rights, of the question of where technology is leading us. We have a technology of HIV testing and we don't really know what to do with it and how to use it. If we look at the AIDS crisis in the broader context, we should be learning from it. We should be seeing that AIDS is the tip of what is, in fact, an iceberg of a massive health care crisis and it is not necessarily AIDS that should bear the brunt of the kind of difficult allocation questions that are coming up.
Thank you.

CHAIRMAN WATKINS: Thank you, Dr. Blank.
Dr. Beauchamp?

DR. BEAUCHAMP: Thank you very much. I am pleased to be here.

My name is Dan Beauchamp. I am a professor at the School of Public Health, and I want to talk a little bit about allocation in a broader sense, focusing primarily in the areas of prevention.

I would first like to say that I hope the report and recommendations of the Commission will challenge the false harmful dichotomy by which we talk about this particular epidemic, the dichotomy between the public's health or the community's welfare on the one hand and civil liberties on the other hand.

I think this is a very simplistic view of this epidemic or of any epidemic. As a matter of fact, it is bad public health history. There have been many times when public health has had its villains and its episodes we are not too proud of, but in plain truth most progressive public health leaders have argued against the notion that public health always means quarantine or isolation and also against finding out people finding out those who are infected and reporting their names. Benjamin Rush, for example, the physician patriot of the Revolution was a spirited opponent of quarantine and argued that it destroyed communities. Rush advocated domestic sanitation to battle disease, in other words, promoting the rights of ordinary people to have clean water and air, better housing, a safe and clean workplace.

Today, I think most in public health would subscribe to the idea that turns up in Camus's The Plague. Tarrou said this. "All I maintain is that on this earth there are pestilences, and there are victims, and it is up to us not to join forces with the pestilences."

What this means is that there are always two epidemics, the one that runs its natural course and the second one that rages in our collective unconscious, the epidemic of our fears and latent cruelties. I think most public health leaders know that they are required to fight both epidemics all the time, and that their central resource in doing this is trust. So, I would urge this Commission to spend a good deal of its time on the issue of building trust. Trust is the primary resource we have against the epidemic; the Commission and public leadership in this country should see the creation of democratic trust as the essential defense for the republic.

So, that leads me to the first resource that I wish the Commission would spend time on its report; time to the issue of rights of victims or potential victims. To me all of us at one time or another are going to be at risk because of disease. It seems to me that first we must assure people who are at risk, or those who are infected, or those who are already cases, that they can trust their government, their leaders, and public health community, public leadership and the rest of the community. Only then can we begin to speak of the duties of victims or the infected. Building trust and duties is a reciprocal process that needs always to go hand in glove.

The second thing that I hope that we focus on as an allocation decision of the highest importance is public leadership. It seems to me that trust is a gamble that others will reciprocate. The current policy of permitting 50 different states to determine what it is they want to do about this epidemic is disastrous to building trust in the nation. The Commission ought to focus in its recommendations on the need for a national policy, one that focuses on the crucial issues of protecting the rights of individuals or in establishing standards for screening, on confidentiality, and so forth.

I often wonder what we would think if Canada, rather than the United States were the leading country in the Western World in the AIDS epidemic, and if they saw them slowly allowing each of the 10 provinces developing separate standards, all the while permitting some very wild ideas to float around among the various provinces. I think it would seem to us that this particular state of affairs would be very dangerous, not only for Canadians but for people who live outside of its borders.

My third recommendation touches on a very broad concept of AIDS education. It seems to me that in this epidemic we are spending too much time talking about health education in

the narrow programmatic sense of those activities that health workers, doctors, other people perform for patients and communities. But the most important resource that we have at our command is not education in the narrow sense but public discussion and that comes from our political leadership. The best example of the connection between discussion and public health over the last 30 years is the smoking controversy and the declining rates of smoking; the fruits of this public discussion in safer sex has already begun now in AIDS.

The issue of free discussion come up a few months ago on the floor of the Senate in a discussion about AIDS in which the author of a bill limiting what CDC may say about safe sex said that every AIDS case in the United States can be traced back to a homosexual act. In my opinion, this aggressive ignorance should have been refuted at the very highest level by our political leadership. Public leadership as making the truth about AIDS plain to see is the primary weapon we have in education.

Here we are one more time regarding treatment with another national crisis in what is charitably called the health care system, a term that tries to make a virtue out of the fact that no single level of government or even government itself has a responsibility for remedying seemingly eternal medical inflation. The fact that as many as 35 million individuals lack insurance and that poor AIDS patients will join the others, those "too small fish" who are economically unattractive to a commercializing health care system.

One of the worst things I think we can do, in this crisis would be to respond to AIDS with a special program, exclusively for its victims.

I am not at all challenging the interim report of the Commission for funding for special programs for the special needs of AIDS patients. I thought the Commission's report both in advocating drug treatment on demand and for spending to meet special needs is commendable and courageous. I am simply saying that we are ethically at the point of trying to decide whether poor AIDS patients should go to the front of the line of other poor people who do not have insurance, and I don't think that is a dilemma -- it is simply wrong. See, poor patients should receive the medical care they need. I would urge the Commission in its findings to point out once again to the leadership of our country, to includes both political parties and all levels of government, that our health care system needs a fundamental overhaul.

An epidemic is the ultimate challenge to life lived together. The central issue of AIDS is not only what we are willing to permit it to do to its victims but, also, what we are

willing to permit it to do to us as a people and a republic. If we permit thousands of the infected or stricken to lose their jobs, to be tested at will, to be turned out of their homes and churches, spending the last days of their lives like modern-day lepers searching for a place to die, we will have lost far more than the lives of our fellow citizens.

CHAIRMAN WATKINS: Thank you, Dr. Beauchamp. We will probably have more limited time for questions than we would like, but you should, also, recognize that we would like very much to keep the dialogue open with you subsequent to the hearing, and perhaps you will be getting letters signed by me as Chairman of the Commission coming to you to ask additional questions as we look at the testimony in greater detail, and we have witnesses coming from other vantage points, we can begin to flush out some of these important issues addressed today. So, I don't want you to think that we are going to leave you alone. We like to take advantage of you. You have been excellent witnesses and have come all the way down here to help us on this issue. We would like to keep that dialogue open. We will start with the questioning from Dr. Walsh.

DR. WALSH: I was particularly interested in the fact that each of you has made a point in which I firmly believe, and that is the allocation of resources. We have to think of all of the ill in our country and not only of those with AIDS as having a special disease and deserving special consideration.

I think that part of the problem, Dr. Beauchamp, in a national health policy which you are advocating is the fact that AIDS is centralized in a few specific areas in this country, and it makes it very difficult to get, at least it is my experience, it makes it very difficult to get individual congressmen from low-risk behavior areas to get terribly interested in a national policy because they are responding to their appropriate people. Resource allocation is resulting already to my mind in fact finding. Now, I know I spend a good bit of time on the Hill myself last week, and it was interesting. Every congressman I saw commended us for our interim report, thought it was wonderful, but I couldn't find one who was going to really vote any funding for it. I said, "You think it is great; you have got to vote funding."

"Well, no, we cannot do that because we cannot vote funding for one disease at this point with the limitation of resources." If you were to advise this Commission in our long-term report, any one of you, while we must show special interest in AIDS because that is what we are convened for, how would you approach getting balance enough into our report so that we could not only fill the gaps in the prevention and care of patients with AIDS but, also, draw attention to the fact that we are not ignoring other problems because when more than 60

percent of the Medicaid funds in New York State are being used for AIDS patients this is depriving people of care, and Medicaid law was not passed for the purposes of caring for sexually-transmitted diseases which depend upon a positive individual act, and I think that is much more common now than with the hemophiliacs and so on and the blood products thing is pretty well under control, and this does give us both a moral and public health issue and especially a resource allocation issue because it will be only 2 percent of our health care by 1991 which when you look at it isn't bad, but how can we get a Congress to vote for what we think is needed and at the same time demonstrate we are not ignoring other problems in a report of the type that we are trying to get together? Anyone or all of you?

DR. BEAUCHAMP: I think it is a real dilemma. I think that you might, if you are asking a sort of practical question, look at how Medicaid has been expanded recently through the Omnibus Budget Reconciliation Act. There is a real logjam on Capitol Hill and a real struggle between the Administration and Capitol Hill about a lot of issues that need not be rehashed here, and the only way in which we have been able to expand Medicaid funding is by tying it to a large budget reconciliation bill where there are so many other things going on that it becomes almost veto-proof. So, if you are looking for a sort of veto-proof way of going about it, I would look at the experience since 1986, and the last several years, where we have found some successful ways of getting Medicaid expanded. I would also say that if you take a look at the Medicaid expenditures in any state, you find an awful lot of people treated for heart disease who all their lives have smoked. As far as I can tell, this nation like any nation is saddled with a disease burden that in one way or another we all contribute to through our behavior. It is unfortunate as human beings that we contribute to our own demise all the time. I don't think AIDS patients are any different.

DR. BLANK: I agree with you that it is very difficult. You have two different aspects though. First, you have care for the patients who now have AIDS. Second, you have what I see in the interim report as a major allocation for prevention. I think you should be able to sell the second to Congress. That is distinguished from caring for the AIDS patients where you are talking about the allocation of health care funds in competition with patients with other diseases. I think on cost/benefit grounds alone, prevention through the provision of drug treatment programs is an investment that should be made. If the policy makers do not go along with it, I think it is a tremendous failure in allocation of funds. It is a good expenditure, and it should be sold on those grounds.

In terms of the allocation for health care of organ transplant patients as opposed to cancer patients as opposed to AIDS patients, there I believe that the case has to be made that AIDS is no different in the sense of allocation of funds for care. It has to be integrated into the broader framework. Otherwise, you are going to see, as you have indicated, this backlash of other patients (organ transplant patients, patients who are denied long-term intensive care, cancer patients) against AIDS. In the long run, that is far more dangerous and has more potential for discrimination and stigmatization than even some of the testing that you have been talking about. So, I think you have to distinguish the two aspects of the problem. That is why I so fully support the interim report in the sense of allocation policy. I think this is money very well spent which down the road will alleviate some of the other allocation problems.

DR. CRAWSHAW: I would like to respond to that by suggesting the Commission take a philosophy based on trust rather than fear. It is expected that your report is going to terrify people. If possible the report should say that we should build trust, that we should be building trust about how to build a better health delivery system through the whole country and that AIDS represents a challenge for us to reorganize our thinking about this. In a practical way what we have done in Oregon with Oregon health decisions is try to build trust, what we call a constituency of courage for the state legislators. We have legislators who are making terribly difficult decisions because the media is staring right at them. Why are you letting these little kids die? For them to make that kind of decision, they have to know that there is a constituency of people who are going to back them in the sophisticated way they need backing. What we have done is we have drawn legislators into our health decisions process. The Chairman of our Steering Committee for our health priorities for the 1990's is the president of the senate in Oregon, so that we have an interrelationship for we are genuinely going after sophisticated health policy in a grassroots way.

DR. WALSH: Do you think, any of you, that AIDS testing for people applying for insurance in the private sector is an invasion of their right or do you consider that discriminatory because, again, you know, you get a lowering of your premium, as you point out in your paper for not smoking and so on, because it seems to me that this is a growing problem in states in which people who should be able to buy insurance cannot because they have isolated legislation passed under the pretext of protecting confidentiality. I just want a quick comment because I know time is short.

DR. BEAUCHAMP: The problem, we are sort of halfway toward a totally commercialized health care system with a lot of

residual islands where we treat everybody as if they are one group. So, in a commercial scheme and looked at from the perspective of the insurance companies, insurers are in the business of avoiding people who are sick or might be such; looked at that way, testing for AIDS is no different from anything else that we do except that when you add all that up, it is a crazy way to run a health care system from the standpoint of a democratic community.

DR. WALSH: You are buying insurance, too. It saves you.

DR. BEAUCHAMP: But I am, also, a taxpayer and far more important than that, I am a citizen, and I am offended by the fact that we are more interested in the liability of an insurance company than the needs of victims.

DR. WALSH: Would you waive the requirement for physical exam when applying for insurance?

DR. BEAUCHAMP: Not for life insurance, no.

DR. WALSH: That is what I am getting at. You test for hypertension. You test for smoking.

DR. BEAUCHAMP: In terms of health insurance, I must confess my druthers. I would rather the United States had a system where health insurance is something that was a pooled affair where we all were simply treated as one group.

DR. BLANK: Again, I think we have to look at the context. If AIDS were a heterosexual disease affecting the broad cross-population, I don't think there would be any question that we would agree that there should be testing. You get into the question of rights, into the question of civil rights, a question I wouldn't want to address today, in the sense of a quick decision. I think that unless we look at the context and balance things out, our policies will fail. As I note in my written testimony, we have to find a proper balance between social responsibility and individual responsibility. Individual responsibility for health, however, does not mean that the social responsibility is abrogated. In fact, it strengthens it. It means that we have to put more emphasis on education. I would hate to use the HIV test to force people into categories where other things happen to them. So, I favor testing only under the circumstances where there are protections in terms of jobs and some other type of legal assurances. I agree with Dr. Beauchamp that our system as a whole is failing in many ways. A system that does this type of thing and puts us in these types of dilemmas is a very difficult one to deal within a logical way.

CHAIRMAN WATKINS: Dr. Lee?

DR. LEE: Dr. Crawshaw, first of all, I hope you did not hit that cab driver.

DR. CRAWSHAW: I listened to him though.

DR. LEE: Secondly, I was reading your bibliography which is absolutely fascinating. The one I liked best though is doctor-patient or patient-doctor and the Foley catheter that stuck.

DR. CRAWSHAW: I will send you a reprint.

DR. LEE: Send me that one. The other one is fraternizing with the enemy, a conversation with Senator Edward Kennedy. That I would, also, appreciate. You people have fascinating backgrounds, and I will ask you one question. Americans are not accustomed to understanding that any resource is finite. We will cut down as many trees as we possibly can to cut up as much paper as we can to throw away, etc. Dr. Day back there is a finite resource. There are not endless Dr. Day's, and if she quits, we have a problem. Now, in my field, this marrow transplantation thing which is brought up in one of your papers is there. What do we do about getting across the point that our resources, all our resources are finite and that health care may as Americans think of it may not be a right. It may be a privilege, and it is becoming a scarcer privilege. Could you comment on that?

DR. CRAWSHAW: You are absolutely right. The American public does not wish to believe that resources are finite. However, when you deal with the people who are in policy positions in communities, they know they are finite. Those people are very lonely people. They will educate the public, if they are given support in being able to say that we can just put so much into prisons and no more. We can just put so much into health care and no more. Now, you people have to face up to this. It has to be said again and again. My answer is that we are in some kind of a great social transition, and that we do need the leadership backed by the people, informed people. There are about 5 or 10 percent of concerned citizens who really have thought about the dilemma of limits. They have to be mobilized, and they have to back up the leaders for the kind of expression that will take us to where we can realize that we are finite. We are mortal. You cannot buy a cryogenic paradise. There is no future that way. We have to live within the day. It goes against everything we see from the TV set. It goes against everything that the rabid politician has to say, but that is the truth, and it will prevail if the people of goodwill can organize and speak clearly to the limits that are real.

DR. BLANK: I agree with Dr. Crawshaw. I think we have to look at what we are doing to future generations. We have been willing to spend money as if it is infinite, but this cannot continue. This will take strong leadership from the political leaders. It will reach the point at which we simply are not allocating money for some uses. AIDS comes at a very difficult time to that extent, as well because we are seeing a transition from a mentality that says that anything is possible through technology--anything is possible through more spending. We are reaching this point. I think it is coming soon, but it will take leadership, and it will require some very hard decisions of saying "No!" Hopefully, it won't come in the area of preventive medicine and allocations of the type that you are looking for because I think that would be counterproductive but, unfortunately, I think these decisions are being made. I address them more fully in my recent book on Rationing Medicine.

DR. BEAUCHAMP: I think Americans know that resources are finite. I think they just don't have an opportunity to express that belief. As a matter of fact, I would be willing to bet that health care providers are less interested in the proposition that health care finances are finite than the American public. If we had a structure by which all of the resources for health care were evaluated in terms of our needs, not only of what we each individually need, but what we could collectively afford, if we had that kind of structure, I think the American public, while it might bridle a bit from time to time, would understand the need for that immediately. We just don't have that structure. We don't have a national health program. So, I don't blame the American public for demanding the most it can out of the situation because the situation gives him or her every incentive to do so.

CHAIRMAN WATKINS: Mrs. Gebbie, we have about 15 minutes for all of the rest of the questioning. We have to terminate at twelve-thirty. I would like to move right along as quick as we can.

MRS. GEBBIE: Thank you. This is one of those things I think where some reflective written response might be helpful with what you say here because I confess to being one of those that Dr. Beauchamp knows, and you probably know a couple of panel members, elsewhere. The way you present all of this is very rational, and Oregon sounds like we are getting something to tackle it, but in fact, I think on a day-to-day basis each of you sometimes if rather lonely, with the point you are making, and I think we need to hear some very down-to-earth comments on what happens when you try to surface these discussions, how you have been turned down, turned away; what are the counter arguments you get when you try to engage people in the sort of rational discussions that we have been hearing about today, and if you have a 2-second answer, that is fine, but I would really

like to see coming in some lengthy discussion of that issue because it is crucial to what we end up being able to recommend.

DR. BLANK: The counter argument that I face as I speak publicly on the subject is that, I am pitted against the 3 year old who needs a bone marrow transplant. The point is made, "Would you deny this young girl a bone marrow transplant?" This, of course, is very difficult to deal with. As I look around, I notice the news media is not as interested in the broader allocation questions as they are in the emotional and certainly very touching issues of individual cases. Again, this reflects our values that we follow very carefully on individual cases at the expense of the bigger picture. All of us are in favor of cutting health care costs, if we can deliver the services. All of us or at least most of us in the allocation and public policy area are concerned with cost containment, but when it comes right down to the individual cases rationality is out the window. All of the logic is out the window. We have a value context that says, "Spend as much as we can on an individual patient. Do as much benefit as we can for the patient." That is changing. It is changing certainly at the end of the life cycle. We are seeing major changes on how to treat terminal patients, but this is a value that is very basic to us. It is going to be very difficult to change. To answer your question directly, it is very discouraging at times when one tries to present what one thinks is a rational approach is beaten down by emotions. But on the other hand, that is the context within which we are dealing and rightfully so. I suppose that is certainly understandable given our context of individual rights, given our emphasis on prolongation of life and the idea that medicine is a right as opposed to some kind of privilege. So, it is very difficult. I find myself in situations where I, myself, am torn. It is very difficult to say, "No, don't fund the bone marrow transplant for the 3 year old or the liver transplant." But when I see some children getting three or four liver transplants in what, in fact, might be a case that the child dies anyway. What I have to point out is that the money going into those transplants could have done perhaps a lot more good for a broader range of individuals. So, I think we have to get that message across and as Dr. Beauchamp says, "It is very difficult."

DR. CRAWSHAW: I would just like to respond and say that anyone who surfaces these issues with the public stirs a deep primal anxiety in the public, and you get two kinds of answers. It has been my experience to be portrayed by a certain segment of the public as a Nazi concentration camp doctor who is crushing the heads of children. These are the kinds of pamphlets they put out about my work. On the other hand, I have congressmen who come up and grab me by the hand and say, "Thank God, somebody out there is trying to put the issue to the public." So, it is those wide feelings that you are open to if you as a commission begin to take these deep issues and present

them to the public. Be aware that you are going to be exposed to the salvaging that the American public does to leadership.

CHAIRMAN WATKINS: Dr. Conway-Welch?

DR. CONWAY-WELCH: I have a quick question. This is a sidecar issue, but I would be interested in any help you might be able to give me. AIDS is nursing intensive. The average salary for a nurse is $18,000 a year. We are told that there are no magic sources of new money in the health care system. We are, also, told that the double testing and the extra x-rays, etc., that occur in our system for physicians to protect themselves against malpractice add something like 30 to 50 million dollars to the total cost of the health care system. So, there are dollars that could be reallocated. I wonder if you might share with me if any of you have information that would be helpful in terms of dealing with what is a real nursing shortage, a real allocation problem and the fact that salaries are part although not all of that issue. If you have some suggestions, I would very much appreciate it, and I can be reached here at Vanderbilt at the School of Nursing, and the zip is 37240. Thank you.

CHAIRMAN WATKINS: Dr. Primm?

DR. PRIMM: I don't have a question. You know, Dr. Crawshaw, had I been in that cab this morning, and he said that to me, I think that I would have tried to educate him, and I seize upon those kinds of opportunities to talk to individuals who would voice that kind of opinion about the profession and not only that about AIDS itself because I feel that we need to at all costs to educate everybody. That is not to be critical, as much as that we need to use every opportunity. So, this cab driver probably hauls maybe 50 and 60 people a day, and maybe voices that same opinion to them, and maybe if I could change his attitude, maybe I could get the right information out. I think we need, everybody needs to be an ombudsman or a teacher, and of course, I know you are.

DR. CRAWSHAW: I couldn't agree with you more on that point, sir. You have to meet the problem where it is.

CHAIRMAN WATKINS: Dr. SerVaas?

DR. SERVAAS: I wanted to address Dr. Blank because our fellow Commissioner here, Penny Pullen was instrumental in getting that Illinois bill into effect. The information we had from her was 4 out of 8000 tests, and then when you mentioned $200 that some doctors were charging, I immediately went to ask Dr. Schwarz what can we do about that, and he, from the AMA, and he said that they are really working right now to get a flat, you know, get something resolved so that we won't have that kind of

thing happening, and the thing I wanted to tell you is that I have had extensive conversations with the people who do supply tests to the military and to other places, $3; the Red Cross is now paying less than $4; the military is paying, and the laboratories, for example, who do it for the military would be happy to do the states in the area of 4 or 5 dollars. Now, that makes a tremendous difference when you are talking about allocation of costs, and of course, in her instance the people are paying it for themselves, and it is really felt by the medical profession it is too early to draw conclusions about whether or not you are causing people to not marry because of this, because they had a lot of people early on in January when they announced this was going to happen who were allowed to get married and keep their licenses because they were good for 6 months. So, I think that since we are all looking at Illinois, at what is happening there and how many they do fund, and it is giving them some good information, I believe that we should maybe expand on what the facts are.

DR. BLANK: It may be an area where we should look. What I am saying is we should look very carefully at that type of expenditure because we are changing people's lives to some extent. When I first heard that $200 to $400 was being charged for some premarital HIV tests, I was aware that the two ELISA tests plus the Western blot that insurance companies are using costs $8.50 total. And here you are finding people being basically ripped off under the auspices of a state program. So, what I meant in my written testimony was that there is a tendency of policymakers today to do what might be seen as very easy technical things--simple solutions to show that something is being done about AIDS by some of the state legislatures. I think it is dangerous to jump into those programs without more data.

It may very well be that it is good that some states like Illinois are doing such testing and that we collect the data and are able to see: (1) whether we do identify a reasonable number of cases and (2) whether it has any impact on marriage license applications. I do know that the newspapers, at least, the news media in Northern Illinois is saying that the rates have increased for marriage licenses in Southern Wisconsin; it has increased substantially since January 1 when the Illinois law went into effect.

DR. SERVAAS: And we have lost two young women in Indiana who married and didn't know that they were, and it depends what you call cost effective.

DR. BLANK: It is also questionable as to what extent at the marriage license stage that this program is going to stop heterosexual transmission or even infection of the fetus. There is an assumption, I suppose, that I disagree with that sexual

intercourse is not engaged in until after the marriage license is obtained, but that is the kind of thing we can find out from these testing programs. Perhaps that is the one advantage, the only advantage I can see in having 50 different states writing legislation--we can have some experimentation on a local basis, but overall I think that is not a good way to do AIDS policy.

DR. SERVAAS: We do rubella, but you could use the same argument. The woman is already pregnant.

CHAIRMAN WATKINS: Dr. Lilly?

Let me close out this panel and assure all of you that the Commission is extremely sensitive to the broader issue in which the HIV epidemic and our actions regarding that are found. We are extremely sensitive to the other aspects. So, any decision we might make in its impact on other infectious diseases, terminal diseases, drug development are all taken into account. I think you can see that is why we put bounds on certain things.

Obviously there are certain areas that when we make recommendations, such as dealing with the nursing shortage, alternate health care settings and so forth, that will impact positively on health care delivery and drug development. The whole drug abuse issue in the nation which is far beyond IV drug abuse, as you know, but we have to be HIV specific in our recommendations. So, I would like to make sure that you understand that we are sensitive to the broader issues and that we will be addressing the broader issues because out of this epidemic I would hope that we are bright enough to take advantage of opportunities here, not only to take care of the care and the preventions for the future in this epidemic but that we are ready for the next one, and we certainly have demonstrated that we are not ready in this nation. We have a very weak health care delivery system for the needs of the nation, with the growing elderly, the problems with our young, the ethnic groups; we have got real problems in the nation, and so here is an opportunity, and so, I would encourage all of us to think positively and take Dr. Crawshaw's approach that here is an opportunity for the nation to turn itself around that will impact positively on every aspect of the fabric of our society and how we do business in the country, and I think we have got to keep that in mind, too. I think too often this business about money upfront, in this case it is difficult to do an amortization regime as we might do in business against some product delivery or as we might do in defense against a research and development option for future cost effectiveness, but we have to do it, and we certainly have anecdotal information of all kinds for prevention. Maybe 4 ounces of prevention is worth a pound of cure. We need to prove it, and we don't do it very well in the medical area, and I would hope that in the Institute of Medicine

in the other work we start putting some real attention as Sam Thier is now trying to do at IOM in a cost analysis of this that gets real tough on how we look at the most optimal approach to funding, not only this but the other medical care in the country, and this is desperately needed and maybe the doctors aren't the ones to do that, and they ought to call in some helpers from the financial management point of view. People on this Commission are in business because there are at least some elements of costing out that will amortize over a period, a short period of time, but we need to harden that up and stop worrying so much about upfront investment in those cases where we can, in fact, show a cost effectiveness a few years downstream. So, that certainly is in my mind as we go into the final few months of our report writing.

We will certainly be sensitive so that we are not impacting on others who are severely in need of medical care and continuing recipients of proper drug development and the like, and it is foremost in our thoughts as we go through all of the recommendations.

Thank you very much for coming before the Commission today, and we will be in communication with you.

CHAIRMAN WATKINS: Our next panel today is entitled Congressional View and we are privileged to have Congressman William E. Dannemeyer, 39th District, State of California, here with us. We very much appreciate your willingness to come down to Nashville, Congressman, to chat with us today. I know it is a busy schedule there are you would like to proceed with your statement.

CONGRESSMAN DANNEMEYER: Thank you very much, Mr. Chairman. Admiral Watkins, ladies and gentlemen of the panel. I personally thank you for the privilege of coming here and sharing my views on the public health response that in my judgment should be adopted to deal with the AIDS epidemic. To give you a little brief overview of my background, I am the senior member of the House Subcommittee on Health and Environment, the Subcommittee that has jurisdiction over the health care legislation for the House of Representatives. This is my 10th year in the House, and I have been involved in struggling to develop a public health response to this epidemic in the form of legislation at the federal level for at least the last two or three years.

I have a written statement that has been presented to each of you. I am not going to read it because I have been privileged to hear testimony of other witnesses and when witnesses come and read statements, you tend to let your thoughts wander. It is only human but I will make reference to it at appropriate time just to give it the emphasis I think that it

needs. If I can outline what I intend to cover, it will be the following points.

First, I will deal with the major issue currently being debated in the Public Health Service of the United States government. That is, to what extent has the infection entered into the heterosexual population of the country, a very significant question. The second point I would like to spend a little time with deals with the issue of reportability for those with the virus, a very important issue in developing any public health response to the epidemic. The third issue will deal with whether we should, as a public policy matter, adopt laws of anti-discrimination, protecting those with the virus? The fourth will deal with recommendations that I think are appropriate and that hopefully you will consider when you make your report to the President. The fifth will deal with some of the deficiencies that I believe we are witnessing on behalf of the highest public health officials of this government today, and the last point will address a little bit about the politics of the whole issue because, in my judgment, from the outset of this epidemic, the issue of developing a public health response should have been forthcoming but the issue, has been up to its eyeballs in politics.

With respect to the first point that I mentioned, to what extent has the virus entered the heterosexual population of the country? The reason I consider this to be an important issue is because unfortunately, there the view on the part of some is that since the epidemic has evidenced itself up until now in mostly male homosexuals and intravenous drug users (which together comprise over 90 percent of the cases), we do not particularly have to worry about the epidemic spreading beyond those two groups. At this point in time it is believed that the virus has afflicted those two groups extensively but it has not gone beyond that, therefore we need not worry that much about it.

The first chart, I have given you copies, shows us the extent the epidemic is entering into the heterosexual population. CDC estimates it is .021 percent and 30,000 as of December 1987. We have the record of the United States Army which tested recruits during 1987 and found that the incidence was .15 percent which almost doubled from what it was in 1986 when it was .083 percent. If you extrapolate this percentage across the age group to which it relates, it translates into about 106,000 persons in America in the heterosexual population who have the virus. Then in addition to testing recruits in the Army the U.S. Army has been testing active duty personnel, and these figures,(this is everybody serving in the Army in 1987), the incidence of the infection is .21 percent, and that extrapolated across the entire population our country produces an infection in the heterosexual population of about 150,000 people.

In the Masters and Johnson study, published in a Newsweek article this week, they said that infection among monogamous heterosexuals was .25 percent, and among promiscuous males was five percent. Their methodology has been criticized by some treating it essentially as a civil rights issue. This is one of the issues that will be debated I suppose for some time to come.

The chart also indicates a testing of premarital women applicants in Alameda County in my home area of California. The health officer during 1986 illegally tested the blood of female applicants for a marriage license and found that .5 percent of the applicants applying for a marriage license in that county in California had the virus. If you extrapolate that number across American for all women, in that percentage, it would work out to about 600,000. The Baltimore study for females is three percent, the Baltimore study for males is 6.3 percent and then Masters and Johnson 7.0 percent for promiscuous females.

This is most significant data. The story that this information tells me is that the United States government, the CDC, one whose responsibility it is to tell the Americans what communicable diseases exist in this country and the numbers that are involved have underestimated the heterosexual spread. Their estimate is, that the incidence of infection is .021 percent in 1987, or 30,000. That is merely an estimate on their part.

I would say that with regard to all of these studies, you can take your pick as to which one is the most accurate or significant one. However, the Army study is not based on estimates. It is based on actual testing of every active duty Army person in 1987. They found that .21 are infected and the point I want to share with you is very simple. When other studies indicate that the incidence of the infection in the heterosexual population is 10 times more than what CDC says it is, I think that the credibility of what CDC is telling the American people is seriously impaired. That is what I think this chart says.

What we should be doing, and should have been doing two or three years ago, is testing requisite groups of people in our society so that we know what the extent of the infection is to the people in this country. You cannot formulate a rational public health response to any communicable disease unless you know what quantity of people are infected, in what regions of the country, in what age groups, and in what occupations. Then as you test them over time, you find out whether the epidemic is moving and in what direction. Right now we are not testing groups of people. I will address that issue a little later in my remarks.

The next issue I would like to talk a little bit about is reportability. There are M.D.'s on this panel, and I suspect you have been hearing a lot from doctors, and to those that are here, please excuse my resort to basics in terms of explaining something. For any American to understand the real struggle in the public debate on this issue, we much come to appreciate and understand the whole concept of affordability. Please excuse me if this has been gone over but I will take just a few moments with you, and I thank you for this chance to express my thoughts along these lines.

When any of us are ill, we usually go to a doctor if we are sick enough, and the doctor listens to our complaints. That doctor in private practice, with no compensation by the way to the public health care system, is our first line of defense against any communicable disease. Historically it has always been this way. The doctor listens to our complaints, and provides medicine or hospitalization or surgery or what have you, and that is all in confidence, as it should be. It is simply nobody's business who has what disease. The doctor and the patient are entitled to that information and nobody else, except when a physician finds that a private patient evidences what is called a communicable disease. In my state of California, there are 58 of them on the list of reportable diseases. Fully developed AIDS is one of the 58, a half a dozen venereal diseases are among the 58 as well as syphilis, gonorrhea and chlamydia. These are among the most common. Any time a physician encounters one of these or hepatitis, meningitis, whooping cough or measles, by law the doctor is required to breach the confidentiality of that patient and report the name, and address of that patient to the public health authorities usually at the city or county level where that data, as to identification, reposes. Then the statistical information that it contains is sent to a central state location and the state forwards the statistical information to the Centers for Disease Control in Atlanta, Georgia.

Now, this historically is how this country has dealt with and controlled communicable disease. I will say again, we have had reportability for fully developed AIDS for the last five years in my state of California, beginning in March of 1983. However, the political debate in America centers around whether or not we are going to report those with the virus whose status has not yet evolved into ARC or into fully developed AIDS. Eight states in the union today mandate reportability for those with the virus, but those eight states contain less than 10 percent of the AIDS population in the country. Two states in the union, my state of California and New York, present 52 percent of the cases. There is no reportability required by law in either of those two states.

I mention this because Dr. Bowen, head of HHS, has come before our Health and Environment Subcommittee and testified on this specific point. His position is that the issue of reportability should be at the discretion of the state. If the state wants to decide we are going to report, then that is the way the national policy should be. Given the numbers we are dealing with, and nobody knows for sure, but it is estimated that between a million and a million and a half to three million Americans have the virus. We know there have been over 55,000 cases reported so far. The loss of life that we are looking at and the potential devastation to the very stability of the American society is so profound that I believe we are looking at a national problem of severe significance to all of us, and for us to pursue a policy of giving a state the option of reporting the virus is like trying to run World War II by giving governors of our states the option to decide whether or not they are going to send citizens of their states to defend the national government. We could not have waged World War II on that basis. We certainly cannot operate and devise a rational public health response by continuing to give states the option of whether they are going to report those with the virus.

This issue of reportability is, I think, very interesting and politically significant. I do not make any secret of the fact that politically I am on the right. Those of us on the right have historically looked to local governments as much as we can to solve problems in our society, and people on the left who are often identified with the Democratic party in America have been just the opposite. They have felt that the cause of social justice is served by moving power into the central government because that is where things happen and things get done. In this instance, the Chairman of the Subcommittee where I serve, Mr. Waxman from Los Angeles County, representing a district in Hollywood and West Los Angeles, is where Dr. Bowen is - giving states the option on the issue of reportability. So it is a little amusing to me that a person on the left, who historically has wanted to move power to the central government as a means of solving the problem, is in this instance opting for states rights and an individual like myself, on the right of the political spectrum, is suggesting that as a matter of national policy, we should have a federal law that says that those with the virus be made reportable.

Very candidly, it is not an accident that Mr. Waxman, my good friend from Los Angeles, is pursuing this policy option because the state of California, having 22 percent of the AIDS cases in America, has one of the most obtuse, ridiculous laws on its books of any state in the union, and I could sum it up this way. If a doctor in California today finds a patient with a curable, communicable, venereal disease like syphilis or gonorrhea, the doctor is required to report that patient's name, and address to the public health authorities. If, on the other

hand, the same doctor finds a patient with a non-curable, communicable, venereal disease, like the virus for AIDS, if the doctor reports that patient to public health authorities in California, the doctor commits a crime.

Now, nobody can defend that statement as the basis of a sound public health policy. But you can begin to relate to it and defend it if you understand the politics of the issue. The status of what I have described about non-reportability in California came about as a result of the adoption of that law by that state's legislature in March of 1985. This law is still on the books, presents the paradox that I have described. It is a law that should no longer be there. It is not sound public health policy, and I hope the legislature and the voters of the state will soon change it. I believe as a matter of national policy, and I hope you will consider this in your report, you should say that any sound public health policy at the national level must include reportability for those at the state level for those with the virus.

The third point I want to talk about deals with a very sensitive issue in our society, namely anti-discrimination. The statement is being made time and time again that people with the virus, people with ARC and people with AIDS are being discriminated against. Therefore in order to preclude this discrimination, it is necessary that we have anti-discrimination language adopted to deal with this problem. Let me break it down if I may. If you have the virus, or if you have ARC or if you have fully developed AIDS, let us start with that. Since male homosexuals and intravenous drug users contribute 93 percent of the cases, if an individual is a homosexual and presents a case of illness, I happen to believe as a matter of philosophy that just on the issue of being a homosexual or being a drug user, an employer should have the right to decide whether or not they choose to hire that individual and affirm or disaffirm that lifestyle.

For instance, I do not have any problem with affirming, as a matter of public policy, the heterosexual ethic as a foundation of western civilization. I will not apologize to anyone. I do not think we in America should say to the people in this country that you are going to be required to disaffirm the heterosexual ethic in order that someone who is asserting homosexuality as a lifestyle should be entitled to protected status as a matter of civil rights. So that is a public policy question, that will have to be debated. It is the same situation with a drug addict. I think an employer or a property owner should have the privilege of saying to a drug addict or a homosexual, if that is what you choose to do with your life, you are not going to work here, you are not going to live here. As a matter of public policy I think I can defend that without hesitation or reservation at all.

Let us talk a little bit more about when we have an individual who is not only a homosexual or drug addict but they have also AIDS or ARC or the virus. Now, if they have AIDS or ARC, I think it is preposterous to claim that an individual who manifests diminution of their immune system to the point where they are diagnosed as having AIDS, is entitled to a civil rights protected status where we would say to an employer or landlord in this country you must rent to such a person or you must hire such a person. It is absurd to say that. A person with fully developed AIDS is a very sick person, manifesting such opportunistic diseases as tuberculosis, cancer or a form of cytomegalovirus or Epstein-Barr syndrome. All of these are very debilitating illnesses. Some of them are in themselves communicable, and I do not believe that such individuals with AIDS have the right to claim the privilege of anti-discrimination status.

The same with respect to ARC. The manifestations of outward illness of a person with ARC should not be able to make a credible claim to anti-discrimination status. The interesting point in this whole controversy begins to develop when we talk about the person who has the virus who ostensibly is asymptomatic. Nobody knows, as I said, how many people have the virus, 1.5 million to 3 million in America, some people have said higher than that. Two years ago our medical professionals were telling us 20 to 30 percent of those with the virus would go on to get AIDS and die. Today the figure is more like 70 to 80 percent. Some researchers are saying it is just a question of time.

Each of those individuals with the virus, researchers are now telling us, is contagious and infectious. That is, with a transfer of bodily fluids, those individuals with the virus may transfer a fatal condition to any human. Sadly, most of them who have the virus do not know they have it because we are not requiring reportability and we are not requiring testing in our society to any degree. But the claim is made that, well, if they have the virus and they are not yet evidencing illness outwardly, that person is entitled to anti-discrimination status. Let us look at that.

If they are not sick, who knows if they have the virus, and I would submit that if they are not ill, there is no need for anyone to know they have the virus. Therefore, such a person in my judgment does not need the anti-discrimination status of the law. Now with respect to the individual that begins to develop symptoms of illness but does not yet have ARC or AIDS. Here, I would like to make reference to a portion of my testimony because the claim is made that a person with the virus who has not yet developed ARC or AIDS is perfectly normal and capable of functioning in our society and is therefore entitled to anti-discrimination status. The AIDS virus does not just attack

the immune system. Scientists now know it can also infect the brain. Dr. Robert Gallo, a leading AIDS researcher, reports that AIDS infects the brain and can cause dementia as well as death directly.

These are cases that often go unreported because they are not showing up as classic AIDS but as brain disease. People often do not know that the virus is present. Some people infected with the virus can experience mental problems long before they show serious symptoms of the disease. One example, is a man who has only a mildly damaged immune system. He states,

> " I used to have a real good memory. You could give me a list of 100 items in the store and I could read them back to you frontwards, backwards, what sequence they were in, all that stuff you know.
>
> I mean now it is like I go to the store for five items and I forget three of them."

Brain scans reveal the damage that can be done by the virus. The brain literally shrinks and fluid fills the space. Over 50 percent of AIDS patients may ultimately suffer from dementia.

Dr. Alexander Becket, Massachusetts General Hospital states, "The complaints we most often hear are that people are having difficulty concentrating. We have commonly had people describe episodes during which they have sudden strong emotion, unprecipitated by anything they can point to, and that they feel that they are performing less well than they used to at tasks that they are quite familiar with. The indications are that brain damage is something that many people infected with the AIDS virus will increasingly have to face."

Dr. Grant of the University of California in San Diego now reports that mental impairment occurs in the majority of persons infected with HIV beginning early in the course of infection and frequently without any symptoms referable to AIDS or ARC. Researchers have found that among homosexual men infected with HIV, but who have not yet developed ARC or AIDS, 44 percent had neurophysiological abnormalities.

A paper presented at the Third International Conference on AIDS, June 1987, stated that among ARC and/or AIDS patients, over 80 percent exhibited abnormal neurological findings and almost half demonstrated memory loss and poor concentration. It has also been claimed and I have heard many times in public appearances, debates that I have had with different people, in and out of the medical fraternity that the only method of transmissibility of the virus is sex, blood and drugs, and when I hear that, I take offense at it because I do not believe it is a

correct expression. The fair way to state it is that main means of transmissibility, is sex, drugs and blood, but we cannot exclude other means of transmissibility, and this is relevant on the issue of whether or not our society is going to adopt and grant anti-discrimination status for persons with the virus. There are cases in the literature where an individual acquired the virus by means other than sex, blood or drugs and it is not sound public policy for we in America to say that each of us must accept the risk as a result of the adoption of the anti-discrimination laws that we are going to be one of those who ends up with the virus, having acquired it by a means other than sex, blood or drugs.

There are a few cases that I will make reference to here. Three nurses were infected when they came into contact with infected blood. One nurse held a catheter in place to a comatose AIDS patient with the tip of her ungloved finger, and she became infected with AIDS. The CDC reported a woman who contracted AIDS by caring for a man in his home. She had small cuts and eczema on her hands. The same CDC report told of a mother who got AIDS while providing nursing care for her child who had contracted AIDS from a blood transfusion. The mother was exposed to the child's blood and body secretions and excretions.

A young boy of five died of AIDS from receiving a blood transfusions. Testing of other family members revealed a brother three years older who was positive for the AIDS virus. The mother related that about six months before the boy died she had seen teeth marks on the shin of the older boy but no bleeding. Horizontal transmission is implicit in the transmission. A National Cancer Institute (NCI) researcher apparently contracted the AIDS virus from having no known direct contact with it. The researcher was processing highly concentrated amounts of the AIDS virus in the laboratory. NCI officials are investigating a centrifuge that the researcher was using. They are trying to determine whether a broken seal may have allowed the virus to escape. The researcher claims to have no high risk factors. Health officials isolated the virus from the researcher's blood and confirmed that it was the same type as that being grown in the laboratory. Officials said that it was unlikely that the worker was infected in some other way because there are many variants of the virus in nature.

In addition, relatively new research done by the Los Alamos National Lab suggest that the AIDS virus is a complex family of rapidly mutating viruses that can "constantly change its weaponry, its camouflage, its defenses and even its targets in the body." The findings indicate that the AIDS virus is mutating its genetic code as much as five times faster than the influenza virus, thought until now to be the fastest mutating. The Los Alamos findings "cast the lingering shadows across the prospects for reliable diagnosis, broadly effective treatment and

a vaccine" said Gerald Myers, a molecular geneticist who measured the rate of change at the New Mexico lab. Dr. Myers stated that these findings have implications for new patterns of transmission but that such a possibility was remote.

I have one other reference on this point, the status of those with the virus. Similarly, recent medical data indicate that as many as 30 to 44 percent of asymptomatic individuals infected with the AIDS virus have evidence of neurological impairment. Now it is ridiculous to suggest that people manifesting brain impairment in this way should be given the status of anti-discrimination in our society as a result of the federal or state law. It would require individuals who come into contact with them to be at risk when dealing with people evidencing this type of physical demeanor. This impairment ranges anywhere from slight memory loss to schizophrenia and poses serious safety questions about the ability of these persons to function in society. In some cases, advanced neurological impairment may proceed any evidence of infection. These neurological complications can include seizures, profound depression, incontinence, paraplegia, muscle spasms, severe psychiatric disturbances and psychotic behavior. The reference here was The Lancet published in 1985.

This whole idea of anti-discrimination comes into interesting and ridiculous contrast when you make the following observation. We set a policy by virtue of President Reagan's Executive Order of about six months to a year ago, which states that you cannot come to this country as immigrant if you have the virus for AIDS. We will not let you in. We have said that as a matter of policy. But look where we would be if we give anti-discrimination status to a person with the virus. On the one hand, as a matter of national policy, we would say you cannot come into this country. On the other hand, if you are in this country, we would establish affirmative action for you in the job place as a result of such handicap by establishing this as a law in the Congress of the United States. Now, how in the world could you explain that to anybody in terms of rationality? It is absurd to have such a policy in our laws yet we have people in this country apparently believing in their heart that anti-discrimination status is something that we should adopt.

You know, I am aware that the U.S. Supreme Court handed down the Arline decision last year. It interpreted Section 504 of the Rehabilitation Act adopted by the Congress in 1973. The decision said in effect, and it was a split decision, that the definition of "handicapped" included a person with a communicable disease, without specifying or limiting what type of communicable disease, and it remanded the case to the trial court to determine whether or not such a person, in that case it was tuberculosis, would be otherwise qualified to hold that job. Essentially meaning are they infectious or do they present a

risk of health to other people? Now, I do not believe it ever was the intention of Congress to have within the definition of a handicapped person a person with a communicable disease. In the Carter Administration, the Attorney General came out with an opinion in 1976 that said if you are a drug addict or an alcoholic you fit within the definition of a handicapped person as that term was developed by Congress and in 1978 Congress passed a law disavowing that Attorney General's opinion.

In Congress today, as a matter of public policy, we should debate this issue of whether or not the definition of a handicapped person includes somebody who has a communicable disease. I do not think it is sound public policy for the reasons that I have shared with the Commission up until now.

The recommendations that I think that this commission should consider: (1) Mandatory reporting of persons with the virus, in confidence as a matter of public policy. In other words, states would be required to have reportability in their laws as a condition of getting federal money in the health care field. Let me stress my support for the whole concept of confidentiality. It simply is nobody's business who has what communicable disease in our society except the doctor, the patient and the public health authority, and let us put it into perspective. We have over 55,000 cases of fully developed AIDS reported to public health authorities in the country. I challenged my friends on the civil rights side of this controversy, to point out one instance where the existing system of confidentiality has failed. Our public health authorities around the country have reported all of these cases of AIDS, some 55,000 plus. Where has somebody claimed that that information has been leaked, or that the identity of the individual with the disease has been compromised, by public health officials. They have not come up with one yet, and I do not think they will. My point is that the existing system of confidentiality that is in place around this country has served Americans well in protecting their identify from anyone who desires to find out who has what disease in our society. That system of confidentiality has worked well to protect those who have AIDS and I submit it will work well to protect those who are unfortunate enough to have the virus.

(2) The second thing we should be talking about is testing. We should be testing requisite groups in our society. Groups that we should test are federal prisoners, applicants for a marriage license, convicted prostitutes and drug abusers, persons receiving treatment for drug abuse. We should be testing hospital patients, (persons admitted to the hospitals of the country between the ages of at least 15 and 49), persons who are being treated for venereal disease and persons with tuberculosis. These groups that I have described would reach roughly 50 million Americans a year, and you will note in the instances that I have

described, for instance when any of us go to a hospital, our blood is tested routinely for many substances or compounds or pathogens or viruses or what have you, and it is no more of an intrusion on a patient in a hospital to have the person conducting the blood test administer another antigen to that sample of blood to find out whether or not they are positive for the virus. Testing this quantity of people will give us, in my judgment, the handle that public health officials need to formulate a rational public health response as to what regions of the country we have the disease, what age groups, what occupational groups and whether the number is going up or going down. This data will allow us to determine approximately how many are infected and that answer will be determined by tests conducted over a year or two in each of those groups.

The third recommendation that I would make is to make it a crime to knowingly transfer body fluids if a person is infected with the virus. If we were all angels, we would not need laws. But since none of us are angels, we need laws or standards to set ground rules for the conduct of affairs in our country. We have not yet exhibited the courage in America in the face of this epidemic to set a standard of what we expect from those with the virus. We have relied on education. Dr. Koop's reliance on the use of condoms is out of proportion to the popularity that they should enjoy. Public education is important but we need to say, as a matter of public policy, that any person with the virus in our country who has knowledge of that fact, who intentionally engages in conduct and transfers the fatal virus to other humans, a criminal offense. We are not going to tolerate that type of behavior. Such an individual, in my judgment, has forfeited the privilege of moving about as a free citizen in our society. We have established a standard which says if I have a gun and I kill somebody, that is a crime. If I take a knife and take somebody's life, that is proscribed. If I take dynamite and blow up a train, that is proscribed. For goodness sakes, what is the difference between what I have described, -- somebody who has the virus and transfers it to another individual when we know that that virus is fatal unless we find a cure -- that transfer of a fatal virus should be made in my judgment, a public offense. Well, you say, well, wait a minute now, Congressman, is that not kind of hard to enforce?

Here, again, the paradox of the failure of public health officials to protect us all is readily apparent. In my state of California, so profound is the public policy to prevent the transmissibility of a curable communicable venereal disease that since 1957 there has been a law on the books that makes it a crime for a person in my state who has a venereal disease in an infectious state to have sexual relations with another human. Section 301 of the Health and Safety Code defines six venereal diseases. Would you be surprised to hear that the virus for AIDS is not one of the venereal diseases that fits within the

proscription? In California today, the result of this paradox, is, if you have a curable, communicable, venereal disease, it is a crime for you to have sexual relations. If, on the other hand, if you have a non-curable, communicable, venereal disease like the virus for AIDS, there is no prohibition on your conduct at all. I believe that the public health officials in California and any other person in charge of state government should be called to task by the appropriate political authorities. How they would tolerate that kind of, scenario must be an oversight.

The fourth recommendation is that states should implement contact tracing for those with the virus. The state of Colorado has adopted a good program which is effective, and I believe it is the leading one for the country. It effectuate a means of reducing the transferability of this fatal virus to other people.

The fifth recommendation is that we should flat out prohibit high-risk individuals such as intravenous drug abusers and male homosexuals from donating to the blood supply. We should say, as a matter of policy, that any individual who has the virus who donates to the blood supply commits a crime. We have not said that yet. I think the Surgeon General has made this recommendation but I do not know if the Commission would continue to include within its recommendation that anybody contemplating surgery in this country should, if they have time, donate their own blood beforehand or get donations for obvious reasons. Masters and Johnson, in their report a week ago Monday created quite a sensation about the problem of getting an infected sample of blood from a blood supply. The blood supply is much improved in terms of its integrity of the day, but there is still a small statistical chance an individual could get the virus from a blood sample or blood supply and that small chance should be reduced by the use of autogolous donation of one's blood.

The sixth recommendation is that confidentiality should be strongly protected and sanctions be adopted by states for the breach of confidentiality. The seventh recommendation would be that the states and the Congress of the United States refrain from legislation adopting anti-discrimination for the reasons that I heretofore outlined, mainly persons with the virus who do not yet manifest symptoms of ARC or AIDS are manifesting brain impairment that, I believe should prevent them from enjoying the status of anti-discrimination laws.

The last recommendation is that states are encouraged to form risk pools. We have a very profound problem on our hands of how to handle the financial cost of caring for persons who have come down with AIDS. We have all heard the figures. It is roughly $150,000 per patient. The numbers are staggering, the loss of human life is absolutely tragic. It is mind boggling to

look ahead to the years of the 1990's and realize the loss of life that we are going to sustain, the impact on our health care system. We need to encourage risk pools in states where uninsured people have a chance of getting health insurance so they are not required to resort to Medicaid or Medical as it is known in my state of California, as a means of providing for the cost of health care for those people that are so unfortunate as to have this virus.

I have one other letter that I would like to leave with members of the Commission. I have written a letter to the President dated this month, and so far I have gained the signatures of 20 of my colleagues in the House. That a number of members of the House have signed it is significant. I am working to get a majority of the members on the Energy and Commerce Committee where I serve on the Subcommittee on Health and Environment as a part of this Committee and I am still in the process of getting signatures on this letter, but I believe it points up five deficiencies in what our public health officials have failed to at the federal level to protect the integrity of the blood supply of the country.

This is relevant because I think in your report to the President and the nation, you should cite the failure of responsibility on the part of public health officials in charge of the integrity of the blood supply. This story needs to be told to the American people. They should be told that we are making the blood supply as safe as we can, but there are still some loopholes that need to be covered. In terms of the roughly 9,000 hemophiliacs in this nation who depend on the blood supply for their life, a large number of them have the virus today. Of the roughly 21,000 in this country who are required to use the blood supply as incidental to an operation, roughly 30,000 Americans, they have the virus and they are going to die unless we find a cure.

The incidence of what happened was that we did not take the action that we should have back in March of 1985 to protect the integrity of the blood supply and it can be explained it this way. When the antigen for detecting the presence of the antibodies was discovered to medical science, it began to be used in March of 1985. The CDC adopted standards for its use and at that point we knew that male homosexuals had contributed 73 percent of the AIDS cases in the country, and intravenous drug users contributed 17 percent of the AIDS cases. In March of 1985, the CDC said to the group that contributed 17 percent of the AIDS cases, you may not donate blood to the blood supply. But to the group that contributed 73 percent of the AIDS cases, male homosexuals, they divided them subjectively into two categories. If the male homosexual considered themselves subjectively to be monogamous, there was no restriction on their donating blood to the blood supply at all, but if the male

homosexuals subjectively considered themselves to be polygamous, CDC exerted enough courage to say to the individual you should not donate.

Now get this. If you are in the group that contributes 17 percent of the AIDS cases, you are told you cannot donate. If you are in the group that contributes 73 percent of the AIDS cases on that bifurcated status, you are told you should not donate. I have pointed out this paradox to the CDC in a letter of August of 1985. In September they changed their policy and later they came up with a new rule. They said, whether you are monogamous or polygamous you should not donate. To this day, they have not asserted the courage to say whether you are polygamous or monogamous, if you are a male homosexual, you cannot donate. If it is sound public policy to accept that for the group that contributes 17 percent of the AIDS cases, ergo it should be sound public policy to have said the same thing to the group contributing 73 percent of the AIDS cases.

Now, there is a courageous doctor at Stanford University by the name of Dr. Edgar Engelman. In May of 1983, he realized that the integrity of the blood supply was at risk. He knew that we did not at that time have a test for the presence of the virus or the antigen for the virus to detect the antibodies for the virus but there was a distinct high correlation between those with hepatitis B and those who had the virus for AIDS so he had the courage in May of 1983 to direct the blood bank at Stanford University to say we are going to test for hepatitis B, which they do routinely, and if you have it, you cannot donate to the blood supply.

The male homosexual community was outraged at that because they claimed it was discrimination but that doctor had the courage to set that policy and I reference this because it is important that we understand in this whole debate on public policy that we Americans are truly witnessing what is the first politically protected disease in the history of this country. The action that I have described, the failure of proper responsible action on the part of the Public Health Service in protecting the integrity of the blood supply, is one of the failures of leadership.

The second failure of leadership of the Public Health Service deals with the failure of the Surgeon General of the United States, Dr. Koop, to exercise the power that he has had ever since this epidemic began. That is, to shut down the bath houses in this country. We know as a fact that promiscuous, anonymous sex is taking place in these bath houses today. There are 12 of them still in operation in my home area of Los Angeles County, California. Public health officials have not asserted the courage to shut them down. The Surgeon General of the United States should be ashamed of himself. The public health officials

of every state in the union where they bath houses should be ashamed of themselves that they have not had the courage to shut them down -- To Take boards out there and nail them up. Just say we are not going to tolerate this in our society because we know that fatal diseases are being transmitted there. They failed to do that.

In June of 1987, the President of the United States directed the Health and Human Services Agency under Dr. Bowen and Dr. Windom to develop a seroprevalence study for the country. It is now nine months later and it has not even been started. I do not know why they are delaying doing it, but they claim all kinds of problems. A gentleman by the name of Robertson, a private researcher in Georgia prepared a prospectus of how we could conduct such a prevalence study. He is a very competent epidemiologist and we sent it along to HHS and said if you cannot figure out how to do this, this is a way it can be done. They failed to adopt that process.

I think the Public Health Service of this country is doing a disservice to the American public in not properly representing the extent of the infection in the heterosexual community as I previously outlined in this chart. And finally I think the current policy of the Public Health Service of the United States government on the issue of reportability is a tragedy that we should not be tolerating. Namely, it is not sound public health policy in this country to be suggesting that states should have the option on the issue of reportability.

One final point on the politics of this issue. It has been said by a lady in New York recently that if 73 percent of the cases of AIDS in America were found in people with gray eyes, our public health officials would probably have quarantined them two or three years ago, and I think that is probably true. But since 73 percent of the cases nationally come from one highly organized group, male homosexuals, that group has effectively been able to tilt the whole response of the public health up until now to the civil rights side rather than the public health side. It is a tragedy and it should no longer be tolerated. It has profound political implications in this country today because in 1984 at the Democratic National Convention in San Francisco this resolution was adopted. The Democratic National Party shall during the 1984 National Convention create the Fairness Commission which shall be responsible for the review and revision of the Democratic Party rules in an effort to establish equitable rules as they relate to the full participation of the party process of persons of all sexual preference.

That resolution was implemented. The National Democratic By-laws today provide, adopted April 30, 1987,(in rule 5-C) as follows, " With respect to groups such as ethnics, youth, persons over 65 years of age, lesbians and gay men,

workers, persons with a high school education or less, the physically handicapped, persons with a low or moderate income and other groups significantly underrepresented in our party affairs, each state party shall develop and submit party outreach programs for such groups identified under plans including recruitment, education and training in order to achieve full participation by such groups in the delegate selection process in all levels of party affairs."

What we are witnessing in America today as a part of the sexual revolution is an effort to change the culture of our society so that we Americans will accept and equate homosexuality on the par with the heterosexual lifestyle. Tragically, we are seeing unfold before our eyes that one of the two great political parties in America, the Democratic Party, has placed in their By-laws what I have just read, a sexual preference plank which means affirmative action for male homosexuals. If time would permit, and my time is just about over and I thank you very much for your indulgence and the time that you have given me. If time permitted, I could give you chapter and verse of how representatives of august organizations in this country and I am talking about the California Medical Association, the American Medical Association, the American Hospital Association, the American Dental Association, the American Nurses Association, through their highest leadership in interfacing with the political process in Washington, to this day are attempting to deal with this epidemic in America as a civil rights issue, not as a public health issue.

These representatives unfortunately in my judgment are tilting to the side of attempting to give impetus to this movement that I have described earlier, as a part of the sexual revolution in our society whereby we want to give, or they want to give, civil rights protected status to those expressing a sexual preference. It is a direction that I do not believe our society should be pursuing, and I guess in summary I can make this observation.

You know, when you really look at the whole thing, a President's Commission and the august members of this panel coming from distinguished careers and backgrounds are all looking at what we can do and really, when you look at it, it is kind of funny because the existing system of how we have historically treated communicable disease has been on the books for 200 years of the existence of this republic. There is no mystery as to how you control communicable disease. You identify those with the disease, you treat them and cure them if you can, and historically, the way we have dealt with incurable communicable disease is we separate those that have the disease from those who do not.

Politically in this country, I do not think we are anywhere close to taking that step but it needs to be debated in this country because if the figures of Masters and Johnson are right, that 500,000 people in America a year are getting the virus, that is an exponential growth, and a question we all have to ask, is how long can American civilization exist if we are losing a half a million people a year to the tragedy of the death of AIDS? You can stand it for maybe a year or two but bear in mind that during World War II, we lost a little less than 300,000 to the category of "killed in action." And we are looking at the death of just literally millions of people in our society who are in the most productive years of their lives. We need these people badly for the talents and resources they bring to our society and we are going to lose them. I pray we will find the cure. I pray we will find a vaccine. There is not time to go into the probability of all that today, but in the meantime, I guess you can sum it up by saying that we should be pursuing routine steps which have been historically pursued to control communicable disease and reportability and testing and standards such that if you have the virus you do not transfer it to other people. I thank you very much for your attention.

CHAIRMAN WATKINS: Thank you, Mr. Congressman. Our normal process following statements from our panelists is to open up for questions. Now, we apologize for starting 15 minutes late. We pretty much made that up. I would just like to know if you have time, and approximately how much time, for the Commission to continue to question.

CONGRESSMAN DANNEMEYER: I will be going to California hopefully at 3:35 out of National, Mr. Chairman, so I have got whatever time you need. I would be happy to accommodate you.

CHAIRMAN WATKINS: I would like to start out the questioning, and we will shift down to my right. Do you believe that there is room at this point in the infectious disease, having been exposed only in recent years to most of us, for a recognition of some of the transitional difficulties to get to, let us say what you would like to see. In other words, if you said that is where we ought to be now, is there room for a transitional strategy to get to that end point that perhaps would take into account things like we heard yesterday from young Dwayne Mowery who is quite a famous case here in Tennessee. Dwayne is the young 12-year-old hemophiliac who has been thrown out of his school and whose family has been significantly hurt. I have seen all of the tapes and perhaps you have seen some. He is not protected in any way in this state and yet under the 504 law that you outlined earlier, most states would allow him as a handicapped individual to be protected. There was some authority that was authorized to place him in the school subject to the review by competent medical authority, if it was determined that he was not a threat to those in the school place.

That simply does not apply here, but it applies in most states in the country. We saw it in Northern Fairfax County, Virginia recently. That young five-year-old hemophiliac girl was placed back in school as a normal student.

So I guess I am just asking you the question do you believe that the handicapped people under that context should be protected by federal civil rights laws?

CONGRESSMAN DANNEMEYER: Mr. Chairman, my answer is when you look at the victims of this tragic disease, your heart goes out to them because we all can relate to them, and there but for the grace of God go I, but the fact of the matter is that the civil rights of the uninfected are entitled to just as much protection as the civil rights of the infected, and I think based on the references that I have cited in my testimony, what we are learning about AIDS is evolving every day, every week, every month, and I am suggesting, sir, and members of the Commission, that we should be very careful about establishing as a public policy that one of these tragic individuals for whom our heart goes out, the parent who testified yesterday, is going to be, as the result of a court order, placed in an environment whereby potentially other persons will acquire one of the opportunistic diseases that individual is destined to get. That is on the physical side. On the emotional side, we still have to respect him. Emotionally, are we to say to the parents of those school children, your children are going to be exposed to a possible risk of acquiring a fatal disease because the civil rights of the infected are so profound in our society that they deserve protection.

That is a question that has to be debated, and as I say, since, the way I would come down on the issue is you have got conflicting values, the civil right of the uninfected, the civil right of the infected. Considered we are dealing with a fatal virus, when you come to the ultimate question of choice, I do not think it is unreasonable to suggest we will come down on the side of protecting the healthy rather than the side of protecting the civil rights of the affected.

CHAIRMAN WATKINS: We had an interesting presentation by another young hemophiliac boy from Indiana who moved to a small town called Cicero, Indiana, a young boy named Ryan White, essentially rejected from one area and accepted with a very fine planning concept put into effect by the teachers, the parents, the local authorities, health officials and so forth, and is now successfully going through that high school. Would you then, under the protection of Indiana law, remove that? The 48 states as I understand it pretty well include protection of individuals like Dwayne Mowery and Ryan White under the 504 provisions. Would you remove that?

CONGRESSMAN DANNEMEYER: Well, Mr. Chairman, I do not support the idea of adopting a federal law to accord anti-discrimination status, nor would I support the adoption of a state law affording anti-discrimination status for a person with the virus, but I see no problem with a community, a school board, deciding that on the basis of evidence in their local area they are going to permit the student with the virus or with ARC or with AIDS to be a part of the school community. That is a decision they should be permitted to make, and I do not quarrel with that but, you know, I think it would be appropriate for any school board to do that, to say to the parents of the child that they want to put into the classroom with the other kids, bring us a certificate from your family doctor that the child being here is not likely to result in the transmission of AIDS or any of the opportunistic diseases the child may have. Get the family doctor to certify that.

Also get the county health officer to make that same certification, and when you require the county health officer to make that certification, and you require the patient's doctor to make that certification, then you begin to get an interesting result because I believe what you will get at that point, is that those doctors would not sign that certification. To be honest with you, Mr. Chairman, they are not sure. And is it fair of our society to place that uncertainty, that unsureness, of transferring that risk to the healthy in order to protect the sensitivity of the infected?

CHAIRMAN WATKINS: In this particular case, I think, Mr. Congressman, that the public health officials pleaded very strongly with the parents of the other children in school that, in fact, there was no danger to them and would certify that.

I called on Congressman Major Owens not too long ago, and he talked a little bit about his pediatric AIDS bill that I understand was recently introduced by him, which grants the states and localities the authority to set up foster care programs and group housing for children. Primarily we are talking pediatric AIDS cases. As you know, the data coming out of both the Congress and other studies indicate we will have 10,000 to 20,000 pediatric AIDS cases, the large majority of which will be infant AIDS cases with a life span of about 18 months to two years. Most of those will be boarder babies, meaning, of course, as you know, they must board in the hospital because there is no other place to go.

The costs of doing that are somewhere between $200,000 and $300,000 a year for those infants. This would improve cost effectiveness and I am just wondering how you come out on that. Do you support that pediatric AIDS bill concept?

CONGRESSMAN DANNEMEYER: Mr. Chairman and members of the Commission, there is no question that we citizens of this country are humanitarian people. As a matter of public policy, we have said that the requisite medical care of any person in need in our society will be met. I support that concept. The taxpayers of America support that concept, and we will take care of people in our society because that is our humanitarian duty to them.

CHAIRMAN WATKINS: Just one final statement. You talked about potential neurological damage and dementia. We will be holding one full day of hearings on that issue alone because it is a very, very key issue. We had counterbaling testimony to the very study you mentioned in your testimony from three totally unconnected and out of the blue pieces that happened to come out in the press that day we held the hearings. They felt that their evidence flew in the face of compelling evidence to the contrary at that stage in the HIV asymptomatic period. While they would all agree, and did agree, that the neurological damage eventually may occur, at some point in the cycle, that premature acceptance of that data essentially without the complete peer review that normally goes along with something like that and balancing off with worldwide evidence from the World Health Organization, perhaps is the kind of thing that raises ethical questions about other things coming out earlier, before competent scientific authority can really take a look and see if decisions are going to be made prematurely on the basis of emerging studies of various types. We plan to look a lot more into that because we have conflicting data coming with the kind of result that you brought up and I want you to know that we are going to spend a day on that.

CONGRESSMAN DANNEMEYER: I commend you for that, sir.

CHAIRMAN WATKINS: Dr. Lilly?

DR. LILLY: I have several questions that puzzle me. It is not entirely clear to me, Congressman Dannemeyer, exactly who vou want to test. On the one hand, you gave us today a list of individuals such as those applying for marriage licenses, those going to the hospitals and so forth. In other places, you have recommended, for example, that children of five or six years of age going to school should be tested --

CONGRESSMAN DANNEMEYER: I never said that.

DR. LILLY: I am looking at the Congressional Record from July 28, 1987. Children should be tested on school admission prior to any required vaccinations.

CONGRESSMAN DANNEMEYER: That is my testimony?

DR. LILLY: Yes. Unless there is some problem with this xerox copy.

CONGRESSMAN DANNEMEYER: Not a problem with the xerox. It is a problem with authenticity. I do not recall having made such a statement.

DR. LILLY: Well, I am just a little puzzled because further on in this same place it says essentially wide ranging antibody testing on a voluntary basis for all segments of society, old, young, heterosexual, homosexual, child, adult, should be encouraged and mandatory. I mean, it is voluntary and mandatory. How broad would you like testing to take place?

CONGRESSMAN DANNEMEYER: Well, I think, you know, from a standpoint of rational public health policy, given the magnitude of the problem, it is responsible to assert that we should be testing everybody in the country at least once a year.

DR. LILLY: And what is the penalty for avoiding that?

CONGRESSMAN DANNEMEYER: I do not think you are asking the right question. The question that we do ask, when we find out somebody who is positive for the virus, is how do we treat them? Historically how have we treated anyone with a communicable disease. We report them to the public health authorities in confidence, that forms a part of the statistical basis on which we develop a rational public health response. That is one of the reasons we have no data, because we have not reported them.

DR. LILLY: That brings up another point that I just want to have a comment on. You seem very convinced that you know what sound public health policy is. I would just like to say that we have had a great deal of public health testimony given to us, some portion of which has been in agreement with some portions of what you have suggested today. But many of them have not agreed with that at all, and have proposed measures quite different from that so my comment is that there is a range of feeling about what is sound public health policy.

CONGRESSMAN DANNEMEYER: I do not doubt that there is.

DR. LILLY: So, okay, yours is one portion of that range.

CONGRESSMAN DANNEMEYER: That is correct.

DR. LILLY: Okay. I have another problem. Let us go back to your gray eye analogy. Let us just say that there are about 20 million people with gray eyes in the population.

CONGRESSMAN DANNEMEYER: I have no idea.

DR. LILLY: I do not either. I made that up. Let us say there are about 20 million. That happens to be the number that many people have estimated for people who are homosexual in the population and that actually is why I picked that number. But, people who have gray eyes, we can readily ascertain. It is a little more difficult to ascertain who is homosexual if a person will not admit it and it is a great deal more difficult to ascertain who among the married population goes off every couple of years and has a little fling in the toilet for example. So since one to three million people are estimated to be HIV positive and two-thirds of those have gray eyes, we are stuck with 20 million gray-eyed people that we are very suspicious about. That is more than the population of Wyoming, North Dakota, and South Dakota. Are we going to turn over those states to them in order to isolate them?

CONGRESSMAN DANNEMEYER: Well, I think you understood or maybe you are attempting to misconstrue my metaphor beyond all limits that it applied, but it illustrates the point that, you know, people with gray eyes, to my knowledge, are not a highly organized, militant group in our society.

DR. LILLY: They certainly would become that very fast.

CONGRESSMAN DANNEMEYER: Let me say that, you know, we are a pluralistic society and anybody can organize in any way they want to. That is assured to us in the Constitution of the United States which gives us a right to petition the government for grievance.

DR. LILLY: Right. I get back to my point. Are we going to isolate all gray-eyed people because two-thirds of one to two million people are HIV positive?

CONGRESSMAN DANNEMEYER: Dr. Lilly, the historical way that people concerned for the survival of the civilization have dealt with an incurable, communicable disease is to isolate those who have it from those who do not, and it is not a matter on which any of us should practice a measure of levity because it is a very serious subject for all of us today.

DR. LILLY: How are we going to isolate them? How and where?

CONGRESSMAN DANNEMEYER: Historically, the matter of quarantine has been used to control those with a communicable disease.

DR. LILLY: We quarantine them to their bedrooms, to a geographical area, to a building? I really want to know what are

the restrictions that you propose? What would you think is reasonable?

CONGRESSMAN DANNEMEYER: I am not advocating that we quarantine people with the virus today. Do not misunderstand me. I am just interested that this august body, representing the appointees of the President of the United States, I as a member of Congress am concerned with what some have described as a species threatening problem in this country. We have the responsibility to address the issue of truly how we stop this virus in our society. We need to debate that because we have to express ourselves to deal with the ultimate question of survival of the species. We cannot continue as a people, sir, if we are going to lose a half a million of our citizens each year to death from this tragic disease. We cannot continue to function. We have to face that, and we have to face the reality of how we stop it.

DR. LILLY: One last point, a rather different one. With respect to your very strong belief that the foundation of our society is based on the Judeo-Christian idea which includes that idea that homosexuality is anathema.

CONGRESSMAN DANNEMEYER: That is right.

DR. LILLY: I really feel, there are, in fact, fewer and fewer people that we can discriminate against, and that is perhaps unfortunate because maybe we need that. Maybe we need to be able to --

CONGRESSMAN DANNEMEYER: Let me say it again. I have no intention today or ever of apologizing for affirming the heterosexual ethic is a foundation of our civilization.

DR. LILLY: Right, well, I would just like to point out that there is a considerable disagreement in the literature on that subject as to what extent homosexuality as anathema is intrinsic either to Judeo-Christian ideals and furthermore, to the other bases of our society which are the Rico-Roman and a number of other inputs into our society in which homosexuality was definitely not anathema.

CONGRESSMAN DANNEMEYER: Well, Dr. Lilly, I think you probably are aware of these statistics as well as I am. Historically, the bulk of the enteric disease, the bulk of the venereal disease, is found in the male homosexual community in America. It is a very tragic, unhealthy lifestyle, and so long as we are talking about it, I think the American people should be told this because if we are going to change the culture of our society so that we would accept and equate homosexuality on the par with heterosexual lifestyle, we need to know what homosexuals do in the pursuit of their sexual preference, we need to describe

to the American people precisely how they participate in their sexual lifestyle so that we will make an informed judgment as to whether we are going to accept that as a part of our culture and condone it as a value system we will accept for ourselves and transfer to our kids.

DR. LILLY: Do you think that the lifestyle that you are referring to is intrinsic to homosexuality or is it perhaps something that has been imposed because of the lack of acceptance of homosexual behavior in society? Furthermore, do you find that the homosexual lifestyle, there you are talking largely about promiscuity, is that unique to homosexuals?

CONGRESSMAN DANNEMEYER: I do not think promiscuity is unique to homosexuals, but it is a matter of empirical evidence that the promiscuity in the male homosexual is of a magnitude that boggles the mind.

DR. LILLY: You are talking about some male homosexuals, right.

CONGRESSMAN DANNEMEYER: To think that one human would have 1,000 sexual contacts in a year, I mean, people cannot believe that.

DR. LILLY: Many people get cold chills from it. I pass.

CHAIRMAN WATKINS: Dr. Crenshaw?

DR. CRENSHAW: You are strongly opposed to anti-discrimination legislation protection for persons infected with the AIDS virus. How can you remain so firmly opposed when the passage of this kind of legislation will certainly encourage a lot of the people to come forward and get tested voluntarily so that we would, in effect, be making headway towards more individual responsibility and self-acknowledged search to identify antibody status?

CONGRESSMAN DANNEMEYER: I will not accept the premise, Dr. Crenshaw, that the existing reportability requirements or the lack of anti-discrimination laws is going to deter people from coming forward to be tested. The reason I say that is because when the individual is infected, sooner or later they are going to manifest illness in some form. It is just a question to determine, and at that point it is not curable but it is treatable. They are going to seek recourse from the only place they can go and that is the health care system, and when they

come into contact with the health care system for treatment, that person should be treated no better, no worse, than any other person with a communicable disease. We should treat them in confidence and report the existence of the communicable disease to the public health authorities.

DR. CRENSHAW: There are two issues that I think very murkily mix. One is the issue of HIV infection and the best way to stop the spread through our society which from my perspective is so democratic a disease that we are far beyond thinking in terms of risk groups. And the other is the issue of the lifestyle advocacy of it or the tolerance of it, and I wonder if even though it is clear that you will not ever advocate or be expected by most people to advocate gay lifestyle, if tolerance for those who are behaving responsibly that do happen to be gay is not possible from your point of view? Could you not be a little more flexible in that regard so that without advocating it or encouraging it or changing your moral stand, that we could accept the reality that gay lifestyles exist and do our best to pull together along the same direction?

CONGRESSMAN DANNEMEYER: I appreciate that observation. Let me make this response, Dr. Crenshaw. Let me say that what two men or two women or a man and woman do in the privacy of their domicile is none of my business and it is none of the government's business and I respect that. When they come out of the privacy of their domicile into the public square of debate, and they seek by virtue of affirmative action to change the law of our society so that all of us are going to accept and equate homosexuality with a par of heterosexual lifestyles, they have got my attention and they should have the attention of any individual in this country who believes that those values and the heterosexual ethic specifically. We have 67 members of the House of Representatives today who are co-authors of legislation to amend the 1964 Civil Rights Act to make sexual preference an enforceable federal civil right. They have the right to do that. I have the right, on the other hand, to say that is not the course that our society should go. I will not support that.

DR. CRENSHAW: But you will not fight what two people decide to do in private, regardless of the sexual ramifications.

CONGRESSMAN DANNEMEYER: That is none of my business.

DR. CRENSHAW: The second issue that I wonder is regardless of others, this is the mechanics by which this is done, could you not support a concept that anyone who is infected with the AIDS virus, whether ill or not ill should be treated with care, compassion and dignity in our society regardless of the source of infection?

CONGRESSMAN DANNEMEYER: No question about that at all. I support that entirely.

DR. CRENSHAW: The last thing then that I would like to say is I do not think there is much argument against any of us that we do not want to see houses burn down or hostile behavior toward people who are infected, and I guess it would be terribly helpful if some of the catch-22's of this epidemic were resolved. From my experience, it is very difficult for gay men to form exclusive relationships when there is so much prejudice against that lifestyle, if it is exclusive and so this has been one of the reasons why so many multiple sexual encounters and anonymous encounters come up. I think that even with the Lambda Group that testified before us, they were not asking anyone to become advocates of the gay lifestyle but just give some acceptance and tolerance so that some of the behaviors that even they do not like among their own community could be changed, and I appreciate hearing your ability to support some of those things.

CONGRESSMAN DANNEMEYER: Well, you know, I hear you, and I respect what you are saying but you know, life is full of choices and heterosexual ethic or the homosexual ethic are in conflict and we are either going to tolerate it in the sense of changing the loss to give it equal status or we are not, and I think I would express my position as to where I have. What two men or two women or a man and a woman do in their domicile is just none of my business, and I mean that sincerely, but our society has evolved far beyond that.

We have got the California Medical Association today for which Dr. Mervin Silverman, former health officer of San Francisco, is the chief spokesperson for the AIDS issue in California. Dr. Silverman is a fine, intelligent man, and he is coming at it from the civil rights statutes. I mention this because institutions of America have been influenced with a posture in this AIDS epidemic from a civil rights side rather than a public health side. That is a tragedy to all of us.

DR. CRENSHAW: On the medical issues, it seems to me that if, regardless of why we achieve it, we can stop ill treatment and maltreatment of people who are infected, whether it is obviously disease or through the knowledge that health care workers treating them have testing. We would be very, very far along toward incorporating many of the public health measures that have been in abeyance for a long time, and I think we are all struggling with how to achieve them.

CONGRESSMAN DANNEMEYER: I am not sure that is a question.

DR. CRENSHAW: No, it is a statement.

CONGRESSMAN DANNEMEYER: Okay, thank you very much.

CHAIRMAN WATKINS: Dr. SerVaas?

DR. SERVAAS: You mentioned the blood supply. I was wondering if you could give us an update on that blood bank in San Francisco and how things are changing in California?

CONGRESSMAN DANNEMEYER: Dr. SerVaas, I do not remember the, it seems to me that recently data came out during an interval of time from about 1983 to 1985, you have a 1 in a 100 chance of getting the virus from blood donations from the Irwin Memorial Blood Bank in San Francisco. I hope, Mr. Chairman, I will have a chance to correct the record. That could not be a correct, but it was a surprisingly large possibility of getting a bad sample of blood, and they supposedly are making corrections to improve that, but it is, as I said before in my testimony, we need a standard which says if you have the virus or knowledge of that fact, you committed a crime to donate to the blood supply. We have not said that yet.

DR. SERVAAS: You mentioned in 1985 I believe, in the case of hemophiliacs, we knew in 1982 that we had hemophiliac children and it took a long while to say, even suggest, that we did not take blood from the high risk groups. Right now, we are probably in HTLV-I where we were then in 1982 when we first had our hemophiliac children from blood factor eight. They were given the blood clotting factor. Do you think, in the case of HTLV-I, which is a lentivirus, a slow growing virus that is going to give leukemia and lymphoma maybe decades later (it is in blacks; it is in Hawaiians; it is in Orientals) do you believe that it is also sexually transmitted exactly as the HIV is transmitted? Do you predict that this time it will be different in the length of time it takes to get routine health procedures, public health procedures with that virus? We have a test for it now and it is being held up at the FDA, but do you predict that because it is not what you call a politically organized group, hardest hit by it, that we will be able to get on with that one?

CONGRESSMAN DANNEMEYER: I am not sure I have the gist of your question but I think I have a sense of it that I may respond this way that medical science today knows of the existence of HIV as its current name. We have a test to test for the presence of the antibodies for that virus. There is supposed to be a test pending approval that will test for the virus which is certainly a better one than testing for the antibodies for the virus but we also know that medical science has developed HIV-II and III, and we know that we have detected a small, one or two people in America that have HIV-II and III. We do not have a test for that today, and we are just hoping that it is not coming into the blood supply because we cannot test for that today and we should, again I will come back to the standard, we should be

saying that if you have the virus, whether it is HIV, HIV-II or HIV-III, you cannot donate to the blood supply. That would, I think, be a constructive step to take. It sets the standard for what is expected of us in our society.

DR. SERVAAS: Thank you.

CONGRESSMAN DANNEMEYER: Thank you, Dr. SerVaas.

CHAIRMAN WATKINS: Dr. Primm?

DR. PRIMM: Congressman Dannemeyer, I was very impressed with the very elaborate preparation that unquestionably you and your staff have done in relationship to forming knowledge about the virus and its manifestations, etc. I am very impressed by that. Most Congressmen and politicians in the lower level, the state and local level, do not do that, and I would hope that your efforts would indicate to others and be contagious to others as this virus is so that other legislators like yourself would prepare themselves as you have on this virus. I mean, I do not necessarily want them all to have your opinions, but on the other hand I think certainly you were prepared.

CONGRESSMAN DANNEMEYER: Thank you.

DR. PRIMM: I would like to talk to you about two specific areas of great concern of mine, and that is you showed some placards earlier and included in your written testimony that you submitted to the Commission, results of the Baltimore-Johns Hopkins sexually transmitted disease clinic studies that you referred to. Then you also talked about the Department of Defense studies, both among recruits and indeed among active duty personnel. I am particularly concerned with that data primarily because if we present the data as you have presented it, it looks rather small in terms of the numbers of people in the armed services or in the Army on active duty that would be positive for the antibody to the virus, the incidence of seroprevalence.

However, if we look at that data and we look at it among blacks and Hispanics, it is terribly alarming and I am quite concerned that when you show this data you do not point up to the American public with the same vehemence that you do with the data and the other stuff that you talked about, that there is a disproportionate amount of this infectivity among young blacks and young Hispanics. We had better target those communities with a blitzkrieg of education efforts and everything else because, coming from someone who is supposedly and admittedly on the right as you have indicated you are today, it might be very, very effective in Congress and in our nation to bring about a change in relationship to the efforts that we now see that are not effective at all or not even being done for that matter. That is the first question.

The next thing is, I am wondering, if you support the federal anti-discrimination law for racial minorities? In hearing you talk, I just wondered how you would comment on both of those particular issues.

CONGRESSMAN DANNEMEYER: I would affirm, Dr. Primm, that it is sound public health policy and I support the concept in our law that says that no person may discriminate against a person in employment or housing or in business opportunities based on race, creed, color or religion. I accept that and affirm that. Those are sound values in our society.

With respect to your observations about the data on minorities with AIDS, let me observe and perhaps you will have to excuse my provincialism, I am a Californian. What you have described statistically is correct nationally. It is not true in California. In California, actually, minorities are under represented in terms of persons with the virus, in terms of the virus in New York State, minorities are over represented. Whenever I speak to this issue, it would be appropriate to make that statement clear because minorities, Hispanics and blacks in the eastern parts of the country are over represented in this virus.

DR. PRIMM: I think you are an outspoken member of Congress in this particular issue and when you speak, Congressman Dannemeyer, you do not speak just for California. I think you speak for a segment of American society that you know. Your followers respect the fact that they are not your direct constituents from your Congressional district, and I think that that is a quite a perch from which you speak and quite a power base. As a consequence, you could change a whole lot of minds about a whole lot of things. I do not want to at all get into a discussion with you about the numbers and the representation of minorities in California who have this problem. I do not think California has looked at the intravenous drug using population quite as thoroughly as they could have. In Los Angeles or San Francisco or Oakland or the other major cities so that seroprevalence studies done in California on that population are just not accurate. I think the estimates are way off. But I ask you another question. I ask you about your support for anti-discrimination laws for racial minorities in this country because I think that is really important too. I do not think you answered me.

CONGRESSMAN DANNEMEYER: I thought I answered, Dr. Primm, that I affirm the desirability and the importance of anti-discrimination laws in our country that now exist in the fields for employment, for housing, for business, for educational opportunities which say very clearly we will not permit discrimination in our country based on race, creed, color, or

religion. I accept that and I affirm that because that value speaks to, I think, improve society goals.

DR. PRIMM: Thank you, Mr. Dannemeyer.

CHAIRMAN WATKINS: Mr. Congressman, we do have additional questions. We would like the opportunity to submit those to you for record purposes. I know we are constrained on time and so I must close out this portion of the hearing. We appreciate your willingness to stay on longer and answer some of these questions. I hope we will be able to keep up the dialogue between now and the end of our Commission. Thank you very much.

CONGRESSMAN DANNEMEYER: Thank you, Mr.Chairman and members of the Commission.

CHAIRMAN WATKINS: We will now have Panel 3, which is on ethical issues in research. Dr. Charles McCarthy, Office of Prctection for Research Risks, National Institutes of Health; Dr. Earl Shelp, Center for Ethics, Baylor College of Medicine; Gene, a person with AIDS, on personal issues in research protocol and Dr. Alexandra Levine, Professor of Medicine, Executive Associate Dean, University of Southern California School of Medicine.

Thank you very much for your patience in waiting for this panel and I would like to start out with a statement by Dr. Levine, who has to present first and then we will go to Dr. Shelp.

DR. LEVINE: Thank you very much. I very much appreciate this opportunity to speak regarding issues of such real importance to our society. I will be discussing the theme, Ethics in AIDS Research, in a very broad sense to include what I perceive to be the large issues, as well as a few more limited ones.

The major ethical issue, as I see it, is the fact that we are dealing with an illness, which has affected and disturbed every aspect of our society in the short period of only seven years. Over 55,000 cases of full-blown AIDS have been reported. It is estimated that approximately 300,000 additional individuals have ARC, while another 1.5 million are infected but currently asymptomatic.

Essentially all studies have confirmed that HIV infection is a progressive process over years and that the majority of HIV-infected individuals will eventually develop ARC and AIDS, given enough time. In other words, if not one additional individual was to be infected beginning today we would be faced conservatively with approximately one million new cases of AIDS in the years ahead.

And, yet, the federal budget for AIDS research through the Public Health Service was only $327 million in 1987, which represented only 0.03 percent of the total federal budget. This is unethical in my view. I will put it in another context. As of 3-16-88, a total of 3,250 individuals had been registered onto all national AIDS Treatment and Evaluation Unit, the ATEU, and Clinical Study Group clinical protocols.

These units represent the largest group of institutions funded by the National Institute of Allergy and Infectious Disease to conduct clinical trials of new drugs and therapies in patients with HIV infection. With approximately

two million citizens currently infected, this would mean that only 0.15 percent of all infected patients have had access to federally-funded clinical research trials. Unethical, it seems to me, in a country such as ours.

In my opinion, the problem in AIDS is not whether or not we can find the needed answers. I believe that we can, although the challenges have been great. I base my optimism on the tremendous amount of progress which has been made in a very short time. Extraordinarily sophisticated research has been accomplished and has taught us that HIV retrovirus is the cause of AIDS.

We have identified how the virus is transmitted and how it is not transmitted. We have identified and localized every single gene composing the genetic material of the virus. We have tested numerous new drugs, one of which has proven efficacious and licensed for clinical use, Zidovudine.

No, the rate limiting step here is not the capability of our united scientific efforts. The rate limiting step is money. Because research is of no value unless it is good research and the fact remains that good research costs money. And in thinking of the real issues here in this area, the biggest issue, simply because it is the easiest, it is attainable, it is possible, the biggest ethical issue is money for research.

I would like to mention some other more specific concerns. One, the ethical concern of a placebo-controlled trial, when the patient who theoretically may receive that placebo already qualifies to receive a drug, Zidovudine, for example, which has been approved and licensed for us in his particular condition. This is not a simple matter and it is important to me that I make myself clear. I have no problem with placebo controlled trials and I feel that they are mandatory in many instances. However, it is difficult in certain circumstances to be asked to withhold specific therapy in a given patient, who may actually qualify to receive an already licensed drug.

Two. The issue of informed consent is another ethical dilemma. It is extremely difficult, if not impossible, to truly inform the patient and to educate in such a way that he or she really does understand the nuances of the issues at hand. We as clinical researchers must deal with the ethics behind this issue on a daily basis. How do I inform the patient, for example, regarding his participation in a placebo-controlled trial, when I know that he qualifies for Zidovudine?

Three. There is another ethical issue which we face. Who is to be treated on these experimental protocols, since we

have already defined that only a small fraction of infected individuals will have access. I have found that the successful study applicant must be assertive to be included in our protocol studies. Patients from the inner cities, from the ghettos, patients from minority groups and backgrounds are likely to be excluded from this system, excluded by virtue of the fact that they may be far, geographically, from the university setting, less well-educated, less assertive.

Who gains access to the precious few study positions available? Several years ago, I had a call from an individual in the community, who offered a million dollars if I would put his friend onto a certain protocol. It becomes an ethical concern when access to experimental protocols is limited and when some patients will be included, while others will not. Again, it comes down to more access, more good research, performed as quickly as possible, with the necessary funding to allow rapid success.

I would suggest the funding of consortiums of private practitioners in the community, who would apply for peer-reviewed grant support to conduct Phase II and III clinical trials on the large numbers of patients for whom they are currently providing care. This would allow us to utilize this vast amount of patient material, which is now being wasted in the scientific sense.

I would further suggest the specific appropriation of grant funds for clinical research, which would be conducted in centers which serve the underprivileged and minority communities, which have been affected disproportionately by this epidemic.

Four. I am concerned about the ethics of a society which was faced with an extremely serious threat, HIV, and yet did not and does not put major emphasis on prevention education and prevention research. Let me give you one example. We recently completed a small research project at USC in the high schools around our area in which we were able to prove that we were most effective in teaching the facts about AIDS.

When we tested the students six weeks later, they had remembered these facts well. But when we asked if these students had changed their high risk behaviors as a consequence of these facts, the answer was no. We certainly must educate, but apparently we must do more. The sponsoring of behavioral research in the social sciences, as well as the basic sciences, is crucial to the overall AIDS effort. To neglect this area would be terribly foolish, unacceptably short-sighted and most unethical, in the broad sense of that term.

What specific recommendations might the Commission take back to the President?

Number one. The virus is here to stay and any short-sighted view of its impact is not based upon reality.

Number two. The entire range of scientific endeavor into basic research, clinical, behavioral and social areas must be supported to the fullest extent possible by this great nation.

Number three. Clinical research could be amplified by the development of consortiums of private practitioners to allow greater access to patients and more rapid attainment of information.

Four. Major emphasis must be placed on funding clinical and behavioral research in centers which serve the disadvantaged members of our society; the poor, the minority.

In conclusion, the AIDS epidemic is a crisis of national and international proportions, which deserves the mobilization of all resources which our nation can provide. Under the leadership of your Commission, I would hope that this message could be delivered emphatically to the President and to the people. Thank you very much, once again.

CHAIRMAN WATKINS: Thank you, Dr. Levine. If you have to go before we have a chance to ask questions, I would like you to have a copy of our interim report. I think you have touched on at least three areas that we have addressed very thoroughly in there and I think you will be satisfied that we have been sensitive to many of the issues that you have already raised during earlier hearings on research, drug development and the like.

DR. LEVINE: Thank you.

CHAIRMAN WATKINS: Dr. Shelp.

DR. SHELP: I am honored by your invitation to speak on the ethics of AIDS research. My comments will reflect two levels of involvement with AIDS during the past three years. One level has been as an ethics consultant at an AIDS Treatment and Evaluation Unit.

The second level is as a clergyman involved daily with hundreds of patients, their loved ones and people at high risk for HIV infection. Based on these experiences, I shall identify several issues, addressing them briefly orally, but more extensively in written testimony.

The first issue is the moral basis for research involving humans. The moral basis for AIDS research is a primary commitment to the interests of all people infected with HIV. This commitment ought to motivate research and justify the use of human subjects. There must be a reasonable balance between the demands of science, on the one hand, and the speedy availability of therapies with probable benefits, on the other hand. These are, in my opinion, complementary objectives, not competing or mutually exclusive objectives, unless people in positions to make them such, wrongfully decide to do so.

The second issue concerns how these objectives can be frustrated. In short, it is the question of whether current policies and procedures encourage or discourage the development and testing of possible therapies. Policies and procedures ought to stimulate the study of many promising therapies simultaneously.

It appears to me that too many bets are being placed on the promise of the highly toxic drug AZT, while other drugs are effectively on hold or being tested on a limited scale. This situation appears highly questionable morally, especially when a drug like ribavirin was shown in clinical trails in patients with lymphadenopathy syndrome to delay progression to AIDS.

From a moral point of view, serious questions must be asked about why additional studies of ribavirin are not underway. A delay of over one year illustrates my concern about research prejudice and scientific and regulatory myopia. Why would it be bad policy or immoral to give people an opportunity to choose between the risk of progression associated with no early intervention and the risk that a safe drug will not produce the desired benefit for everyone? One person ought not be treated unjustly to benefit many people. Similarly, many people ought not be treated unjustly because every person may not benefit equally.

Similarly, the practice of conducting placebo control trials warrants review. This is the third issue I wish to address. In a situation of almost certain progress to illness and death and the availability of at least AZT, no person should be denied access to treatment of one form or another in clinical studies.

It is more morally legitimate, once safety is established, to compare treatments directly, rather than to delay possible beneficial drugs by conducting placebo controlled trials prior to conducting comparative studies to determine which drug achieves a better result.

My fourth concern is the autonomy of people infected with HIV. Self-determination is a highly valued principle in ethics and law. Self-determination involves the freedom to take control of one's life by receiving therapies likely to delay progression to disease. To wait until people have AIDS or ARC to start treatment for HIV infection, given the current state of therapeutics, condemns to death and constitutes a great moral evil. People can be harmed by receiving dangerous substances. Similarly, they can be harmed by denying them access to reasonably safe substances that might improve or prolong their lives. Both forms of harm are morally wrong. Autonomy ought not be restricted unnecessarily and the burden of justification rests on those people who wish to limit or deny the self-determination of others.

My fifth concern is access. Being situated to make choices regarding participation in research not only provides people with control over their lives, it engenders hope for an improved and prolonged life. Limited or no access to experimental drugs undermines autonomy and hope and renders people almost defenseless against the likely devastating effects of HIV upon them.

In order not to be so disadvantaged, many people are going to Mexico and elsewhere to obtain drugs that might benefit them. Others are purchasing drugs in a domestic black market. Sill others are mixing compounds in kitchens. This is not only an unfortunate situation, it is an unjust one. The high cost of drugs in Mexico and the cost of travel denies poor people an opportunity that wealthier people have. Income and distance from apparent hope can deepen despair and compound injustice, possibly resulting in people taking even greater risks to receive some form of treatment.

Greater availability of more numerous safe and possibly effective compounds would reduce the risks associated with these practices. Further, better monitoring of patients would be likely, thus decreasing the risk even more. Finally, valuable data could be gathered to determine the relative efficacy of the drugs in question. Safety already should be established for drugs available in this manner and for this purpose. Finally, injustice would be lessened because access would be increased significantly.

Lastly, I address the issue of regulatory review of completed clinical trials. HIV infection and associated illnesses comprise a varied and complex clinical entity. Reviewers knowledgeable clinically about AIDS and its effects on people's lives might be better qualified than routine reviewers to balance regulatory concerns with a humanitarian concern for the prospects of improved and prolonged life.

The interest of infected people, not excessively rigorous interpretations of rules, in relation to their prognosis should be of primary concern. Once safety is established, then every reasonable opportunity and hope should be offered. A denial of opportunity can be as injurious and as wrong as a direct assault on someone.

In my written testimony I discuss FDA rules regarding Treatment INDs. The intention of a Treatment IND is to make drugs available that are reasonably safe and may be effective to people for whom immediate treatment is necessary to prevent premature death. Yet, it appears that this objective is not being realized. To offer hope to desperate people, as the Treatment IND does, and then to snatch it away is cruel. Every instance of such a practice should be condemned and corrective actions should be taken.

In conclusion, I have tried to place the ethics of AIDS research in a broad moral perspective. I am convinced that the interests of people with HIV infection are unjustly being overlooked or manipulated by the numerous individuals and institutions who wish to advance their interests in the present crisis.

Without doubt, mistakes have been made by all parties with the costs being borne primarily by people infected with HIV who end up being pawns in the grand contest of competing interests. I am not sure who the villains or heroes are or will be as controversies surrounding AIDS research arise and are settled.

I am quite certain, however, who the victims are; people infected by HIV who presently have little hope. It is my hope and plea that the recommendations of this Presidential Commission will remind researchers and regulators that the nobility of their activity rests on a primary commitment to the welfare of people. When any other objective or interest takes priority, the moral integrity of the enterprise is damaged and the ethics of research involving humans is compromised. Thank you very much.

CHAIRMAN WATKINS: Thank you, Dr. Shelp. Dr. McCarthy.

DR. McCARTHY: Thank you, Mr. Chairman, Members of the Commission. I am pleased to have this opportunity to report to you about a number of activities that are currently being undertaken to address ethical issues related to AIDS and infection with the HIV virus.

I should like to sketch for you, in broad terms, the steps the Public Health Service has taken to address ethical

issues, provide a few examples of the practical problems that face us, and describe procedures we have developed to address those problems.

The generic ethical question was stated succinctly in a recent article by Dr. LeRoy Walters in Science magazine of February 5th of this year (Vol. 239, p.597). Dr. Walters said, "The epidemic of infection with the human immunodeficiency virus, HIV, and the acquired immunodeficiency syndrome, AIDS, poses a major ethical question: How can we control the epidemic and the harm that it causes without unjustly discriminating against particular social groups and without unnecessarily infringing on the freedom of the individuals?"

I think virtually very speaker you have heard today has in one way or another addressed essentially that same balancing kind of problem.

Our efforts have been directed primarily in three categories: First, public health policies; secondly, policies for health care delivery and, third, research policies.

In the brief time allotted to me, I will address only the third category. That is what your letter of invitation asked me to do; namely: to address ethical aspects of research policy. I will be pleased to comment on either of the first two areas in the question period if you should so desire.

I have chosen to address ethical aspects of research policies because this is the area where our ethics policies have been developing for more than 20 years, and consequently, where we have in place a well developed system for protecting the rights and welfare of human subjects, which must be adapted and made applicable to the AIDS epidemic.

Our system for protecting the rights and welfare of research subjects is both simple and comprehensive. It is simple because it requires that each institution that carries out research activities involving human subjects, funded or supported by the Department of Health and Human Services, shall provide written assurance to the Secretary -- that is a responsibility delegated to my office -- that it shall comply with the requirements set forth in the Department's Regulations for the Protection of Human Subjects (45 CFR 46).

It is comprehensive because HHS regulations are applied to every research project conducted or supported by the Department. Moreover, institutions that conduct AIDS or HIV research have extended coverage to all such research involving human subjects, regardless of the source of funding.

The main features of our regulations include, first, a requirement that each awardee shall establish and maintain an Institutional Review Board (IRB), a group within the institution, which conducts prospective review for each research project involving human subjects.

Secondly, these Institutional Review Boards must certify to the Department that: each project meets all requirements of the regulations, including informed consent; and that levels of risk which will be reasonable in the light of expected benefits to subjects and the knowledge to be gained. In the case of AIDS research, frequently, the principal risks addressed by Institutional Review Boards are associated with possible breaches of confidentiality and, consequently, special instructions have been developed in that area.

IRBs are required to conduct continuing review of each approved research project involving human subjects at intervals no less than once each year and, finally, institutional officials are required to notify OPRR of any serious or continuing noncompliance or unexpected problems.

In 1984, under the direction of the Assistant Secretary for Health, OPRR sent guidance to all IRBs concerning AIDS research. I will submit for the record a copy of that guidance. At the present time we are updating that document with particular emphasis on notification to subjects of the results of HIV tests.

I should like to note parenthetically that we heard a lot of discussion today about testing--which groups should be tested and so forth. I think the HIV tests are valuable as epidemiological instruments, but they are also valuable as a preventive measure, if the test is accompanied by appropriate counseling. We have not heard today from any of the witnesses the importance of developing and funding counseling to accompany testing so that those who are found to be HIV positive can obtain on both an individual and continuing basis the necessary counseling to make certain that they do not continue high risk behavior and that they are not instruments in the spread of the disease.

Your letter of invitation has asked me to include any recommendations we may have for this Commission. We feel that our policies are well-suited to address the special ethical problems that have been surfaced by AIDS. However, there is much written about AIDS, both correct and incorrect, and it is difficult for us to communicate accurate information to the general public, to the Congress, to the state health officials and special groups associated with AIDS.

Because of the prominence of this particular body, your final report will, of course, attract nationwide attention. Therefore, we would encourage you to include a summary of sound ethical principles and practices that have been developed because it will make our task of public education that much easier. We are trying to use every avenue of public information at our disposal, but I can think of none better than for this Commission to include these principles in your final document.

We will be pleased to provide a draft of such information for the Commission. Mr. Chairman, in the interest of time, I will conclude my remarks at this point but I will be pleased to answer any questions the Commission may have.

CHAIRMAN WATKINS: Just quickly, Dr. McCarthy, we would like very much to receive that in the Commission, if you would forward that to us.

DR. McCARTHY: Yes, we would be pleased to do that.

CHAIRMAN WATKINS: Gene.

GENE: I am Gene Bixler from Denver, Colorado. I am a retired reserve officer of the U.S. Air Force. As a person living with AIDS, I have been asked to recount my experience and thoughts about participating in an AIDS drug research protocol.

This is primarily my personal story. I am not an ethics expert but some of the issues I have had to face do bear on the problem.

I was formally notified that I had Kaposi's Sarcoma in the spring of 1986, when a spot on my right thigh was biopsied and read by a pathologist. This, of course, meant that I had AIDS. I was not really surprised at the diagnosis since I knew I was a member of a high risk group; namely a gay man. I had observed similar spots on my right calf and the roof of my mouth from as early as 1983. These spots, too, were later diagnosed as Kaposi's Sarcoma by physicians at the National Institutes of Health.

In the summer of 1986, I knew that there was no medicine for AIDS available from the medical community that had FDA approval as safe and effective. It seemed to me that given my fervent desire to beat the odds and survive, I would have to pursue holistic alternative therapies and seed admission to a drug research protocol. Fortunately, I was able to find a physician in Boulder, Colorado, who was willing to work with me on both counts; Dr. Charles Steinberg.

He had learned from another of his patients about the protocol at NIH that it appeared that I would meet the criteria,

which was a study of Kaposi's Sarcoma on AZT. You had to be a person with a relatively intact immune system and could not have had additional opportunistic infections. After considering the study, which was a placebo-controlled study, I decided I would go ahead and seek admission to it. Really, I had very little choice because my health insurance at the time was questionable and there was no other medicine available. So, I figured if I could try this AZT trial, even if I did get the placebo, after 12 weeks, they would give me the actual AZT.

As it turned out, I did not receive the placebo and I spent three months in the hospital receiving intravenous AZT. Although I now believe I had a slow-progressing form of the disease in the summer of '86, I really felt, like I said, I should get into treatment as soon as possible and that the delay of 12 weeks, should I get the placebo, was really the only choice.

Regarding the issue of confidentiality, I had some real concerns at first, given that I had never discussed my sexual orientation with my family, nor were they aware of my medical condition. I decided I must tell my immediate family, my parents and siblings about my situation. Fortunately, they have all been quite supportive and loving. I find, however, that confidentiality is still an issue when it comes to business associates and the public at large, especially those persons and institutions, who may have an ax to grind. I have successfully avoided contact with these discriminatory elements myself and have not suffered.

I feel that participation in the research study, given the necessary contacts with government bureaucrats and contractors, along with the other patients, does lend a certain amount of risk to confidentiality. In the final analysis, given my intention to be a long term survivor of this disease and my belief that openness and honesty do contribute positively to one's health, I have decided that prudent discussion of my case is the best thing for me.

I was never highly concerned about participating in a research study involving a placebo control since I had the feeling that I had some time to wait for the drug, if necessary. Also, I do understand the scientific need to conduct trials in this way. However, for AIDS patients, who are very ill and do not have time to wait, should they be given a placebo, I feel that promising drugs should be made available to them on a compassionate basis, especially when enough of the drug can be made available.

At the present time I continue to participate in clinical trials at the National Institute for Allergy and Infectious Diseases in Bethesda and have recently completed a

study using alpha interferon along with AZT. The results look promising but point up the need for intervention as early as possible in the disease. I would say that the treatment at this point I would characterize as a whole really has not seemed to a permanent cure, although the Kaposi's has been biopsied as negative after eight months on the interferon.

I travel from my home to the NIH Clinical Center in Bethesda, Maryland every two weeks for follow-up analysis and blood testing. Recently, I went through a difficult period with anemia and side effects caused by the drugs and wondered if I should stay with the protocols and medication. I have read and heard of other long term survivors, those having lived more than three years beyond their diagnosis, most of whom are not using AZT or experimental drugs.

Would I have done as well without the drugs and thus have avoided possible unknown long term side effects of the drugs? I will probably never know for sure, but for now I feel confident that I have chosen the right path. Because of constant monitoring of my health by NIH, I am sure that any complications or deterioration of my immune system will be identified early on, allowing for timely intervention. I would urge all persons positive for HIV to obtain timely monitoring of their immune systems and be assured that something can be done if treatment is started early enough. I am speaking primarily of the aerosol Pentamidine as a prophylaxis for PCP, the AIDS pneumonia that kills so many now.

I would like to say a few words about how I am surviving financially and living day to day. I am receiving disability from Social Security. Although I sometimes feel like I could work, the necessity of weekly medical appointments of one to three days and side effects of the drugs often leaves me without enough energy.

I have completed 21 years of combined active and reserve military service, which qualifies me for retirement as an Air Force Lieutenant Colonel when I reach 60 years of age. I was, however, on federal active duty with the Wyoming Air National Guard from 1980 to 1984, during which time the Kaposi's began to appear. I did not report these spots to the military medical authorities because I was an officer on flying status, whose job depended on maintaining continued flying status and any serious medical condition would likely cause revocation of that status and loss of my job.

I was not give a physical examination when I left active duty, contrary to the normal case. I have applied to the Veterans Administration for medical benefits or a pension and have been turned down because "the AIDS/Kaposi's Sarcoma was not incurred or aggravated by service." This, as I have stated,

contrary to the facts and I plan to appeal, but I fear the evidence I have may be insufficient.

Finally, I would like to say to Admiral Watkins that the sensitive treatment of gay men and women in the recent recommendations of this committee speaks well of a military leader and it would be my hope that all military persons of good will would look at your example in deciding the future of gay men and women in the Armed Forces of the United States.

One point that I have come up with, listening to the other panelists today, is that there really is a need for assistance in transportation and expenses for those of us living in smaller communities, where the AIDS treatment evaluations and other research is not taking place. If I were forced to pay my own expenses to travel to and from Washington, I would be unable to do it.

As I understand it now, the ATEUs are not providing this sort of travel expense for people around the country. The NIH constitutes the only research facility that will provide this.

Finally, I am rather hot under the collar after listening to Congressman Dannemeyer and I feel that I have to say that he is one of the persons that has an ax to grind. I feel that his only purpose and his big interest in this subject is further discrimination against gay people. Thank you.

CHAIRMAN WATKINS: Thank you. I would like to open the questions then with Dr. Walsh.

DR. WALSH: Thank all of you. I don't think that you will find any disagreement on the panel. You may find varying ways of trying to help you find a solution, but I doubt that you will find any disagreement on the fact that we all feel it is essential that patients receive treatment as soon as possible and that also that things be made available to get those who are seropositive under treatment as a form of prevention.

We recognize that with existing medication, seropositivity will never disappear probably, but if we can prevent the onset of clinical AIDS or ARC, we will have all achieved a success.

I would like to ask you a question, Gene. You brought up the problems of Congressman Dannemeyer and we all know certainly how he feels and thinks. He is pretty outspoken about it. Dr. Levine brought up prevention. What is your feeling as someone who is a patient with AIDS about -- obviously, on confidentiality, you yourself chose to disclose this to your

family and those close to you, which I think was a commendable and wise decision. You found they welcomed you for it.

Do you share the concern, as expressed by some of the witnesses, that in the area of prevention, that if people with AIDS or people with seropositivity, that know they are seropositive, do you think they should disclose this seropositivity or do you think actually that some form of penalty should or should not be considered if they do not change their behavior? Because I have been impressed with the educational programs that the gay community has undertaken in this country. We all have been and I find sort of a dilemma when it gets to where if one of the members of the gay community refuses to participate or chooses to continue bad behavior or an IV drug user or whatever, knowing that he has AIDS.

Should there be any penalty from the standpoint of someone like yourself, who has the disease, how would you -- what would you recommend?

GENE: Well, of course, from an ethical standpoint, the only proper thing to do is to disclose your status to any close sexual partner or anyone you may be contemplating having sex with. As far as a penalty against somebody who does this, I really have no comment. I don't --

DR. WALSH: Do you have any feeling on it at all?

GENE: I don't think it would be any kind of thing that could be enforced.

DR. WALSH: Because it is a dilemma with which I think we as a commission are faced because there are bills before the Congress, as was pointed out, which will penalize physicians, but there is nothing that penalizes someone who does not choose to disclose that he or she may be infectious, whether it be a prostitute or -- it is not to any one community anymore because this is everyone's disease now.

GENE: Really, the only protection that any individual can have along those lines is to insist on safe sexual practices.

DR. WALSH: Do any of the other panelists have any feeling on this from the standpoint of prevention? It is a dilemma really.

DR. SHELP: The only comment I would make would be simply to echo what Gene has said. The burden of responsibility for protection, in my judgment, seems to be misplaced if it is placed solely on people who either know they are infected or who have reason to believe they may be infected. The burden of

responsibility for protection should rest on us all. We, as he says, should require that all parties, all partners, if we engage in high risk behaviors, take certain precautions to minimize or reduce the risk of infection.

DR. WALSH: That seems like a strange bit of reasoning to me, but, again, you are certainly entitled to it. I mean, in other words, everyone should practice safer sex whether they are in danger or not of infection or just assume that everyone is in danger. Is that what you are saying?

DR. SHELP: I think if anyone engages in a high risk behavior, one should assume that they are at risk for infection and, therefore, should take whatever precautions are necessary to limit that risk and not trust your partner to be honest with you at every point about his or her infectious state.

DR. WALSH: Do you have a comment on -- like I never knew about this law in California that the Congressman spoke about. I assume he described it correctly. Do you have any comment about the fact that every other sexually transmitted disease is reportable in the State of California except this one?

DR. SHELP: I have no knowledge of that.

DR. WALSH: I don't either. I never heard it before.

DR. LEVINE: I don't know the law either and I it is not appropriate to speak of topics on which I am not fully informed; however, I want to make a point. It seems to me that one of the major issues here is the freedom to really be tested in a confidential way that would never be discoverable. Gene said that he had Kaposi's and he knew it before he left the service but he was afraid to say that to somebody because his care might have been jeopardized, all kinds of things could have happened to him.

Because of that, he is now in trouble related to insurance and so forth. What we say regarding confidentiality and what we do may be very different things.

There is tremendous fear in the community even to seek entry onto protocol studies because if a patient is on a protocol study and a bill gets to the insurance company, that is the end of that patient's insurance policy, as an example. The insurance company hears that they cannot discriminate, due to HIV, so they will find another way to disallow the insurance of an infected individual. There are all kinds of ways to evade the intent of the confidentiality laws.

The nursing homes hear that they are not allowed to discriminate against AIDS patients, so they don't. On the other hand, they are filled when I call to get an AIDS patient into that nursing home. You know, what happens in the "field" may be very different from the laws and it is this reality that the patients are confronting.

If you are not totally free to get that test and know what your status is, then you can't behave in a responsible manner.

DR. WALSH: Well, I understand that. There is nobody here, none of us, I don't think, every opposed confidentiality and so on and I really don't think even our most antagonist witness opposed confidentiality. I am just trying to establish what the general thinking is on an ethical, societal basis and I think -- the reason I asked Gene was that, to my mind, he made a courageous and correct decision. I wish that he had made it while he was still in the Air Force so he would be getting his disability, but, again, I recognize -- perhaps if that had happened four years later, you know, like today, he might have. Maybe, too, you know, you weren't so sure. You were hoping against hope that maybe this isn't the kind of disease it turned out to be because I am sure Gene would have been equally upset if he was one of the rare people who did have the virus cross the meningeal barrier, if he had crashed an airplane that hit somebody else, he would -- and killed someone else, he would felt very badly if he could have, I
am sure, but we didn't know that much in those days.

It is just a question to my mind of what is the -- we have had several witnesses talk about individual responsibility and just as I get nervous, as you are, with the placebo trials, where you know some patient is really going to die rather quickly and that it is not fair -- what is the moral, ethical feeling of those who know they are seropositive about whether they should not educationally persuade their peers and I am sure they must.

I mean, they have never talked about it in all the witnesses we have had from the gay community before this Commission. I have never heard any of them when they talk about education ever say that they do persuade their peers to really either become abstinent or that they should tell their partners. We are against discrimination. We are against violations of confidentiality. I don't think there is any member of this Commission who is for it, but this is a prevention dilemma that we are facing and that is the thing.

How are you going to get into a scientific protocol if you don't admit that you have -- you have got to do it and you have got to do what he did because you have got to protect

those or make them understand more about the disease, as he did. That is why I asked the question.

DR. LEVINE: The issue of penalty, it seems to me, is really the issue of inability to enforce a law of that sort. Again, what an individual does in private is not available --

DR. WALSH: I have no problem with that, but it is a question of when something has resulted from what you have done in private that is potentially a cause of death to someone else, how do you answer the moral dilemma, as someone who has been on the side that have had it. None of us can project ourselves in that situation. There is no way we can.

That is why I was curious to see how Gene looked at it or others that may be suffering the disease looked at it.

DR. LEE: Gene, I think we all share some of your anxiety about the last speaker. The problem always comes up when you confuse morality, sexuality issues with AIDS. Fortunately, you are in the presence of the Presidential Commission on the Human Immunodeficiency Virus Epidemic not the Commission on Sexual Mores in American Today. We have managed to stick to the subject matter and we plan on continuing to do so.

Could I ask this particular panel -- I am particularly interested in how you -- what are your thoughts on the community research initiatives in New York, where we have community-based organizations doing clinical research? Could I hear your thoughts on this?

DR. LEVINE: I would be most supportive of that kind of an effort. It again will allow access. My only problem is that, again, good research will require money and just to say that everybody can now be put into a trial is not enough. The groups have to be supported with sufficient funds to allow the appropriate answers to come forward. Again, given adequate support, these community-based groups would be a significant step forward.

DR. SHELP: I couldn't agree more. I agree fully with the effort and the concern.

DR. WALSH: May I just have -- may I get 10 seconds on that particular question?

Again, I am reading the press not a scientific journal, but there was an article in yesterday's paper about the problems with Pentamidine and the problem with its manufacturer, that there were some 54 violations found by FDA in their meeting

not even standards of strength of the drug or anything else and, yet, there was quite a positive article on the community-based institution doing a research project on Pentamidine.

How do you prevent a group like that or how do you warn a group like that in such a situation? That, I think, is an important question.

DR. LEVINE: I hate to say it but it is money. In other words, very similar trials are being conducted via the AIDS Treatment Evaluation Units and those units are supported by all the scientific wherewithal to assure that the drugs we are testing are valid and pure, so that the study can be monitored every step of the way. If you are going to put these studies into the community, and I believe they should be there, it is certainly possible to avoid those kinds of problems. You just need to provide the money for all of the different monitoring aspects along the way.

DR. LEE: Dr. McCarthy, what are your thoughts on that, on the CRI?

DR. McCARTHY: I would agree with that. I think we need to move forward as quickly as possible with testing every drug that offers any reasonable hope of either alleviating the infection or the disease itself or any of the accompanying secondary kinds of infections.

I think the ATEU units are proceeding quickly now. The organizational problem of getting those up and running, establishing the funding and so on, was enormous. I think you have heard from Dr. Fauci already on one or perhaps several occasions, in which he talked about that. But on a weekly basis, we are seeing the numbers of patients enrolled in those studies rising dramatically. So, I am quite optimistic that many of the original start-up difficulties are overcome and we will see a lot better performance out of those groups.

They are also being expanded and extended as more money becomes available.

DR. LEE: We have supported the CRIs and NIAID and the NIH want to support them. I am a real proponent of them. I assume, Colonel, that you would also go for a CRI in the Boulder area.

GENE: That is true. We have about 150 PWAs in Colorado at this time and very few of them are able to get on any sort of research protocol at all. So, in the Denver area we could certainly use some sort of an initiative like this. There are some doctors who have taken it on themselves to administer this aerosol Pentamidine and my hat is off to them, but certainly

the organization, from what I have read about it in New York and other places, is something that we should have, too.

DR. LEE: Dr. Levine and I are in the same field. We are in the lymphoma game and it is my hope that this branches out into the cancer world.

DR. LEVINE: I don't think there is any question about that.

CHAIRMAN WATKINS: Mrs. Gebbie.

MRS. GEBBIE: To focus again on the ethical issues and the dilemmas that are pointed out and they are really very common in what all of you have said today about ready access to trials, trials that are constructed to be the least risky to those persons who are wanting to have access to care and so on.

The model of the Institutional Review Board was created a number of years ago around a different set of ethical questions for a different patient population, but basically to make certain that the right people queried the studies before they started to make certain they went well.

I am aware that if any study involves prisoners, you have to bring in a whole separate group along with your normal IRB to make certain you check out that you are not doing something unusual because that is viewed as a population at extra risk and with some peculiar problems. That is sort of my purpose for the question.

Is the IRB structure, as we now know it, set up to include the right people to ask the questions about the AIDS-related research studies so that we really are protecting the best interests of those subjects and of those in need of care or ought we reconsider either the basic structure of the IRB or the addition of some special panel when it is an AIDS-related study, the same as we do for prisoners. And I address that to all of you or any of you.

DR. McCARTHY: Let me begin a response to your question.

I think the regulations, in principle, already address that. They require that the expertise on Institutional Review Boards be appropriate to the type of research that is being reviewed. So, consequently if a Board moves from review of one kind of research to another, the membership needs to change. I think institutions have found, partly because of the enormous strain on experts in the field of AIDS and HIV, that to provide needed expertise is asking the extremely busy people to take on another obligation; namely, to serve on IRBs and to review

carefully a large number of protocols. Such experts are already called on to meet many other health care obligations or research obligations.

So, there is a catch-up process. As more and more people become expert, that problem will correct itself, but we are trying to insist that if a board cannot command, on a routine basis, the expertise that ought to be there, at least that they bring in consultants on the difficult or problematic cases so that these can be addressed. In that way the IRBs can be reasonably sure that they have heard from the best available experts.

MRS. GEBBIE: Let me ask for some clarification. I think when a lot of people hear the terminology you just used, talking about the best available experts, what they might assume that to mean is to get somebody who is an expert in lymphomas, if you are talking about that kind of research and somebody who is an expert on orthopedics if you are going to talk about bones, but not necessarily hear it as being we ought to go get five people with asymptomatic HIV infections because this is an AIDS-related project or we ought to go get five gay men because this project is going to involve that group and we are going to have some ethical problems.

Are your instructions clear that the expertise includes related social expertise, as well as medical?

DR. McCARTHY: It is both ways. It should include both the people with the technical expertise -- certainly that is essential to properly-designed protocols -- but it should also include people from the gay community. What is more difficult, I think, is to recruit people from the IV drug abuse community. Such individuals tend not to want to surface. At least IRBs can include people who deal with IV drug abusers and are familiar with that community. So, yes, both aspects should be met.

DR. LEVINE: I would like to comment if I could.

I have been very interested in this concept, as you mentioned. My problem is not the IRB mechanism. I really do think it works and it is careful and that is not a problem to me, at least, in my experience. The problem is beyond that. In other words, a piece of paper that the patient signs is not an informed consent. It isn't. I would be very interested in the concept of impartial medically-trained individuals, physicians, who would serve from the IRB as patient advocates to explain as much as possible to the potential patients coming on to study.

It can be done. It takes a lot of time and I do it, but it is very hard to explain and educate in sufficient breath

that the patient can truly give an informed consent. You can say to a patient: "You want to go on the trial, don't you?" You can say to a patient: "You don't want to go on this trial, do you?" It is the intonation of your voice that may speak to the patient -- and when you really come down to it, it is pure and simple trust and that is fine.

On the other hand, that kind of trust can be abused, and I don't know that the patient is protected. It would be so nice to have that kind of representative from one IRB, whose purpose would be that of advocate of the patient, and who would have the necessary time, impartially, to spend with him, to educate.

MRS. GEBBIE: And, I gather, who is not vested in any way in the particular sacrifice.

DR. LEVINE: Exactly, exactly.

DR. McCARTHY: I would also like to see something along those lines. Our regulations clearly distinguish the documentation of informed consent, which is largely for the protection of the investigator and the institution from the informed consent process, which is for the protection of the subject. The paper protects against certain kinds of legal recriminations. It is the process of bringing the patient in as a partner in the research that is important in the entire research -- in the informed consent process.

That is very much more difficult to regulate and to measure, because as Dr. Levine says, it requires high quality communication. Those same words can be spoken in two settings. In one case they meet the spirit, as well as the letter of the law. In the other case, they may meet the letter, but fail in the spirit and, yet, it is very difficult for us to distinguish those.

The way to get at that is through education. We have conducted regional education programs in every segment of the country, trying to sensitize the research community to these issues simply because we think -- although the regulation is stated as a principle -- that to make rules effective in practice, we must sensitize the research community. They are already very busy. They are harassed people. It is very easy to cut corners in this area and, therefore, a great deal of persuasion is important here.

CHAIRMAN WATKINS: Dr. Conway-Welch.

DR. CONWAY-WELCH: One of the somewhat more tangential issues regarding the protection of the subject has to do with the liability of the institution conducting or participating in

the research and the opportunities for an individual to receive some sort of monetary consideration if problems occur.

Could you -- does this fall within your purview or do you have knowledge of an update in terms of the liability issues surrounding the research?

DR. McCARTHY: All I can tell you is that this has been discussed at various levels in the Congress, at virtually every level within the Department of Health and Human Services and that legislative proposals have been developed and are currently under discussion, both in the Department and in the Congress.

I think given the history of this issue which is not new. Liability questions precede the discovery of AIDS. There has been a great deal of discussion about this issue through the years. On one hand, most everybody can cite the needy case. On the other hand, Congress, facing the kind of budget deficits that it is facing now, is reluctant to support a program where the actuarial people find it nearly impossible to estimate what the ultimate costs of providing that kind of indemnification will be. So, it is very hard for me to predict the outcome of those considerations, but, yes, they are discussed on almost a daily basis at every level through the government.

DR. CONWAY-WELCH: Could you hazard a guess as to the time frame that is ahead of us until it is resolved?

DR. McCARTHY: I think it is finally up to Congress. There is no authority at the present time, at least on the national level, for any such provision and, therefore, in order to provide it, it will need to be, in my best judgment, a Congressional initiative. You may be aware of some provisions that were provided for children injured in vaccine trials a year or so ago. That program currently is underfunded and it found great difficulty getting through the Congress.

So, I would not predict easy passage for liability legislation. I think such a prediction would be a mistake. Nevertheless, -- because AIDS is not different in kind, but different in magnitude from other serious health problems -- the very magnitude of the AIDS problem, may, indeed, merit a different kind of consideration in Congress than we have seen on other issues.

MR. DeVOS: Dr. McCarthy, the NIH, I believe, had a budget this year of about a billion dollars?

DR. McCARTHY: That is my understanding, sir.

MR. DeVOS: That is a request. We are speaking here of research ethics and a lot of witnesses keep saying that if we only had more money. People say to me why don't they throw more money at this. Could NIH intelligently spend another billion dollars ethically? Are there that many minds around you could apply to this problem?

DR. McCARTHY: I should say by way of demure that I have not been involved in the budget discussions and, therefore, this is not an area of my expertise. I believe that right now it is very difficult to manage all the different fronts on which we are operating and, therefore, to have a billion dollars for ethics research would blow my mind. A modest increase --

MR. DeVOS: My point is, to answer the critics and the people who say to me or the other witnesses who say they could use more money, it just seems to me there is a limit as to how much money we can ethically and intelligently spend at one given time and monitor it with a ethical base to it. You are just confirming, I think, the fact that, yes, maybe we could do some more, but you have to have minds as well as money.

DR. McCARTHY: Exactly, and it seems to me that in the research ethics area, because this has been developing over 20 years, we do have a system in place. It is a human system; it is not perfect, but, nevertheless, it is an important way to address the question.

I think in the area of education there are ethical dilemmas that are truly new or at least new in terms of a major public thrust. But I also believe your Commission has already addressed those areas very firmly. So I am not sure that I can add anything to what you have already said, except to say "amen."

DR. SHELP: Excuse me. Admiral, I will have to asked to be excused in order to reach the airport in time. I hope that is permissible.

CHAIRMAN WATKINS: We would like each one of you to have an opportunity to review the final interim report that went to the President and from your vantage point, in this particular area of research, take a look at us and see if we have left some ethical holes anywhere in our armor in there or if you have other ideas that might be able to enhance the value of the document. We have certainly looked at it from your point of view. So, I will say that now and won't have to say it later. Thank you very much, Dr. Shelp. Dr. Primm.

DR. PRIMM: I would like to ask Dr. Levine a question and make a statement.

Community mental health centers and community health centers themselves have been denied pretty much the opportunity to utilize their capabilities for a long time because the drug research trials have been pretty much as a rule awarded to academic institutions. You suggested in your recommendations that certainly we should expand that so that we should include others and you specifically mentioned minorities in relationship to being on the trials.

I would also think that that would be a resource that one could utilize to not only encourage more minorities to come on drug trials, because I think you all are busy, as Dr. McCarthy has indicated. You are harassed so much that you really can't go out and recruit people to get on your drug trials to probably fulfill a wish that you might have to include them, rather than to be exclusive.

Now, as a proponent of that, what would you propose, Dr. Levine, as a way to implement that and make that functional? We have also recommended that in our interim Chairman's Report to the President, as you may recall.

DR. LEVINE: Thank you. There is a mechanism that could be used at this point. HRSA has funded some area AIDS education and training grants; in other words, an attempt to train large numbers of health care providers of all sort, physicians and doctors, social workers, and so forth. These grants have been asked to use already existing mechanisms of administration and organization.

One of those existing mechanisms has been the AHECS, the Area Health Education Centers, which very often serve minority populations and rural populations. If we already have established or are establishing mechanisms to get education in to those areas, it might not be that difficult at all to put on a treatment component as well. In other words, once you already have an organizational structure, now it is just a matter of adding on to it and using that structure.

Going back to the money just one little bit for a moment, I understand the concept that you just aren't going to throw every piece of money into this. On the other hand, as far as the federal budget, what we have spent here on AIDS last year is .03 percent of the federal budget. I agree, there will be a rate limiting step where we don't have new ideas, but the fact is that these ideas are still forthcoming far faster than the money to answer these questions and ideas. I could name ten drugs right now that have not gone into trial because there isn't the wherewithal to do that.

One of them is nothing that I am really particularly interested in, ribavirin, but, let's face it, you know, people

are going to Mexico to get ribavirin. We have never studied that drug completely. There are ten drugs that haven't been studied. Given a little money to give a good clinical trial and the mechanisms to get those trials done, we could use that money very, very wisely now and answer the questions that would get answered anyway but answer them fast, as opposed to taking three years to answer them.

So, in any event, to get those trials into the minority communities, I would use AHEC mechanisms; I would use the ETC mechanisms, built upon existing NIMH and other NIH projects. So, again, build upon what is there. Don't reinvent the wheel.

DR. PRIMM: Gene, as a young paratrooper officer myself and artilleryman, there were some very sensitive things that I was involved in as far back as the early fifties and late forties when I was in the service, that required some very minute skills and thinking on my part.

You had mentioned in your written testimony and you, of course, testified here today that you were on active duty from January '80 to '84 in September and, yet, you had recognized evidence of Kaposi's Sarcoma both in the roof of your mouth and on the right calf of your leg, if I remember correctly. Were you aware at that time that HIV could cause some neurological deficits that might affect your ability to fly an airplane at that time? And do you feel that there ought to be some responsibility on the part of individuals, who might recognize themselves some symptomatology of HIV infection or full-blown AIDS, that they ought to come forth and voluntarily step down from whatever -- in spite of the consequences?

I am quite concerned about that and I know that is a question that is probably very sensitive but in looking at what you presented here today, I had to ask you that. You don't have to answer if you don't like and I will apologize if I have stepped on your toes, but I think it is a very important issue, particularly for me, who as a retired Army officer, as you are yourself, and I guess as the Admiral is here, too, and I am terribly concerned about the defense of our nation and the use of a very expensive piece of equipment, like an airplane that costs millions of dollars. Would you comment on that, if you would?

GENE: I will be glad to, Dr. Primm. I really was not aware during the time I was on active duty and the subsequent time that I spent as a reserve flying officer, I was not aware of neurological problems associated with this disease. It hadn't been brought to my attention and, really, I couldn't agree more. There is no way that a person with this condition should be operating an aircraft or working in all sorts of

sensitive occupations with the possibility of jeopardizing other people's lives. I couldn't agree with you more.

It is just the fact that we have learned more about this disease in the last few years and, you know, I would have proceeded differently today than I did.

DR. PRIMM: I would like to thank you for your courage also and the candor in your response and I think it will help other Americans to make the right decisions when they find themselves in your position.

CHAIRMAN WATKINS: Dr. SerVaas.

DR. SerVAAS: Pass.

CHAIRMAN WATKINS: Dr. Crenshaw.

DR. CRENSHAW: I would just also like to thank you for that comment. I think that it shows a great deal of personal responsibility and understanding of all the implications of this difficult condition you are already contending with. Thank you.

CHAIRMAN WATKINS: Dr. Lilly.

DR. LILLY: I pass.

CHAIRMAN WATKINS: We want to thank all of you for coming, of course. I would like very much to have you review the report and just in the three areas that we looked at with particular focus on research and to see if you have comments on there, particularly along the ethical lines that you think we have missed, as we go into our final report.

Panel No. 4, this is on treatment and care decisions. Dr. Robert Veatch, Professor of Medical Ethics, Kennedy Institute, Georgetown University; Dr. Molly Cooke, Assistant Clinical Professor of Medicine, Chair, Ethics Committee of San Francisco General Hospital; Susan Wolf, Hastings Center.

Welcome to the Commission. We apologize for the delay in holding you up. We would like to commence then with Dr. Veatch's testimony.

DR. VEATCH: Admiral Watkins and Commission Members, thank you for this opportunity to summarize my written testimony.

The HIV epidemic raises many important ethical issues. For example, critically ill patients have rights of access to experimental drugs outside the protocols, an issue that we have already addressed. I think it is also imperative that no

patient, no matter how critically ill, has a right to all imaginable treatments no matter how marginal and how costly.

I have been asked to focus exclusively on the right of HIV patients to limit their own care or to have care limited for them, based solely on the grounds that such care is not in their interests. Others are addressing other related issues.

The starting point, it seems to me, is that HIV patients have the same rights as any other members of the moral community. In my written testimony, I have made 10 concrete recommendations in the area of refusal of treatment. These are based on what I have learned about the right of refusal of treatment and what others have learned over some two decades of the contemporary study of these issues.

Let me summarize briefly five themes that seem to emerge.

First, all competent patients have the right to refuse any medical treatment whatsoever, provided that care is offered for the patient's own good. This includes the right to refuse interventions no matter how routine. I am talking about ventilators, antibiotics, CPR, nutrition and hydration. The key is not how usual or customary treatments are, but whether the benefits that they offer are proportional to the burdens from the point of view of the patient and the patient's own value system.

That conclusion is approximately the conclusion of Catholic moral theology, of the President's other commission in this area, the President's Commission on the Ethical Study of Problems in Medicine and Biomedical and Behavioral Research. It is the conclusion of virtually all philosophers who have examined these issues.

This means that physicians should never on their own be in a position to decide the limit of care. The decisions will have to be based, if physicians make these choices, on their personal values or on the values of the professional group, rather than the patient's values.

Second, it is key that we make sure that AIDS patients have a chance to express their wishes while competent. This means that it is imperative that both substantive directives and the designation of a proxy be made by competent patients as soon after diagnosis as possible. The Commission ought to recommend that all patients diagnosed as HIV positive must be given an opportunity as early and as often as possible to express their wishes about life sustaining medical care and about who their surrogate should be.

Third, the critical problem is who decides incompetency. All patients must be presumed competent (unless they are in a status group considered incompetent, such as children); unless they agree themselves that they are incompetent or they simply cannot give a coherent answer when asked. Physicians should never be allowed to declare incompetency. If there has to be adjudication, it has to be through due process.

Fourth, a critical arises over who should become the surrogate for the patient at the time the patient is not competent to speak. There is a clear priority emerging: First, court-appointed agents; second, the one designated by the patient and, third, the next of kin. Especially with HIV patients, the question arises: What should happen when there is someone closer to the patient, a significant other, someone closer than the next of kin?

We will hear from Susan Wolf about a report from the Hastings Center that suggests physicians ought to pick among available surrogates. This seems to me to be an extremely dangerous process, and it is the one significant point upon which I differ with the Hastings Center report. It is impossible to tell the nature of the relationship between the patient and various significant others. Asking a physician to pick among two feuding relatives puts the physician in an impossible position. Physicians will, in effect, have to pick based on who the physician thinks will make the best decision. Where the patient has not designated a surrogate, we must presume the next of kin will make these charges until he is replaced by public due process.

Fifth, we will discover occasionally that surrogates make unexpected choices. We tend to say that we should insist that surrogates do what is best for the patient. We are learning through a long process of adjudication that especially with bonded surrogates, that is family members and others with previous relationship to the patient, that that bonded surrogate should be given substantial discretion, maximum discretion possible, within the constraints of reason. Only when there is an adjudication through courts should that bonded surrogate's wishes be overturned.

These themes are developed in much more detail in ten recommendations that I make in my written testimony and I will stop at this point. Thank you very much.

CHAIRMAN WATKINS: Thank you, Dr. Veatch. Dr. Cooke.

DR. COOKE: Admiral Watkins and Commissioners, thank you for inviting me to present some of my thoughts on AIDS.

Although I work with AIDS in San Francisco in several capacities, my remarks will reflect my experience as a clinician.

Three central problems stand out from a clinician's perspective: limitation of treatment, confidentiality and discrimination and access to medical care. The first issue, limitation of treatment, arises because of the gravity of the complications of AIDS and the very poor long-term prognosis of HIV infection. The opportunities to use intensive and invasive technologies, including intensive care, mechanical ventilation and hyperalimentation, are numerous. Ultimately, all patients and their providers will face the question of whether cardiopulmonary resuscitation offers benefited when cardiopulmonary arrest occurs.

These issues have been approached in two ways in San Francisco. First, a systematic effort has been made to establish the national history of various presentations and complications of AIDS so that medical treatments which convey benefit can be more easily recognized. We have learned that some interventions are so inefficacious that it is not proper to present them to patients as viable medical options.

Second, early discussions with patients are advocated, with, as Dr. Veatch underlined, the intent of eliciting the individual's preferences in late care and to encourage the patient to identify a proxy decision-maker should one be required. HIV-infected men in San Francisco and their proxies have been most eager to participate in health care decision-making. This participation has been a great aid to practitioners. In general, increased participation of patients in decision-making about late care has resulted in less utilization of invasive and aggressive technologies and more decisions to forego mechanical ventilation and cardiopulmonary resuscitation.

Several problems remain in this area. First, caregiver fatigue and discouragement is substantial. This discouragement may result in general pessimism about treatment regardless of a real potential for benefit. Similar despair is seen among patients.

Second, the increasing number of AIDS patients from groups which lack the education and social cohesion of gay men in San Francisco make counseling about prognosis and the elicitation of preferences substantially more difficult. There is some evidence in San Francisco that caregivers are more reluctant to undertake a discussion of preferences in late care with AIDS patients whose risk factor is intravenous drug use, compared to gay men.

Third, there is a real danger that in a time of contracting resources for medical care, institutional and public policy decisions to exclude AIDS patients from certain types of care will reflect more the stigmatization and disenfranchisement of AIDS patients and less the prognosis of the disease.

The object of early discussion with a patient is to increase participation in medical care decisions, not to limit treatment, per se. Where particular interventions are not of benefit, that should be clearly stated. Where treatment is likely to produce benefit, the patient preferences should be elicited. To this end, clinicians need more information on the prognosis of various complications of AIDS and more experience in counseling patients.

A simple legal mechanisms for appoint a proxy decision-maker, such as California's Durable Power of Attorney, should be available to all HIV-infected people. A way of communicating the care plan from one provider to another must be developed so that the patients who decline intensive technologies after discussion with their primary clinicians are not resuscitated and intubated by paramedics or in emergency rooms.

More information on the psychological aspects of intravenous drug use and on counseling techniques should be made available to clinicians. Programs to support and assist caregivers must be developed so that these decisions do not flow out of personal despair.

The second area of ethical concern to clinicians is confidentiality and discrimination. Because of the potential for employment and residential discrimination, loss of insurability and the incomplete privacy of the medical records, many practitioners are loathe to order HIV antibody tests and to document the results when serologic status is known. Some physicians encourage patients to ask advise on behalf of a "friend" who is HIV positive.

Resistance to appropriate HIV testing and suppression of information about serologic status in the medical record are unfortunate. There are many instances in which testing for antibody to HIV can be psychologically helpful to the patient and may motivate behavior change. Serologic status is important medical information and its exclusion from the medical records may complicate and impede care. On the other hand, the concern of clinician is, in my opinion, warranted.

What is the best remedy for this problem? Clearly, the patient's chart should be as protected as possible, particularly from curiosity seekers and inappropriate or unauthorized review. However, the medical record is the basis

of communication between care providers and a reasonable degree of accessibility is required for good care. Thus, it is unlikely that the medical record can ever be made truly confidential. For this reason, from the clinician's perspective, fortified protection against discrimination based on HIV status, is the only viable remedy.

The final area of major clinical concern is access to medical care. Several thousand full-time primary care physicians will be needed in 1991 to treat the projected 170,000 living AIDS patients. In addition to primary care, these patients will need invasive procedures, as will the far more numerous asymptomatic HIV positive men and women. In the past year, the problem of physicians and, less frequently, other health professionals refusing to care for HIV-infected patients has been widely publicized.

Increasingly, substandard medical therapies are recommended in lieu of surgery for HIV-infected patients. From the perspective of clinicians providing AIDS care, refusal to treat is a serious problem. It increases the clinical burden on already over-burdened facilities and providers. It intensifies the psychological stress of those already giving care by inflating perceptions of risk and may result in significant logistical impediments to good care of patients who are forced to receive treatment away from home. Some patients have been absolutely unable to get needed surgical procedures.

I would encourage a strong position against refusal to care for AIDS patients. The approaches to assuring access to care include increasing reimbursement for AIDS care in the public section. (Parenthetically, I would say that as a caregiver in the public sector, we have considerable capacity for the ethical, intelligent use of additional funds.) This might not have a large effect on access to surgical procedures but would decrease resistance of hospital administrators and private practitioners to AIDS care, at least in California.

The responsibility of health care workers to care of all ill people, AIDS patients included, must be vigorously endorsed. Several professional organizations have articulated their position with respect to HIV-infected patients. The statement of the American Nurses Association is particularly commendable in my opinion. While the right to select patients is a cherished privilege of individual physicians, there is some experience with requiring or attempting to require hospitals to provide indigent care. An analogous requirement that hospitals and other health care institutions provide care to HIV-infected patients may be hard to enforce but is commendable as a position of principle.

In summary, my central concerns are three: first, that we continue to work to place limitation of treatment on a firmer basis through clarification of prognosis and early discussions with patients and that we do not allow global pessimism or social prejudice to motivate withholding of care to AIDS patients that other patients with different diagnoses but equally poor prognoses routinely receive.

Second, that unwarranted and burdensome social penalties for HIV seropositivity be reduced so that confidentiality and discrimination become less problematic and HIV antibody testing can be handled in a more straightforward manner by clinicians.

Third, that access to the full spectrum of appropriate medical care is improved for HIV-infected patients through increased reimbursement for AIDS care and clear endorsement of the obligation to care by individuals and organizations in leadership positions.

CHAIRMAN WATKINS: Thank you, Ms. Cooke. Ms. Wolf.

MS. WOLF: Thank you for inviting me to testify before you today and summarize my more extensive written testimony. I am going to concentrate on decisions about life-sustaining treatment and the care of persons who are dying. This has been one focus of my own work for quite some time. I am the Associate for Law on the staff of The Hastings Center and a lawyer. I directed a project to which Professor Veatch referred at The Hastings Center, that produced an influential book on this topic last fall and it is an area in which I continue to work.

I would like to briefly describe the project and the book it produced, and then go on to describe some of the special implications of our work for HIV-infected persons. Finally, I would like to suggest recommendations and steps this Commission might consider taking.

In April of 1985, The Hastings Center convened a project group to draft the first truly comprehensive and detailed guidelines on how ethically to make decisions about whether to use or forgo life-sustaining treatments. The Hastings Center is an independent and nonpartisan research institute just north of New York City specializing in medical ethics. In conducting our research we typically draw on a broad group of experts from various disciplines concerned with such ethical issues. We brought together just such a group to work on the termination of treatment: physicians, nurses, philosophers (including Professor Veatch), lawyers and health care administrators. Our goal was to produce a consensus report, a collective vision of what ethical decision-making and care for people who are dying would look like.

We undertook this project for a very specific reason. Termination of treatment issues have been on the public agenda for more than a decade now, certainly since the New Jersey Supreme Court decided the landmark Quinlan case in 1976. However, despite a substantial number of court cases, legislative action in various states, the growth of a vast scholarly literature and, at this point, a good deal of agreement on much of the ethics in this area, there remain very substantial problems in practice. It turns out, of course, that changing rhetoric is much easier than changing the reality of how medicine is practiced and clinical decisions are made.

One promising mechanism for trying to prompt change in clinical practice has been the development of institutional guidelines on decision-making. The first burst of interest in guidelines focused on the development of hospital guidelines for "do not resuscitate" orders. Now, many health care institutions have such guidelines in place and the Joint Commission on the Accreditation of Healthcare Organizations is, indeed, requiring such guidelines as a condition of accreditation. The Office of Technology Assessment has now commissioned a report on guidelines and other protocols for decision-making about life-sustaining treatment. I sit on the panel advising that Office on this report.

The Hastings Center's Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying, a copy of which I have beside me here, are model guidelines that institutions can consider and use or amend as they see fit. The Guidelines consider all of the major treatment modalities involved, from cardiopulmonary resuscitation, to the ventilator, to dialysis, transfusion, artificial nutrition and hydration and even antibiotics.

They also take up the affirmative side of carrying for the dying: palliative care, pain relief and supportive care. In addition, they integrate with these bedside issues some of the systemic questions: how to structure ethics committees or other mechanisms for ethics consultation within an institution, how to get a grip on the currently chaotic way in which patients move between health care settings, and what role economic considerations should or should not play in decisions about life-sustaining treatment.

In addition to providing guidelines on these topics, the book provides discussion of some of the key philosophical problems, such as the line dividing honoring patients' treatment refusals on the one side from active euthanasia or assisted suicide on the other, and the role of quality of life considerations, as they have come to be called, in termination of treatment decisions. The book also includes extensive

reference materials, plus dissents by two project members on specific points.

The book has received very wide attention. It has been cited by at least three courts since its release and it has been cited and discussed in a growing number of articles.

I have provided copies of this book to the Commission and hope you may have an opportunity to review them. The book is really a road map to the ethical issues involved when a patient is critically ill or facing any kind of decision about life-sustaining treatment.

I would like to speak very briefly about some of the recommendations in the book that I think bear particularly on the treatment of HIV-infected persons. Central to this entire document is our recognition that the patient has the right to refuse life-sustaining treatment -- both a legal and a moral right -- and the right to play the key decision-making role in determining, together with his physician, how his treatment should be conducted as he approaches death.

Now, both the law and medical ethics have already clearly recognized this. However, our Guidelines make a number of recommendations for putting this principle into practice. Making these very weighty decisions about life and death is not a simple or an overnight process. Although sometimes these decisions have to be made very quickly, ideally they should be the product of a number of conversations between the doctor and patient extending over time. Each needs to educate himself about the information and attitudes of the other. It also may simply take time for the patient to arrive at a view of what it is he wishes to do.

The earlier this process begins, the better. Many patients in the course of their illness eventually become unable to make decisions for themselves. The most difficult situation of all is when a patient has reached that point and lost decision-making capacity without ever having expressed preferences about how he wishes his treatment handled. In such a case, a substitute decision-maker, be it a family member or someone else, is ethically obligated to decide as the patient would, but is left without any guidance from the patient. Because of these realities, we recommend in the Guidelines that discussion about and planning for decisions about life-sustaining treatment and care at the end of life begin early, while the patient still has the decision-making capacity to express his preferences.

Indeed, in our section on prospective planning, we recommend the use of various types of advance directives to allow the patient to state in writing, while he still has

decision-making capacity, both his substantive treatment preferences and who he wishes to take over the decision-making for him when he becomes unable to do it himself. Appointment of a proxy decision-maker is especially important when there is a possibility of disagreement among those with a close relationship with the patient. It is also particularly important when the patient wishes someone who is not a family member to play the role of substitute decision-maker. In the absence of a formal designation of such a person, the medical caregivers may simply turn to the family.

Another aspect of our recommendations that I think is particularly relevant here is our recommendation on palliative care and the relief of pain. There is a common misconception, I think -- usually a tacit one -- that when a patient has refused life-sustaining treatment or for other reasons is proceeding inexorably toward death, that this is the time for medicine to back away. When there is little that can be done to arrest the patient's downward course or the patient has refused what is available, there may be a sort of resignation and emotional removal from the patient.

One strong message in our Guidelines is that backing off in this way is a mistake. Patients who have refused life-sustaining treatment or who are otherwise moving toward death need particularly attentive palliative care, pain relief, and supportive care of all types. In fact, palliative care and pain relief are areas in which medical personnel need to educate themselves aggressively and become more expert than they are.

Finally, I should take note of our section on economic considerations, because of the special concerns about scarcity and rationing in the context of the HIV epidemic. Our section on economic considerations recognizes that it is very difficult to formulate guidelines at all at this point. The public debate on the proper role of economic considerations in any kind of treatment decision -- on coping with scarcity and on the proper role for rationing -- is at a much earlier stage than the debate about any other aspect of the termination of treatment and care of the dying.

We were, however, able to make some generalizations. Probably our strongest recommendation is that medical caregivers refrain from rationing in their care of a particular patient unless rationing is mandated by explicit policy at the governmental or institutional level. There is a real anxiety that physicians and other caregivers, influenced by the outcry over the costs of medical care and overburdened health care institutions, will begin trying to do something about it in their care of the individual patient. We felt that this would be a serious mistake and unethical. It would lead to undisciplined and unarticulated rationing, which would be

conducted covertly and without any opportunity for public debate on the principles being pursued.

I have been able to give you here only a brief sense of our recommendations. I would like take one moment before closing to suggest concrete steps and recommendations that the Commission might consider.

As I suggested, I think a critical area to focus upon is prospective planning. We know that dementia will eventually rob a substantial number of HIV-infected persons of their decision-making capacity, and many others will simply lose capacity due to the course of their disease. It is therefore critical that patients be able to plan ahead for their care and designate a proxy decision-maker while they still have decision-making capacity. Any effort that in a sensitive and supportive way assists patients to begin this process of planning is important.

A vital part of this is making advance directives available. The use of advance directives, however, is governed by state law and the states vary substantially in whether they recognize advance directives at all and if so, what types of directives. This area has traditionally been a realm for state law and I would not recommend that it become a matter of federal law instead. However, this Commission and the Federal Government may be in a position to encourage improvement in state law and to prompt states that have not yet legislated constructively to do so. Unfortunately, much of the state legislation on advance directives, such as living wills, is overly technical and restrictive. An examination of these laws and of ways to assist patients and caregivers in this process would be quite helpful.

Let me skip ahead then and make just one last point, on the role of economic considerations. Clearly, this is a topic that the Commission cannot avoid and will not avoid. Our report advocates careful attention to the ethical issues and until explicit policy is in place, clear limits on the ways in which caregivers and institutions can utilize economic considerations. Because I know that this is an area on which the Commission will report in any case, my ultimate recommendation is that the ethical ramifications, which are profound in this area, be a central part of that report.

I will hold my response to Professor Veatch's points about the Guidelines, to see whether the Commission is interested in taking up those points or others.

CHAIRMAN WATKINS: Thank you, Ms. Wolf. We will commence the questioning with Dr. Crenshaw.

DR. CRENSHAW: Ms. Wolf, first of all, I tremendously appreciate your in-depth view of the issues on how to deal with death and dying. One of the things that the Commission recommended in its interim report is that all health care personnel become more conversant with how to contribute to the quality of life during the terminal phases of the disease, which medicine hasn't been equal to up to now, in my opinion and we need to do even better than we have ever done before.

I have had quoted to me by administrators of major hospital systems like I believe it was AMI that approximately three years ago they did a five year projection of the number of hospital beds that would be used by HIV positive or AIDS patients in California. And they protected that within five years -- and they may have revised these projections and I am not familiar with it -- that all of the hospital beds in California could conceivably be absorbed in the health care of HIV positives.

I want to propose to you a hypothetical question. That raised the question in my mind, should we outstrip our medical resources and the hospice programs and others and the wisdom of the American public and the policymakers don't provide for accelerating the creation of resources to respond to this need? How would you recommend handling the ethical issues of allocation of hospital beds should there not be enough to go around?

MS. WOLF: Well, let me in part reemphasize what I said in my testimony, that the last way to do it is by simply emphasizing to individual caregivers that there is a crisis and that they have to take care of it in some ad hoc fashion. I, frankly, become very concerned when I give grand rounds or speak in a hospital and hear physicians at various levels say, in effect, "Well, I read JAMA and I read The New England Journal of Medicine and I am aware of the problem of scarce resources and I am doing something about it." I think we have to take very seriously this question of the level at which we are going to formulate any kind of rational policy, and the problem of preventing individual caregivers from prematurely applying a kind of secret policy of their own.

Clearly, there are inescapable and genuine rationing issues posed by this epidemic. I think at this point what is clearest is the process that we must follow in order to resolve them, rather than what the substantive resolution is of your hypothetical. That process has to be open and public and very strenuously debated because as yet there is absolutely no consensus in this country, as far as I can see, on how to approach these rationing issues.

DR. CRENSHAW: I mean, I would love to have the ideal solution that I trust we are all aiming for, to be prepared and have adequate facilities.

With these things that I have heard, do any of you on the panel have the concern that some of these projections could become a reality? Can I just toss that out to you?

DR. VEATCH: The reality is resource constraint with regard to HIV positive patients is already with us. It is simply a fact that there are more things that medical science can do than they are able to do. It would consume the entire gross national product just taking the American framework if we were to do every imaginable thing for every patient.

So, I would see this not as an issue limited to the HIV epidemic, but as a problem that should be solved in a much larger framework. I would concur with Susan Wolf that the most important thing the Commission could say in this regard is that clinicians as caregivers for individual patients should not take on the responsibility of cutting off care in order to preserve resources. The clinician's job is to serve the interests of the patient insofar as the patient consents.

If there are going to be cutoffs and there eventually will have to be in all areas of medicine, those cutoffs have to come as a result of broad societal policy discussions, by asking those in insurance groups where they want care. It can't be a decision that is made at the bedside for each patient, whether he is an HIV patient or any other.

DR. CRENSHAW: You know, the thing that worries me is that long before the HIV epidemic, there are many patients who have died in ambulances on the way from one facility that didn't have room to another. And as much as the legal process can do on trying to get some practical grasp of how we can be prepared, you know, to cope, I agree with you, it goes much beyond the HIV epidemic because I struggled with this when it came to just insurance policies qualifying someone for hospital admission and being turned away as the result. You had a comment, Dr. Cooke.

DR. COOKE: I was just going to add to what Dr. Veatch said. As a clinician, it has been my experience that if we can talk to patients in an intelligent and informed way about what type of care or helpful -- what works and what doesn't work -- that many patients opt not to be treated aggressively or invasively or even in the hospital, for that matter, provided there are adequate support services and in-home care available.

Second, I often worry that we will experience real resource constraints -- in fact, in some respects we already are. Again, as someone who takes care of individual patients

and wants to see the best care possible made available to her own patients, when the time comes to limit, I would argue that limiting access to technologies is most appropriately done not on the basis of diagnosis, per se, but on the basis of prognosis. It should not be AIDS-based or based on any other specific diagnosis. I think we can accommodate constraints of some types of care if it is done justly.

DR. CRENSHAW: Thank you.

CHAIRMAN WATKINS: Dr. Conway-Welch.

DR. CONWAY-WELCH: A brief question for Dr. Cooke. You speak in your testimony about fortified protection against discrimination. What do you distinguish between fortified protection and protection?

DR. COOKE: Even in San Francisco, a community that is, I think, quite sympathetic, we have seen patients lose employment, residence, and insurance. An earlier witness spoke about loss of insurability based on a hospital bill and I have seen that in my own clinical experience. Not being a lawyer or a legislator, I can't make specific suggestions about how to prevent these kinds of things from happening, but I can assure you that unless discrimination can be prevented, clinicians will be loathe to perform tests that could result in a patient becoming labeled with either AIDS or HIV seropositivity.

DR. CONWAY-WELCH: Thank you.

CHAIRMAN WATKINS: Mrs. Gebbie.

MRS. GEBBIE: The discussions you have given, and they have all been very helpful, talk about this decision-making process as if it were a two-party discussion, a party and a caregiver, with occasional rounds out to the surrogates or to the family, but the literature available to us also documents and my own practical experience documents that rarely is the patient cared for by individual caregivers. There are usually many people from several disciplines involved and it is not unusual that over varying times of varying days different caregivers will come away with distinctly different impressions of what the final decision ought to be or what the patient really, really wants and they even take issue with what the primary physician -- could you comment on the extent to which we are beginning to take that very complex piece of the picture into account or what we should be doing further to build those caregivers into a more cohesive group or bring them into the discussion with the patient better so we get out of having conflict on that caregiver side of the equation?

MS. WOLF: The Guidelines that we developed take very seriously the phenomenon you are describing. In fact, we made a deliberate decision to refer usually in the book to the "responsible health care professional," rather than assuming this was always a physician. Various people made us aware that particularly in long term care settings, it may, in fact, be a non-physician professional, usually a nurse, who really handles the day-to-day management of the patient.

Throughout our document, we assume that there are many people involved in this process, who will have various pieces of critical information. Indeed, we acknowledge that they may disagree with one another and we talk about mechanisms for resolving that disagreement, for articulating challenges to treatment decisions.

So, I think there is a trend toward recognizing the caregiving team. At the same time, I think you point toward a real problem: continuity of care and the identification of somebody as the caregiver who is ultimately responsible. I was in a hospital at one point, which I won't identify, where I was shocked to find out that there was no routine identification of a primary caregiver of any type. I think that is the road to disaster.

One of the things that our Guidelines suggest is that you cannot have good decision-making and provide good care, much less ethical care, if there is not caregiver continuity. There needs to be some kind of stable relationship that grows up between the patient and at least one other person, so that they can have these discussions over an extended period of time.

DR. VEATCH: I would concur. It is crucial that a primary caregiver be identified, but also I believe there is now substantial consensus that the patient's wishes about life-sustaining medical interventions must be charted. They must be charted clearly so that everybody on the health care team has a clear understanding of the patient's wishes. In my opinion, the patient ought to see the documentation in every chart to make sure that the patient concurs. If and when other members of the health care team perceive that what is charted is not the patient's wishes, it is a moral obligation to make sure that that difference in interpretation is openly discussed.

A hospital ethics committee is often an excellent mechanism, but it is also in many cases possible simply to ask the patient or the surrogate of the patient. When in doubt, the moral imperative is still there on the side of life and I would support any health caregiver who, for instance, refuses to follow a "do not resuscitate" order on the grounds that he or she has good reason to believe that it is not the patient's own wishes but is a misinterpretation on the part of the primary caregiver.

CHAIRMAN WATKINS: Mr. Lee.

DR. LEE: First of all, let me congratulate you on this constructive and remarkable document. I was unaware of its existence and I work in Memorial Sloan-Kettering, so I can refer to this with just about every patient I take care of. This is marvelous stuff.

Let me say that superficially I just disagree at the 180 degree mark with Dr. Veatch here and maybe the rest of you. I am a clinician. People come to me because they think I am very highly skilled at what I am doing. I spend sometimes 10, 15 years taking care of these people, talking to their families, talking to their loved ones, et cetera. In many, many of these cases, maybe among the most important decisions that I am going to have to make for that patient is when to stop aggressive treatment.

This happens every single time. Are you really going to lead me to believe that I should not be the one to make that decision and it should be a lawyer, which is what you said? You said due process. I can't personally imagine anyone better able to make that decision in a patient of mine than the family and the patient and me.

DR. VEATCH: It is true that I said that in my opinion clinicians in their clinical roles should never make decisions to stop treatment on any patient. Treatment will be stopped either on the grounds of social research allocation (and it seems to me that is not the clinician's responsibility), or it will be stopped on the grounds that the treatment is no longer fitting with the patient's beliefs and values.

The position that I articulated is that it should always be the patient's responsibility in consultation with those whose advice he trusts, including his clinician, to make a decision if and when further aggressive care is no longer fitting with the patient's beliefs and values. These judgments always involve a convergence of medical information and a moral or non-medical component.

I have enormous respect for the medical skills and wisdom of clinicians I have worked with on these issues. On questions of suspending life-sustaining treatment, the critical question is almost always one in the realm of religious or philosophical values, about which, in our pluralistic society we differ tremendously, from broad lay population differences to medically-trained population differences.

When it comes to the ethical or religious component of the decision, the position I am taking, and it is one that is

shared very widely, is that it should be the patient's values that are decisive. I believe what I said on this matter is completely consistent with the views of the American Medical Association, with most of the major religious groups in our country and, incidentally, with court cases.

I certainly never have said that lawyers should be the ones who make these determinations. I did say that in the case of the incompetent patient, where the next of kin surrogate appears to be making a decision that is beyond reason when it comes to expressing the interest of the incompetent patient, then we must turn to due process mechanisms. I mean by that the court process. Only with a court order should the next-of-kin surrogate's wishes be overridden. I don't see how we can come to any other conclusion when it comes to the necessity of overriding occasionally a next-of-kin surrogate, who makes a decision that appears to be beyond reason. We have to have some due process mechanism and that mechanism, it seems to me, at the present time, is a judicial mechanism. We use it very, very rarely.

But never would I turn to somebody just because he is a lawyer. My first priority is to get the patient's wishes as definitive in making these judgments, with consultation with any of those that he considers significant in giving advice. In almost all cases, his primary caregiver would be among those that are most significant as advice-givers.

DR. LEE: Thank you for clarifying that. Do you others have comments?

MS. WOLF: Well, I as a lawyer can assure you that I do not think lawyers should be making termination of treatment decisions. However, let me clarify my view of the doctor/patient relationship in making these decisions.

I think it is a form of partnership, each one of them bringing to bear critical information and an approach that the other one does not have. The bottom-line question as I see it, and as many others see it as well, is whether the burdens of life with that treatment now outweigh the benefits for the patient.

In addressing this question, the physician brings technical knowledge, experience, compassion, a whole set of skills to bear that the patient doesn't have. They are essential. The patient also brings something critical to bear, which is the capacity to introspect and figure out what his experience is and how he feels about starting or continuing that treatment. It is he who can determine what the burdens and the benefits are to him and how they compare.

Ultimately, as I think both the law and medical ethics recognize, it is the patient's body and it is the patient's life or death. The law of informed consent is grounded in the notion that the ultimate decision-maker has got to be the patient.

Now, I want to take a moment to address Professor Veatch's point about when courts should get into the act. This is a point on which Professor Veatch disagreed with the Guidelines and he wrote a dissent on this point in the book. There are those who feel that declarations that the patient is not capable of decision-making should only be made by a court. I am not of that view and the majority of the group that produced the book was not of that view.

It seems to me that perhaps in the best of all possible worlds our courts would be capable of handling that load and capable of discharging that responsibility in a timely and proper fashion. They aren't, not by a long shot now. I think that as long as we keep the courthouse door wide open, so that everyone knows that if there is any disagreement about the declaration of incapacity or choice of a surrogate, they can go to court, then that is the best we can do.

DR. LEE: Thank you. I hope, Mr. Chairman, that when we have our bibliography to this report that this particular volume will be a prominent part of it.

DR. COOKE: Let me --

DR. LEE: I am sorry.

DR. COOKE: -- answer your question as well, if I might. We have substantial experience with this issue at San Francisco General and I don't think I agree exactly with Dr. Veatch. We attempt to distinguish between circumstances in which a particular intervention will be helpful and situations in which it doesn't help, although it may be easily available and relatively routine. The discussion that we have with patients is very different when it is the determination of the primary physician that an intervention of, say, mechanical ventilation, while in a technical sense it is sustaining life, has little to offer. Under those circumstances, the discussion that is helpful to the patient reviews the clinical situation from both the patient and the physician's point of view and the care plan. Typically the physician will say "There are technologies available, mechanical ventilation, or CPR but it is my opinion that those are not useful in your situation. These are the things that we will continue to do: pain control, comfort measures. We do not plan to proceed with mechanical ventilation or CPR."

If the patient understands that and accepts it, then we proceed on that basis. In most cases, in my experience when the physician has made the determination and explained the medical situation to the patient, then things are really quite straightforward. If, on the other hand, heroic therapies or non-heroic therapies offer the chance of benefit but may not be the patient's preference, then we elicit the preference. I am not sure if that is a distinction from your position or not.

DR. LEE: Do you disagree with that?

DR. VEATCH: I disagree only in a very marginal way. The problem is determining the extent to which we can identify something as medically beneficial or non-beneficial without reference to the patient's own value system.

Within the past week I had the opportunity to discuss with a clinician a case where a patient was a candidate for CPR that would preserve life for no more than week and leave the patient in a coma during that week. The physician took the view that was of no medical benefit. In exploration with the patient, the patient was able to articulate why living an additional week in a coma to him was perceived as beneficial.

DR. LEE: But she doesn't really disagree with you, do you?

DR. VEATCH: I tried to use her exact example of CPR and ventilation. The judgment that a week in a coma is of no benefit is certainly one in which I concur, but this particular patient did not concur and eventually, I think, it was agreed that there was no amount of medical evidence that could be brought to bear to determine whether it counts as a benefit to preserve a life for a week in a coma. It turned out we had a value difference. It turned out to be a religious disagreement about which we had to agree to disagree with the patient. If we were going to cut him off from that CPR and ventilation, it would have to be on some grounds other than the patient's perception of lack of benefit.

DR. LEE: We could keep it going but --

CHAIRMAN WATKINS: Dr. Walsh.

DR. WALSH: I think we have covered this aspect of the treatment/care/ethics problem. I would like to stay under the umbrella for a moment, though, and go back the other way and want your comment about the ethical obligations -- we can put it in quotes -- of the patient to the physician.

We heard some horror stories this morning about San Francisco General from Dr. Day and the manner in which she, at

least, felt she had been treated by her colleagues or the administrators, without sympathy. Have you as ethicists, Dr. Veatch or any of you, become involved to any extent in these issues as to how they do bear, indeed, on this question of the physician being willing to give care if information is withheld from that physician deliberately by a competent patient?

DR. VEATCH: You are talking about information withheld about diagnosis?

DR. WALSH: Yes. I mean, in other words, the patient has a known HIV positivity, was going to go to major surgery and refuses to be tested and refuses to tell the physician and, you know, we know all the usual answers about the physician should take the normal precautions and so on, but we have heard not only today but from other witnesses some compelling examples and the ethics involved are extensive. I wondered whether you would have any comment on this side of the coin where the patient is not close to death; that is, is living but the doctor may be exposed to death?

DR. VEATCH: All of my remarks were based on the premise of an adequately informed consent for the doctor/patient relationship. That means that the patient has to consent to treatment. It seems to me if consent is the basis for forming contractual bonds -- in the ethical sense, now, not legal -- in the ethical sense of a contractual bond between doctor and patient, the physician also has the right to give informed consent to that relationship. That means just like the physician must tell the patient what the patient would reasonably want to know, likewise the patient has to tell the physician what the physician would reasonably want to know and that includes information about diagnostic state.

DR. WALSH: If the patient refuses to give that information, is the physician ethically, morally, legally entitled to deny care?

DR. VEATCH: I am not sure just as a practical matter how he would deny care from someone who has not informed him of the risk status --

DR. WALSH: By either changing a procedure or refusing to do a procedure and so on.

DR. VEATCH: The physician would have to find out if the --

DR. WALSH: The result of what we heard this morning brought it back to my mind again. I am sure, Dr. Cooke, as chairman of the committee, you have a few thoughts.

DR. COOKE: With respect to the example that you have in your mind, the surgical patient who declines testing -- it is my feeling that if you believe that HIV-infected patients should have access to routinely performed surgical procedures for which in many cases there is no medical alternative, then it follows that patients who decline to be tested should also have access to the same procedures.

From the infection control point of view, you would simply treat them as you would treat HIV-infected patients.

DR. WALSH: But, again, from an ethical, legal standard, as was brought out this morning, if you treated that patient in the same way, as she indicated this morning, that you would treat a non-HIV-infected patient and you put a pin in a bone, you might really promote infection instead of treating that patient more conservatively and, yet, the patient may have a compelling need to get back to work or whatever it may be --

DR. COOKE: You might promote --

DR. WALSH: You might promote a wound infection in the patient as a result of immunodeficiency activity. Do they have a legal recourse if you choose not to use that procedure?

DR. COOKE: First, there are a number of assumptions in that hypothetical. The first assumption is the important one is that patients who are HIV infected behave differently than non-HIV infected people and that is an empirical question. I think it is important to look at it. If we knew that patients who were HIV infected should be handled differently for their own benefit, then that would be clearly another matter.

DR. WALSH: Well, we do know that they may respond differently or react differently because of their immunodeficiency. We know that. I mean, we can make a judgment but they may or may not and, therefore, the choice of treatment --

DR. COOKE: You can make a theoretical argument but in eight years of working in a population with a very high prevalence of HIV infection, I don't think we have seen that play out even anecdotally.

DR. WALSH: Are you telling us that Dr. Day has no legitimacy to her position?

DR. COOKE: I am saying that I know of no evidence that patients who have open reduction who are HIV infected have any different perioperative course than non-infected patients. I don't know of one piece of evidence.

DR. WALSH: Well, she told of us one this morning, of a case.

DR. COOKE: Well, you know and I know that everybody has one example of everything. So, I believe that there is one example of that.

DR. LEE: Certainly, in my field, in the lymphomas, if you are HIV positive, 80 percent of the time you are history in a year.

DR. COOKE: I totally agree.

DR. LEE: And they should be handled differently.

DR. COOKE: Absolutely, absolutely and that is why if I had a patient in San Francisco with a lymphoma and I thought there was any possibility at all that this was HIV infected, I would vigorously recommend to that patient that he or she be tested and I guarantee that the patient would accept testing. The reason that the patients don't accept testing in the perioperative setting -- there is only one reason and that is because they have a strong suspicion that they are not going to get their surgical procedure.

As a clinician I am actually a strong advocate of testing of selected patients and I have had yet to have someone decline to be tested. People decline to be tested if they are afraid something bad is going to happen to them. The reason that Dr. Day's patients declined to be tested is that they are concerned that they are not going to get their surgical procedure and they are concerned with good reason.

DR. WALSH: I was going to say if they declined to be tested and she chooses a closed reduction rather than open reduction, is she medically liable? I mean, because --

DR. COOKE: I think if it was substandard care, she is.

DR. WALSH: She would maintain that it wasn't and I am just trying to determine is there an ethical responsibility in this whole question on the part of the patient?

MS. WOLF: I wanted to comment on several things. First, it seems to me that as a practical matter much of this would get negotiated out between doctor and patient. You know, the doctor might say to the patient, "Look, in order to care of you properly I really need to know your HIV status, and I will tell you exactly why I can assure you that I am not abandoning you; I am not walking out the door. You are going to have these treatment options but I do really need to know your HIV status."

I would suspect that very many patients would trust that and go forward with the doctor.

Secondly, there are all kinds of spheres in which we already allow patients to limit their care in various ways. Think of Jehovah's Witnesses, a prime example. In that care, the limitation imposed by the patient may be directly life-threatening. Now, not all physicians are willing to go along with that, as we all know. There are plenty of surgeons and anesthesiologists who will not operate on Jehovah's Witness patients, but there are some who will. So, I think that, although we could argue at great length about the similarities and dissimilarities between different realms, we recognize as a legal and ethical matter that there are times when the clinician will go forward accepting the limits that the patient imposes.

Finally, I think that there is a very troubling trend in the direction of seeing the doctor/patient relationship as completely symmetrical morally. It is a difficult topic. We saw in a recent case, the Jobes case in New Jersey, that a health care institution was flatly unwilling to pull a feeding tube despite the patient's wish. Now, terminating artificial feeding is a controversial topic, but the point I am addressing is the assertion of rights and moral concerns by a health care institution.

Undeniably, we have to address and take serious concerns of caregivers, be they of an ethical, religious, clinical, or other sort. But I would strenuously resist the reduction -- which is what I think it is -- of this relationship to some kind of complete symmetry. It is the patient who comes in ill. It is the patient who comes in with a special vulnerability, needing something from that clinician.

DR. LEE: I might just say in all the time I have never had anyone refuse me, refuse to do an HIV test.

DR. WALSH: No one has. It is just that as physicians ourselves we recognize that we are compelled to take care by our oath, by our ethics, you are compelled to take care of patients regardless of what they have, but I was just wondering whether any -- there has been any recognition, particularly with the advent of this disease, on the fact that -- this is the first disease in a long time in which the -- particularly surgeons, that their life can be threatened by a needle stick or whatever, and I wondered about whether there is any way to give them a better feeling of security so that we won't lose them.

As one of our panelists pointed out this morning -- I have forgotten which one it was -- that there is concern that people are even giving up certain specialties or are considering career changes and the like because they feel the rights of the

physician in selected circumstances is so limited, you know, particularly in treatment of these kinds of patients and that there is just no future in it.

Here we heard Dr. Day considering whether she was going to change her career.

DR. VEATCH: Dr. Walsh, we have discussed the case where HIV status knowledge is necessary in order to differentiate appropriate care. That is quite separate, it seems to me, from the case where a surgeon may want this information in order to protect him or herself from potential risk. I think the ethics of those two kinds of cases would be processed quite differently.

If a clinician says I simply don't know what to do for you until we know HIV status, that becomes part of the negotiation process. If it is simply for the clinician to have information about the risk he or she is taking about delivering care, I think that is governed in the first instance by contractual obligations for each party to provide adequate information and following that, by societal understandings about the duty of the clinician to deliver care for high risk patients.

MS. WOLF: I have to make it clear that I am in some disagreement with Professor Veatch on the contractual model of this. It seems to me that if a clinician is told by his patient, "Look, I am not going to take the test," that the clinician is informed. What he is informed of is that he is not getting that piece of information. If he feels that the information is critical to some decision he is going to make, then he deals with that.

So, I don't think that the contract is disturbed by the patient saying, "Look, there is something I don't want to talk to you about."

DR. COOKE: I just want to add that I share with Dr. Walsh a real concern for the support of caregivers, but I think that the relationship between knowing a patient's HIV status and security of the caregivers is much more apparent than real. It is the usual response of apprehensive caregivers, who are facing the prospect of AIDS in their practice to want to test everyone, but I don't think that knowing patients' HIV status really has a lot to do with security in care or motivation to care and I would argue that Dr. Day, since we are using her as an example, would be just as apprehensive if she knew the HIV status of all of her patients.

So, that is not the solution to the very important problem of motivating medical professionals to provide AIDS care

and increasing their security and satisfaction. They are very different issues.

CHAIRMAN WATKINS: We will close out this panel. We are running late and we have another panel to go.

I would like the three of you to view our interim report in the care and treatment section to see if we have any ethical chink in the armor that we already built and then perhaps in the future, indeed, the next edition, we might ask you again to take a look at it. And particularly I want you to think of it in terms of do we have voids in our care and prevention that we did not address and go beyond the social issues that we raised in there and have we really left some blanks. We should have said there should be more concentration in the education of health care providers or certain health care providers. But would you look at it with that in mind and then come back with a letter to us and we will be supplying you with copies of the interim report, which went to press two days ago. Thank you very much for coming today.

CHAIRMAN WATKINS: Let us move on to panel number five on Confidentiality versus Decision to Warn. We have Dr. Troyen A. Brennan, Brigham and Women's Hospital, Harvard Law School in Boston; Randolph P. Reaves, Executive Officer and General Counsel, American Association of State Psychology Boards in Montgomery, Alabama; Dr. Allan M. Brandt, Associate Professor of History and Medicine and Science for Harvard Medical School in Boston, Massachusetts; Carol Levine, Executive Director of Citizens Commission on AIDS in New York; and Dr. Frederick Schaerf, Assistant Professor of Psychiatry and Behavioral Sciences, Johns Hopkins Hospital in Baltimore. We will commence the testimony with Dr. Brennan.

DR. BRENNAN: Thank you for asking me to testify. I would ask you to forego my oral testimony which summarizes my written testimony because patient care duties are going to call me back to Boston probably before this session is over so I would like to be around for as much of the question and answer period as possible.

CHAIRMAN WATKINS: Mr. Reaves?

MR. REAVES: Thank you very much. I appreciate the invitation to be here. I am not really sure why I was invited. I appreciate it anyway. I am a lawyer in private practice back home which is about 300 or 400 miles south of here and my primary practice involves working with people involved in the mental health professions, principally in the field of psychology. Over the past 14 years, I have spent a great deal of time studying the liability of the mental health professional, particularly as we find ourselves in a rather spirited period of litigation across

the United States and I do not want to take up a lot of time and bore you with a lot of what has already been put in writing here by explaining the failure to warn cases that originated in California with the infamous Tarasoff case which has since, in many respects moved to the East to the point where we now have quite a few jurisdictions that have recognized liability and a failure to warn situation.

I simply want to say to you that as a practitioner of law dealing with mental health professionals for quite a while, I have had to recognize that those theories of liability exist whether I agree with them or not, and there is no doubt in my mind that when you are dealing with a situation involving a patient who has contracted the AIDS virus that the liability is much, much greater for the mental health professional than it is when dealing with someone who poses a threat of violence of some other means whether it be by physical violence, use of a gun or weapon or arsonist or whatever. The liability is greater because two of your defenses are unavailable to you in my opinion. The first offence being the claim that members of the mental health professions are unable to predict dangerous behavior to an accurate extent. I do not think anybody would disagree that a person who carries the AIDS virus and has sexual contact with someone else would not pose a risk of danger to that individual. I would feel quite silly arguing the other way.

In the other defense, it really goes out the window as far as I am concerned is the matter of confidential communication. As far as I am concerned, the threat of transmission of AIDS or any other sexual disease to another person is the threat of the commission of a future crime. As far as I am concerned, that is not confidential communication. It should not be kept confidential.

It disturbs me very much dealing with practitioners, particularly those in private practice, that the jury verdicts, even in my end of the country, and these are not in sex cases, they are in cases dealing with the negligent release of dangers to patients, those verdicts are astronomical. We had two verdicts in my state that totalled some $27 million. It is very difficult to post a bond in the area of $40 million in order to try to get an appellate opinion as to whether the theory of liability even exists.

So the only logical alternative that I have been able to come up with, the advice that I give my practitioner clients, is that faced with such a situation, the only reasonable, the only logical alternative, is to do whatever is necessary to avoid liability. In this instance, in these cases, the only way that I see to do that is to breach that communication and disclose. That concerns me because I read the literature and it appears to say to me that if HIV carriers were assured that their

communications were confidential, that we would reach more carriers and would be able to educate them better about the disease, about the way it is transmitted and in effect, we would probably control the disease more effectively if these communications are confidential.

The other thing that troubles me very much is that quite a few people, particularly in the mental health profession, would disagree with me vehemently about the confidential nature of these communications. I can see that disagreement leading to serious debate on the ethics of the release of this information and possibly even leading to practitioners filing ethical claims against one another which may, in fact, harm my primary clients, the boards that regulate the practice of psychology and other mental health professions.

CHAIRMAN WATKINS: Thank you, Mr. Reaves. Dr. Brandt.

DR. BRANDT: Thank you very much for the invitation to appear here today. As this Commission must know all too well by now, there will be no easy answers to the ethical and policy dilemmas raised by the AIDS epidemic. The problem of confidentiality and the duty to warn is, without question, one of the most difficult. It brings directly into conflict two of our most highly prized social values. We have traditionally honored and respected the ideal of confidentiality in relations between patient and doctor. It is the very basis of what we have come to call the therapeutic alliance. Indeed, the notion of confidentiality is so basic to the doctor-patient relationship that the Courts have come to codify this ancient precept.

Confidentiality is the foundation of medical care and treatment. It makes medical care possible. Without it, the basic trust and intimacy that brings patients to doctors would be lost. In this sense, confidentiality is not just an ethical or moral responsibility of a physician, it is a functional aspect of health care, the glue which cements the doctor-patient relationship. It is recurrently realized confidentiality may have both its costs and its limits. Protecting confidentiality of those infected may leave those outside the traditional doctor-patient diad at risk.

In instances where a patient could harm another member of society, how much respect should we give to the principle of confidentiality especially in circumstances where a patient disregards the health of others? Do we not have responsibilities to protect those who may unknowingly be in immediate danger? Does not the public good demand that we make every effort to protect uninfected individuals from becoming infected even if it means temporarily compromising the time honored principle of confidentiality? After all, it could be argued, this epidemic will demand radical interventions in the name of public health.

This, then, is the debate as it typically has been framed. The choice, it would seem, is between honoring confidentiality or protecting the public good. But I would like to suggest that there are significant problems in posing the question in this way. That, in fact, confidentiality and public health are not necessarily in conflict in the AIDS epidemic. A successful approach to the problem of AIDS will lead to both respect confidentiality as well as devise clear programs and protocols for protecting the uninfected.

The debate about confidentiality is, of course, not new to AIDS. Since the turn of the 20th century at least, physicians and public officials have assessed their responsibilities with respect to communicable disease, especially with reference to what came to be called the healthy carrier. It was widely recognized by physicians and public health officials that certain patients, eager to conceal their infections, might put others at risk. Stories were frequently told of physicians upholding the confidentiality of young but wayward men infected with syphilis only to find out that they had then infected their new brides who then passed the infection to their offspring. Many physicians supported mandatory reporting and notification of cases, but feared that this would merely drive patients away.

As effective treatments became more widely available, support for reporting and contact tracing grew. In the 1930's, Surgeon General Thomas Parran called for a Wasserman dragnet as a part of a national campaign against syphilis. Such programs often did bring new cases under treatment. It is important to remember, however, that our system of reporting and tracing as it was developed in the 1930's and 1940's was essentially a voluntary one. Patients were encouraged by trained public health interviewers to disclose contacts who would then be tested and, if necessary, treated. Without the cooperation of the index case, the program did not proceed. It hinged on the persuasion of physicians and public health officials and the good judgment of patients. Moreover, the widespread availability of effective treatments, especially after the introduction of antibiotics both fostered such programs but ultimately led to their demise. As a public health measure, the benefits of mandatory reporting and contact tracing, especially in the absence of treatments which render an individual non-infectious, are extremely limited. While such programs may effectively warn third parties at risk of possible infection, they cannot close down the epidemic by treating individuals and rendering them non-infectious.

In the case of the AIDS epidemic, the rigorous maintenance of confidentiality is likely to be the most effective public health approach. It is critical to attract infected individuals into the health care system where they may receive appropriate health care and thorough counselling. With adequate

counselling and care, such individuals are much more likely to voluntarily inform past, present and future sexual partners and make behavioral and make behavioral changes to protect them from infection.

This scenario, of course, would be quite different without the initial expectation of confidentiality. Further erosion of our commitment to confidentiality in medicine would damage the status of our health care system but more importantly, it could make it literally impossible for us to mount a public health campaign against this epidemic. Driving infected individuals underground where they fear exposure would lead to stigmatization and discrimination exacerbating the AIDS crisis. Only if we build institution programs that infected individuals can trust can we hope to protect others from infection. We need to develop techniques which not only reduce risk, but also heighten the moral sensibilities of those infected.

Infected individuals will only recognize their responsibilities to the community if we steadfastly maintain a respected place in the community for them. Treating HIV infected individuals like pariahs will create a culture in which the virus will flourish. A series of tragic self-fulfilling prophesies will be the result. There will, of course, be some instances in which physicians or public health officials will deem it prudent to warn a third party of possible infection. These instances must be clearly specified and absolutely controlled. They should be left to the discretion of physicians in consultation with public health officials who are convinced that a patient has not taken adequate effort to protect possible ongoing sexual partners.

Moreover, regulations must make it explicit that confidentiality will only be compromised in the specific instance of an individual continuing to place specific third parties at risk, and then only to protect those third parties. Abrogation of confidentiality in these specific and probably unusual instances should not preclude upholding the patient's confidentiality in every other respect with regard to insurers, employers and landlords. Legal provisions for warning third parties should be tied to more stringent protections of confidentiality. Of course, there is no breach of confidentiality when a patient informs others of his or her infection. There is no breach of confidentiality when a patient provides explicit permission for a third party to be notified either by a physician or public health official. Therefore, maintaining confidentiality should be the goal of the medical and public health establishments.

In this respect, it is the duty of physicians and public health officials to encourage patients to act responsibly. Most patients, even those burdened by powerful concerns about

their health and their future, recognize the significance of such responsibilities. Patients need to be assured that confidentiality will be respected except in these most explicit and rigorously defined circumstances. Due to the particular nature of AIDS and the social and legal vulnerability of those groups typically at highest risk, it is imperative that patients feel secure within the health care system. Only in the most extreme situations of immediate risk to a defined third party where the patient refuses to cooperate should there be any breach of the commitment to confidentiality.

In this respect, it makes sense to conceive of the duty to warn in the broadest possible terms. Most of those at risk of infection are not third parties whom a physician can simply call or write to inform them of the immediate danger posed by some specific individual. Those at risk are the thousands of individuals who engaged in unprotected high risk sex or shared needles. If we are to control AIDS we must make every effort to be certain that everyone at risk is warned through explicit public education programs and assist them in making difficult behavioral changes. In this way, we both can maintain respect for confidentiality and protect the public good.

Finally, we need to better educate all physicians and allied health workers to become more adept in appropriately counselling HIV infected individuals and their partners. We need to recognize the full parameters such counselling must take. Simple warnings will not suffice. Counselling will be costly in times and resources. Not to undertake such costs, however, will have dire consequences, and ultimately be far more costly to society as a whole.

In short, maintaining confidentiality is both an ethical and a public health goal in the response to AIDS, only to the degree that confidentiality can, in fact, be maintained, will we be likely to deal effectively as well as humanely with this health crisis. Thank you.

CHAIRMAN WATKINS: Thank you, Dr. Brandt. Ms. Levine?

MS. LEVINE: Thank you. My name is Carol Levine. I am Executive Director of the Citizens Commission on AIDS for New York City and northern New Jersey. Before taking this job I worked for 12 years at the Hastings Center. Susan Wolf and Robert Veatch, who testified on an earlier panel, are my former colleagues. My background is in medical ethics. On behalf of the Citizens Commission, I certainly want to commend the Presidential Commission for its interim report. You reached essentially the same conclusions as our group did, working through a somewhat different process.

The subject of this panel, which is, I think, one of the knottiest facing us and certainly one that our Commission has discussed at various points. I start with a basic premise and quote from LeRoy Walters who is Director of the Kennedy Institute of Bioethics. This was written in 1974, before AIDS. "The physician has a prima facie obligation to preserve the principle of medical confidentiality. This obligation is based on two considerations, a concern for protecting the physician-patient relationship and the desire to respect the patient's right to privacy. Thus, the burden of proof must be assumed by anyone who wishes to argue that the principle of medical confidentiality should be violated. However, there are some cases in which this prima facie obligation can be overridden because of other very weighty considerations, for example, the desire to protect the patient's own life or the lives of other persons. According to this view, then, the physician's duty to observe the principle of medical confidentiality is a very important moral obligation, but not an absolute obligation or one's only obligation." So the question that we are going to be discussing is this: When, if ever, is it justified for a physician or other health care professional to override a patient's desire to preserve the confidentiality of the information that he or she is infected with HIV and to warn a third party of potential risk?

There are some ways to look at this, some answers. The identification of third parties who might be at risk, and the fact that they have not been notified, depends on a voluntary disclosing of this information by the patient to the physician. Therefore, a relationship of trust is essential even to determine who that third party might be. Only third parties who are at actual risk, that is sexual or drug using partners or health care workers in some situations, have a claim that might override the patient's right to privacy. Others who might have an interest in knowing a patient's antibody status, employers, landlords, neighbors, and so on, do not have that right in my view.

Health care workers involved in a patient's care may need to know the patient's antibody status, however, that information should not be disclosed beyond the health care setting without consent. Moreover, disclosing information about seropositivity should not result in a lower standard of care or abandonment of the patient.

The primary ethical and I believe legal responsibility for informing a third party who might be at risk lies with the infected person. The physician's first obligation is to advise such an individual about behaviors that might cause harm to others, to counsel that patient to notify the third party, and to persuade him or her to act in ways that will reduce, if not eliminate, the risk.

Only when physicians conclude that the infected person cannot be persuaded to notify third parties does the duty to warn and duty to protect become an option. That judgment must be made on a case by case basis, and with clinical discretion in considering all the relevant factors. These might include the patient's own statements or their weight; the type of relationship with the third party, as in a marital relationship; how long has it been going on; the likelihood that the third party is already infected; the potential additional risk represented by a delay in notification; whether the third party is pregnant of considering pregnancy; the strength of the physician-patient relationship; and whatever else might be considered a material factor.

When we come to policy options, I think there are at least four. One would be strict confidentiality. That view is expressed by Michael Kottow in the Journal of Medical Ethics, not related to AIDS but just as a general premise. Kottow says that medical confidentiality is an intransigent, absolute obligation. In this view, limitations or exceptions put on confidentiality would destroy it and, "to jeopardize the integrity of confidential relationships is too high a price to pay for the hypothetical benefits this might bring to the prevailing social order."

While this approach has the appeal of removing ambiguity, and everybody would really like to have a simple answer to this question, and of giving primary weight to a very important and time-honored professional value, it also fails to consider the legitimate interests of persons who are at serious risk because of a patient's behavior. Exceptions to the rule of confidentiality, for example, for reporting gunshot wounds, have existed without destroying our basic trust and value.

An option on the other extreme would be mandatory notification. Physicians would be legally required to notify spouses or other sexual partners of the patient's antibody status. This, too, would remove ambiguity but there would be, I think, several drawbacks. Patients who would benefit from counseling and testing would be likely to avoid health care settings in which notification automatically followed testing. Physicians and other health care workers would be likely to avoid caring for patients believed to be at risk in order to avoid the consequences of discovering seropositivity. If you know that you are going to have to tell somebody else it is a little harder to deal with that infected person.

Physicians in general are poorly trained to do the kind of intensive follow up counselling that would be required. Many physicians do not even know how to explain the antibody test which is, in fact, one of the few options that can be offered to a notified third party. Under mandatory notification patients

would have an incentive to lie, to refuse to name their partners, and that would lessen rather than increase the protection for those individuals. What we are looking for is incentives for ethical behavior rather than disincentives to it.

In general, the third option, discretion to warn an identifiable third party who is at risk of imminent harm, is supported by existing law and existing ethical standards. That seems to be the current standard, and legislation has been proposed in a number of jurisdictions to make it explicit with protection from liability. That might clarify options for physicians, but it might also lead them to believe that they must inform in all cases.

A fourth option would be the discretion to warn with the warning carried out by public health agencies. In this plan, physicians could discharge their obligations to inform those identifiable third parties at risk by informing public health agencies that a particular person is at risk, without naming the index case and by relying on those agencies to do the notification. Public health agencies already assist individuals who ask for help in notifying their sexual partners. The advantage to this system is that trained health care workers do the notification. One disadvantage is that in cases where the physician already has a relationship with the third party, he or she may have a greater sensitivity to that particular situation.

One consideration that should guide whatever policy is determined is a concern for the person who will be notified to minimize the harm. Notification is seen as a benefit and I think it is. People who are at risk ought to know their risk and to make their own autonomous decision about what to do, but this does not mean that this benefit comes easy. Given the epidemiological background of the disease and the way policy is being proposed, those who would be notified will be mainly women. Sexual partners of drug users or sexual partners of bisexual men who will not have knowledge of their sexual partner's risk. They may react to this information in a variety of ways, including denial, panic, anger that can be at the messenger, not necessarily the sexual partner.

Their emotional and health care needs must be addressed in immediate as well as long term ways. Notifying without providing adequate services, in some cases even protection from physical abuse, can cause more harm than good. For women of child bearing age, access to counselling about the risks of perinatal transmission should that woman be infected is essential.

I think another concern is a concern to preserve relationships wherever possible. So often this notification is presented in a punitive way to punish that person for being

infected and for not telling that sexual partner who should have been notified. I think that social, public health and, I would argue, moral values, all support the maintenance of stable relationships. Notification, if it is done in one of these ways should be done in a way to encourage couples to maintain a marital or stable relationship rather than to disband it.

My conclusion is that the goal of the physician-patient relationship should be to protect confidentiality, thus enhancing the relationship of trust that is essential to continued counselling and treatment. However, in the few instances, and I think they are few, in which an infected person is unlikely to be persuaded to notify a third party at risk, a physician is justified in overriding confidentiality. These should be seen as exceptions to the general rule, not as a replacement for the rule. Physicians may discharge this duty by notifying public health officers and enlisting them to do the actual notification.

In terms of what the Commission might recommend, I would suggest four things. First, encourage passage of a federal confidentiality and anti-discrimination bill which would reduce one of the main disincentives infected people not to notify third parties, that is, fear of discrimination, while providing for exceptions such as notification of known sexual partners.

Second, encourage state and local health departments to set up mechanisms, policies and programs for notification in these cases. These should include counselling, testing, supportive follow up for people who are notified.

Third, encourage professional medical societies to require education about HIV infection so that physicians are better able to counsel patients and better able to encourage them to do notification themselves.

And, fourth, I think the Commission might encourage the Federal Government to exercise its duty to warn. That is, to fund sensitive, culturally appropriate, in-depth education for groups such as minority women who have not yet appreciated their risk. Educating people about their risks in ways that are meaningful to them can give them the power to protect themselves. I think that is the ultimate goal. Thank you.

CHAIRMAN WATKINS: Thank you, Ms. Levine. Dr. Schaerf, if I pronounce your name wrong, I apologize.

DR. SCHAERF: That is correct, that is fine. Mr. Chairman, members of the Commission, I appreciate the opportunity to share with you my experiences with regard to patient confidentiality and duty to warn. I have submitted my written testimony. I would like to summarize it.

I am a psychiatrist, an attending psychiatrist at Johns Hopkins Hospital on the First AIDS Service where we see approximately 100 to 200 patients on the psychiatric side for a year. As psychiatrists we are really in a unique position because we deal with ourpatients' mental lives. Our patients tell us what they did in the past and they tell us what their behaviors are going to be in the future. It is also unique because we have to balance our role as patient advocates bound by confidentiality and our ethical duty to society to warn individuals of potential harm. I would like to share with you some of our experiences with regards to this issue and tell you how we have dealt with it as it has come up.

The first point I would like to make is that 99 percent of the time, in the majority of cases, our patients are responsible citizens. They find out that they have HIV infection or that they have AIDS, they tell their significant others or their sexual partners, and they become very responsible. They practice safe sex. Patient zero of recent media fame who goes out and spreads the virus indiscriminately is not seen, at least in our practice. Sometimes patients initially hesitate to tell their partners. This is especially true when they first find out their serostatus. They are not going to go with that news and immediately tell their partners, but over time, with persuasion and keeping the therapeutic relationship with the patient, usually these people come around and they do inform the other person and they do develop safe sexual habits and stop high risk behaviors.

A small minority of patients continue their high risk behaviors despite our interventions. So who are these people? Many of these people have major mental illnesses or mental problems that psychiatrists can help, and this makes the point that it is always important to know what a person's mental state is when they are engaging in any behavior. We have treated some patients with mania, who have hypersexuality. That is, they have the repeated motivation to engage in sexual behavior several times a day, and we give them a mood stabilizing drug such as lithium and their behavior decreases. We have also treated some patients with schizophrenia who engage in high risk behaviors and treated them appropriately and their hallucinations and delusions go away and so do their high risk behaviors.

There have also been a few patients that we have given Depo-Provera, which is a drug that decreases sexual behavior and decreases testosterone, and they, too, are able to decrease their sexual behavior and act more responsibly. I think psychiatrists can do a lot to help these people, and there is no real argument about that.

Occasionally some of these individuals refuse hospitalization and refuse treatment and then we are able to

invoke our state mental health commitment laws, put them in the hospital, treat them, and they get better. Then there are those who we cannot help as easily and they are probably the most frustrating for us, and again, it happens very rarely but let me give you an example. We recently evaluated a young man who was carrying out high risk behaviors. We found out he was carrying out high risk behaviors in a local park and we admitted him to the hospital to evaluate him, thinking that maybe he was suffering from a treatable illness such as hypersexuality due to a paraphilic. This is a sexual problem with a specific treatment where we could give him a hormonal agent, and he would decrease his behavior. Or maybe he was suffering from mania and we could treat that with a mood stabilizing drug.

We saw him and we evaluated him and we found out that he was really suffering from mild mental retardation and he had some anti-social traits so we really were in a dilemma on how to help him because he was not going to decrease his behaviors. We clearly could not certify him to a mental hospital. That was probably the worst thing we could do because a mental hospital is not a good place for these people. Putting people with high risk behaviors amongst other patients who themselves have trouble with their judgment is not the prudent thing todo. Also, putting them in the criminal justice system is not in his or society's best interest.

So what do we do with these patients and what is our duty to warn others about them when there is no specific individual to warn but rather society at large was at risk with this patient? According to the AMA and the APA guidelines, when you come to such a situation, you are supposed to notify your local health department. We called the health department and found out what their policy was and what they would do, and basically what they would do was put this patient's name on a list of patients that were a danger to others, but they had no policy and no treatment plan for him. So notifying the health department was not going to do much for the patient and it really left us in the lurch because we still wanted to maintain our relationship with the patient and really help him.

So there is this false sense of security. Having a duty to warn, while it might make me feel better when calling the health department and make society feel that the problem has been solved, does little to address the issue. I still have the patient to deal with and the patient is still out there and doing his behaviors. We need a further plan for these individuals outside of psychiatric hospitals, outside of the criminal justice system. For example, we need some strictly supervised residential centers which would provide the least restrictive environment for these patients and also protect society. We eventually, incidentally, discharged this patient back home. He now is going to go on the antiandrogenic medication. We

also gave him 30 days in our day hospital and also did some behavioral interventions and he is no longer a risk.

In summary, I would just like to say that 99 percent of our patients behave responsibly and less than one percent do not. Some of those suffer from mental illnesses that psychiatrists can really have an impact on, but some continue their behaviors and creating duty to warn statutes is not enough. We need further mechanisms to care for these patients and continue our relationship with them. This would be in the best interests of our patients and the best interests of society. Thank you.

CHAIRMAN WATKINS: Thank you, Dr. Schaerf.

DR. BRENNAN: Admiral Watkins, if I may just say a couple of points. I will take a minute and a half. I would just like to say that the Tarasoff case has created a very broad duty to warn on the part of all medical practitioners, psychiatrists, internists, surgeons, everyone. And the question that arises, why do we not see more health care practitioners out there warning third parties because this is not a problem that arises very frequently and there have not been any cases on it. The reason is that in the high prevalence states such as the state of Massachusetts, the state of New York and I believe the state of California, there is specific statutory language surrounding HIV antibody tests which state that you cannot reveal the results of those tests to anyone but the person who is tested.

So if you go to your hospital lawyer in Massachusetts, for instance, and you say I understand I have a duty to warn, should I warn this third party who may be at risk, the hospital lawyer will say, well, I read the statutes to say that total confidentiality attends HIV antibody tests and you should not warn. That is the way things stand, at least in many of the high prevalence states right now so that, for instances, most physicians do not perceive a legal duty to warn third parties at this point.

However, there is a movement afoot to make an exception to those statutes so that individual practitioners can warn third parties. The Commissioner of Health for the City of New York has addressed this and so has the American Society of State and Territorial Health Officers have begun to address whether or not there should be an exception to this general rule of confidentiality. I think that would be a mistake because what it would do, if you made up that exception in the total confidentiality, what will happen is doctors will go to their lawyers just like doctors now go to Mr. Reaves and they will ask him, do I have a duty to warn and he will say, yes, you have a large liability if you do not warn so you should warn fairly broadly if you have any suspicion that someone else may be at risk. You should warn them or else you may be liable.

But that is going to have some bad effects because as others have mentioned, first of all, doctors are not trained to address these extremely sensitive issues with the third parties. Moreover, doctors are very busy in their practice, and I cannot conceive of anything other than they might send a letter or make a telephone call, which is not an appropriate way to tell someone that they may have contracted HIV.

Secondly, I think that that approach, if doctors perceive that they have to warn very broadly, is going to chill a lot of people's interests in having an open relationship with their physician, especially regarding their HIV status. The third thing it is going to do is promote a lot of litigation which is something that we do not need at this point in the AIDS epidemic.

CHAIRMAN WATKINS: Thank you, Dr. Brennan. Mrs. Gebbie?

MRS. GEBBIE: It is really hard when you get to a topic as vital and as complicated as this one is at this hour of the day. First, a comment to Dr. Schaerf -- I am not good at pronouncing names either -- about your treatments with the local health department. I think in general those of us in public health would say that kind of response is not a very responsible one. I do not know what the specific circumstances were but local health departments when approached voluntarily by physicians saying we need help with a particular patient in this epidemic are willing to look pretty creatively at alternatives. At least, that is my experience working with my colleagues so I hope you have better luck on that one next time.

The resolution of this area, it seems to me, is caught up in sorting out what is the very clear duty on the part of public health agencies to warn, based in a structure that is well supported. We have heard something about the history of that and what it comes from. Also, the individual physician's duty to warn, which is emerging from court cases in contradiction of that traditional confidentiality, and that it is not an either/or answer. I, too, have heard from a number of physicians who have not wanted to get involved with warning. They do not like doing it for syphilis, they do not like doing it for TB, and they do not think they want to do it for this disease either but feel bound.

So it seems to me what would be most helpful to hear from each of you, any of you at this point is in what arena or by what method do we bring together the persons concerned about the confidentiality, the persons knowledgeable about, concerned about the duty to warn. How do you find out how you talk about that that is going to be productive and not get into yelling at each

other or sort of demagogery about speeches but rather be productive in resolving this on the basis of some good principles. What would you recommend?

DR. BRENNAN: Well, I think, there is a big problem lurking in the background here. The reason why the Commissioner of Health in the City of New York, at least in the things that I have read, and other people may be interested in having doctors carry the duty to warn rather than some sort of public health agency is the overall concern about contact tracing. Civil libertarians, gay rights activists, many physicians, are very concerned about getting public health agencies involved in sorting out who may be at risk and doing serious contact tracing the way that was done with syphilis in the 1940's.

MRS. GEBBIE: That is still done today, by the way.

DR. BRENNAN: And it is still done today, right. So they would like to have it done at a level of the individual physician without any police power of the state being involved. I think that is what is going to cause the major conflict when you try to get a state agency involved in warning. If you must get a state public health agency involved in warning, it is going to have to be a state public health agency that has a very clear statutory power to maintain the confidentiality of the names that it receives, even if this is against the wishes of other public health agencies.

In other words, if names are turned over to a state agency to help with this third party warning, then those names are going to have to be kept confidential and not shared with any other agencies within the state, even any other public health agencies. So I think that is the kind of thing you are going to have to approach, but I think it is probably a better way to do warnings than to have the individual physicians try to do it because I think all of us are concerned about the fact that individual physicians just are not well trained to do that in a sensitive manner.

MR. REAVES: One of the things that is going to be a big problem, legally speaking, is that we really do not know what all the questions are let alone what the answers are. Very recently, we are now seeing legal liability in the child abuse situation predicated upon state reporting statutes. The courts are saying that because of these reporting statutes, a child may in fact have a cause of action against the mental health professionals who treated the abuser. That leaves me with the question of what will the courts say about those reporting laws that now include AIDS as well as other reportable diseases. Does that go on to create a cause of action for the victim that could not be notified by the mental health professional, the unforeseeable victim. I do not think we are at the point where

we could possibly get together and resolve this particular situation.

MRS. GEBBIE: So you can just leave it? Because it would be difficult to resolve, do we just walk away from it or what do we do to work on it?

DR. BRENNAN: I think there is a basis for resolution. This confidentiality, the state laws of confidentiality are not part of the common law. They were written by the states. In the common law, there was no doctor-patient confidentiality. This was something that the states enacted because they saw that it was important for patients to be able to share information open and candidly with their physicians. So I think that if a state writes a law in this regard, tries to set up a rational process for warning third parties, the courts are going to generally prefer that. You may disagree about individual states, how their courts are going to come out, but I think that we have the basis for taking some rational steps from the point of view of the state legislatures in this area because this law has always been controlled by the state legislatures.

MR. REAVES: The problem is that there are state legislatures that are addressing the failure to warn situation and are passing laws but the laws that they havepassed protect you from liability only if you disclose. So if you agree that that is the way to handle the problem, then fine, 51 or 52 U.S. jurisdictions could pass a law that says that everybody, once they disclose, no liability is imposed, and I am not sure that this panel thinks that is the best thing from a medical or ethical point of view.

DR. SCHAERF: If I could just respond to that question, I think there are several things we can do. One is certainly to get together and try to settle the problem and in that dialog I think what we need to do is remember that this is a low frequency event, remember that we need to evaluate the mental state of the person because a lot of times it is treatable. I think one thing we need to do is set up some options for the treating physician. One of the problems is that we do not have a lot of options now. We have guidelines and some laws to report somebody or to do this or do that, and that makes it very difficult when you do not have a lot of treatment options.

I also think we need to educate the public more which is obvious but that would decrease the chances that somebody is engaging in high risk behaviors and transmitting the virus. If everyone is educated on safe practices transmission would be reduced. Finally, the most difficult thing is to let me be a physician. It is very hard to be a physician practicing defensive medicine and wearing the hat of a Public Health Service officer part of the time and the hat of a physician part of the

time and the hat of an agent of social control. I really want to wear the hat of a physician and that is the way it works the best with patients if they know that I am their physician. They will come to me and trust me. Another point I would like to make is that there is a lot of expertise I think in medicine and there is a lot of expertise in psychiatry. The emergence of this virus has not changed that expertise and we do have ways in which we can impact on people's lives and usually improve them.

MRS. GEBBIE: Dr. Brandt, did you have any comment on this?

DR. BRANDT: Well, I largely agree with that. I think that you want to create a situation in which doctors can do what they think is right, and I think that in that sense, holding doctors liable if they do report or if they do not report, at least to serious questions, and it is obviously a point where there needs to be considerable consultation between public health authorities and physicians. I think you can set up situations where physicians could call public health authorities on an anonymous basis. I have a patient, this is the situation. I do not know what to do, similar to the situation that Dr. Schaerf described in which there is then a process which goes on, and even without an official notification by name. I think the basic thing to keep in mind, this is really true of the entire work of the Commission and all public health working, is what are the situations that are going to create fewer new transmissions of the virus? It is a relatively modest goal in some way, but it is one that we might be thinking of. What policies might lead to fewer transmissions as opposed to more in the future, and it means creating a system that has a great deal of flexibility.

I do not think single laws are going to solve this problem and so we could create a lot of laws and restructure, for example, notification and contact tracing and that is not going to solve this problem. I am arguing it could make it worse, but I do think you are right. You need to establish very strict protocols. What do I do when I finally hit that one in a hundred or maybe it is one in a thousand patient who is not acting responsibly. What are my choices? And there ways of building in legal precautions to insure that the rights of that patient are affected even while potentially notifying.

I mean, one of the things that Dr. Schaerf mentioned to me that served as a model of this and it has been controversial are policies for civil commitment. In most states, when two physicians agree that a patient might be of harm to him or herself or to others, there are policies where physicians can, in fact, restrict the civil liberties of those patients. They are unusual, they are difficult, they are painful, they raise ethical issues, but we can begin to look towards some of those analogs where in those rare instances we can restrict patients until they

can act in a socially responsible way. And I think those are the kinds of analog policies we have to look at.

I just want to say one other thing about contact tracing for syphilis in the past. It was a program that had certainly possibilities, especially with good treatment. As better treatments become available, the desire to notify third parties could become more intense, and I think that this is going to be an area in which there are going to be significant changes over time but the other thing to remember about contact tracing for syphilis is it is very hard to demonstrate that it ever had a fundamental impact on reducing the aggregate number of syphilis cases. Many people in public health swear by contact notification of syphilis but it would be impossible to evaluate the quality of that program for actually closing down syphilis. As you say, it continues to go on, and yes, as we also know, syphilis has remained an enormous problem and, in fact, a growing one in the United States.

MS. LEVINE: I would just like to add that I think the kind of expertise that Dr. Schaerf and others have, the experience that they have had in persuading those 99 people to do the right thing, should be made available in some way to all of those who will now be facing that problem for the first time, and so that they do not have to recreate that experience -- what works, what does not work, what are the techniques. Physicians can learn how to persuade and I think that is certainly the best way to go about it for everybody concerned, the doctor, the patient, the third party.

DR. BRANDT: I just have one thing to add to that. In terms of your recommendations, one of the things that will be important, I think, is recommendations about medical curricula or public health curricula and nursing curricula in terms of how to educate our helping professions to deal with patients with these problems. This is one area where you can make clear that there are things that doctors, nurses, health care professionals can learn about dealing with patients with this disease that are going to lead to fewer new transmissions. So it is medical education with a real public health utility.

MRS. GEBBIE: My other area of question is one that was not particularly mentioned by any of you, but as an analog, some of the legal liabilities you have been talking about. In conversations with public health agencies about their potential responsibilities in warning, assuming physicians wanted to report cases and that reporting was viewed as the sensible way to go, that is also very labor intensive activity for which very few agencies have been given much new money in the face of this epidemic. It seems to me that this situation then sets up a position of liability on the public health agency who knows about somebody who ought to be warned but has not got anybody to send

out to do the warning. Have you with legal experience any sense of whether that is a real concern or is that a concern just being drummed up because it is useful in begging for money from county commissioners and legislators? What should we do to explore that area as well?

MR. REAVES: It is not as big an area of risk when you are dealing with a public agency because you have a theory of governmental immunity to fall back on.

MRS. GEBBIE: Not in my state.

MR. REAVES: I am not sure which state you are from but in many, states your primary line of defense in such cases ought to be governmental immunity. I mean, it is a definite advantage in most juridictions that I am aware of.

MS. LEVINE: I will just say that, not in terms of liability but in terms of understanding what all of this is going to take, I talked to someone from a public health agency in charge of this kind of program. It takes two months to train somebody; that person can only interview a certain number of people and follow up. We cannot underestimate the resources that are going to be needed if this is going to happen on any much larger scale than there is now. As I said earlier, I feel that to do the notification without that kind of commitment to follow up with these patients can do more harm than good. It can turn them away, can turn those potentially infected people away from the public health people themselves. But it is important to consider in terms of resources not in terms of liability.

MRS. GEBBIE: Thank you.

CHAIRMAN WATKINS: Dr. Lee?

DR. LEE: Dr. Brennan, you should be wearing a green tie, should you not?

DR. BRENNAN: I should be.

DR. LEE: You look like the real article to me. Leo Arnaiz, on our legal staff here, helped me out when I was looking for a philosophic basis for the duty to warn. I feel intrinsically that a physician does have the duty to warn. Different perhaps than a priest might have or a lawyer might have. When you tell a lawyer you are going to kill someone, he never tells anyone but as a doctor, I always feel I should tell someone. Leo pointed out the speech by Ronald Bayer from the Hastings Institute where he points out a quote from John Stuart Mill who seemed to me to go right to the heart of it, and he describes in there the principle of harm as being the final limitation on liberty. What do you people think about that? I

think that is an excellent justification before any jury for justifying the duty to warn.

DR. BRENNAN: I think that is right. Ms. Levine quoted from LeRoy Walters' very well-known article on confidentiality that basically takes that same liberal point of view. There is an ethical duty to maintain confidentiality but there is also an ethical duty to limit confidentiality at times, and that one of the limitations is that if someone else is going to be harmed, then something must be done. I think that all of us agree that something must be done. The question is who should do it, and how should it be done. I think all of us share Dr. Brandt's feeling that we have an opportunity here to decrease the transmission if we do it in a proper way. It may take better education of physicians and it may take, I think it will take, a lot more money for the public health agencies that are involved. Nonetheless it is an opportunity to do something to decrease the transmission of the virus. I think we cannot pass it up. But I agree heartily with the sense that you communicated that we really have to have some limitation on confidentiality or other people may be harmed.

CHAIRMAN WATKINS: Ms. Pullen?

MS. PULLEN: No questions.

CHAIRMAN WATKINS: Dr. Walsh?

DR. WALSH: I tell you, I must be getting dense this late in the day, but as someone who has been a practicing physician and a teacher in a medical school, I came here thinking I knew something about confidentiality in our profession. By the end of today, I am beginning to wonder whether I ever knew anything about confidentiality. I feel that again it is like a broken record, physicians have always practiced the principle of confidentiality and as Dr. Schaerf has pointed out, one of the problems physicians face is that they would apparently like to be physicians and do what they think is best for a patient.

Now, when I was in teaching and when I was a medical student and when I taught medical students, we always talked in very fundamental precepts that the best way to be a good physician is to take a good history and do a good physical and we were instructed to write a complete history and write a complete physical. Now what I am hearing, if I am hearing correctly, is that in many states as a physician, even though you know someone has HIV in recording his medical history, you had better damn right not put it on the hospital chart, you had better not tell the resident or intern or you had better tell the resident not to put it on the chart because, as someone pointed out, this morning, 77 people look at that record.

I hope that I am wrong because that is where the confusion about confidentiality as has been presented leads.

Then we are told that because of these things, in many states, the diseases cannot be reported in the public health sense because this would violate confidentiality and that somehow if we applied the usual sound principles, not only in public health but in just good medicine, that we are going to drive people underground. I find that quite nebulous because if anyone thinks they have a fatal disease, I think the last place they are going to want to go is underground. I think we have built this up into something that is, you know, sort of a ghost on the horizon, that we are going to chase people underground who would rather die quietly than die with dignity and die with attention.

I accept what Dr. Schaerf says, and I think it is probably correct, that 90 percent of the patients that you see are perfectly willing to tell you who their contacts are, are eager for treatment, and eager for help. So the last thing in the world I want to see is a federal law on confidentiality and we have heard repeatedly that we should have a federal law on confidentiality. There are bills before Congress which will penalize physicians, however unwillingly they may violate confidentiality in the interest of good medicine. These physicians think that this is the way they are supposed to practice, this is the way they have been traditionally trained.

I am confused. Are we carrying this confidentiality bit, I mean, we all agree that the principal of confidentiality has always been held in the practice of medicine, but are we carrying this confidentiality bit so far as to create a situation which can potentially be harmful to public health and to the health of the uninfected? Are we creating laws which will create careers for new, young lawyers, a whole new batch will come out and be nothing but experts on AIDS law? We are seeing them already. But it seems to me that we are self-inflicting this wound on those of us in a profession who are charged with really caring for these patients who we want to treat with compassion and we want to treat with all that we have to offer. Yet, it seems to me that we are self-defeating if I am hearing everything correctly. I would welcome comment. Reassure me, straighten me out because you have got me confused.

DR. BRENNAN: If I may respond just to some of the points of confusion. It may have been some of my comments that confused you. In a clinical practice, what happens, at least in the hospitals in Massachusetts where we have a very strong confidentiality law as far as the HIV antibody test, you take a history and physical, and those things go on the chart --

DR. WALSH: They do go on the chart?

DR. BRENNAN: They do go on the chart. Everybody who is taking care of the patient in the hospital knows about the positive HIV antibody status, but they are not supposed to tell anybody else.

DR. WALSH: Well, you are not supposed to under any circumstances.

DR. BRENNAN: Exactly, but you do report it to a state agency. Now, our HIV antibody test law is so strong that there was some concern among health lawyers that perhaps there was a question you should tell the home health agency who is going to be caring for the patient when he or she got out of the hospital about the patient's positive HIV antibody status. So it has created some confusion not in the wards of the hospital, but in the transfer from the time one goes to hospital to the home health agencies. Thus there are concerns about liability.

The point about people going underground, I do not think anybody who has full blown Acquired Immuno Deficiency Syndrome is going to go underground because they are going to need medical care and they are going to seek it. The people who we are more concerned about are the asymptomatic people who carry the virus, who are not ill at present, but with whom it is probably important to set up a therapeutic relationship and advise. Those may be the people who decide not to seek medical care, who are not counseled appropriately.

DR. WALSH: Let me just interrupt to ask you a further question because as we see the CDC prognostications are changing all the time. Currently CDC estimates are that up to 40 to 50 percent of seropositives will die and many experienced and trained people feel that 100 percent will eventually die. Now, instead of impressing seropositives with their civil rights, would it not be more appropriate to impress them with the fact that possibly even with the few interventions we have now, we may be able to suppress their eventual infection? It seems to me that we are using a reverse psychology in making them feel that they should go underground and that does not make any sense to me.

DR. BRENNAN: I think that is where we disagree because what I am saying is by supporting their civil rights, by assuring them of confidentiality, we bring them into a situation where we can counsel them and talk with them and provide a therapeutic relationship. In other words, we do not scare them off because they are afraid that if they go and tell a health care professional that they are HIV seropositive, that health care professional, because he is concerned about liability, is then going to then try to find out who that person --

DR. WALSH: No, we do not disagree on that. I agree on that. What I am saying is that perhaps the ones that are not coming in, the ones that I am concerned with, I do not think they would go underground if they knew that you would establish that relationship with them. There would be no sense to going underground.

DR. BRANDT: But I think the basis of establishing that relationship is a confidence in confidentiality.

DR. WALSH: That is right.

DR. BRANDT: And I think that we have to be quite pragmatic and realistic about this particular disease. It is not like any other disease. It is a special disease, and that is why we are here, and it is a disease that is very highly associated with criminal behaviors relating to drugs, with behaviors that have traditionally been considered illicit or deviant or illegal related to sexuality and it is a disease which holds a great possibility for intense stigmatization and discrimination against victims so in other words, given all those realities, there is a heightened concern about confidentiality in general.

Now, if you take a look at writings about confidentiality in the last decade or two decades of the 20th century and you look at third party payment, the number of people who have access to a chart, you realize that there has been a significant erosion of the basic understanding of what confidentiality means, even before AIDS. When you introduce a very serious diagnosis like HIV infection into a chart without the guarantees of confidentiality, you run the risk of building in very serious disincentives for people to cooperate within the system.

So, I am saying we need to develop the kind of system in which people feel comfortable, confident and trustful coming into it if we are really going to deal with the problem, and anything that we build in that is going to push people away, underground maybe is not the right word, but make people feel skittish about coming to a doctor and talking the truth, then we are really going to lead to what I think is a more serious public health problem.

I want to make one thing really clear. I am not defending this issue of confidentiality on the traditional notions of civil liberties. I am defending it as a public health functional mechanism and I think it is important because it is very easy to say, well, that is a civil libertarian point of view. What about the public good. But this is the public good, confidentiality. I think that is why we are talking about it so seriously.

DR. PRIMM: Dr. Brandt, how would you suggest that we communicate on a medical hospital record to a colleague or someone else the fact that someone is infected with the Human Immuno Deficiency Virus? Let us say I am in a Department of Surgery and I want a psychiatric consult from Dr. Schaerf's the Department of Psychiatry. Would I approach Dr. Schaerf in the hall with, "Look, Schaerf, you know John Doe in 332 that I wrote a consult on, he is infected with HIV. I want you to check him out for dementia?" What would you suggest that we recommend to the President with respect to this issue?

DR. BRANDT: Well, I think you are raising an issue that obviously in germane to this epidemic and more germane in general, given our record keeping mechanisms, the introduction of new technologies for keeping records and who has access to them. I think this raises a question that needs to be confronted. Obviously, health care personnel taking care of a patient may need to have that kind of information. It should be easily accessible but we need to prescribe the limits of its accessibility very specifically, and I think there are ways of doing that, and there are people who know much more about record management in our corporate world and in a variety of record keeping.

DR. PRIMM: I submit to you, Dr. Brandt, that there was a witnessearlier that gave testimony that over 70 people handle a so-called medical chart in an institutional setting. There was something like that if my memory serves me correctly. I think your argument is a good strong one, and I listened to you very attentively when you made it and I agree with you. On the other hand, we have got to have some solutions and I do not see anybody giving us solutions for a very pragmatic problem that exists. Communicating to Dr. Brennan or Dr. Schaerf that so and so has HIV infection certainly would influence him going there or ease his ability, make it more facile for him to make a diagnosis of perhaps dementia or some neurological deficit.

DR. BRANDT: I have a specific suggestion. I think the way we have kept medical records in this country has been pretty shabby and too many people have had access to them. One thing we know about electronic record keeping is you can restrict access to people with very specific codes, and those people would maintain confidentiality. There would not be that anyone in a hospital could pick up any hospital chart, and it should not be.

DR. WALSH: In California you cannot even put it on the chart like you can in Massachusetts.

DR. PRIMM: I hate to say to you that codes have been broken in terms of getting into all the computer archives around the country. You know that, and I do not mean to be throwing a

monkey wrench into everything you might suggest but we might be able to start with that, of course.

DR. BRANDT: I think the point is we have to create the right atmosphere and make clear what our values are and then do the best we can technically. We cannot solve the problem of information technologies when we try to solve some of the problems of the AIDS epidemic, but we need to make clear what our commitments are and then do the best we can to keep them.

DR. PRIMM: But there are many other stigmatizing diseases, too, that are indelibly stigmatizing as you well know. You talk about syphilis, you talk about cancer. We never mentioned that. It is a stigmatizing disease also, and we write that. We got over our fear of writing that so I do not know what is going to happen but I think bright young minds like yours are going to have to come up with some recommendations if we want to do something about the problem.

MS. LEVINE: May I just say that I do not think the problem is so much what is in the medical record. It is in who, what happens to it afterward. The main concern is not that people who are caring for a patient have access to that information but that those people do not talk about it in the cafeteria and the elevator and in their neighborhoods and all of the other places. This is an opportunity for the health caring professions in general to have the value of confidentiality reemphasized. They may have heard it a long time ago, but in the casual way of hospital and other health care settings, it just does not have that urgency that it needs to have. So it is not the chart, it is the people and what they do with that information that we really have to be concerned about.

DR. BRENNAN: I think that is the most important one because the technological ways of shielding identifications are helpful but the most important thing is to reiterate to that core group of people who need to know a person's HIV antibody status that the test result is confidential.

DR. SCHAERF: I agree with that. I wanted to say that at Hopkins, my patients are not afraid about who is going to know about their status in the hospital. They sit on a unit that is a dedicated AIDS unit. They come to a clinic that is a dedicated AIDS clinic. What they are afraid of is their employer -- what they are afraid of is their insurance company and those types of discriminations that happen outside of the hospital setting and that speaks to the point of who gets the chart and who gets the information.

CHAIRMAN WATKINS: Dr. SerVaas?

DR. SERVAAS: Thank you all for coming. I think you have given us a lot to think about.

CHAIRMAN WATKINS: Dr. Crenshaw?

DR. CRENSHAW: Dr. Brennan, you were commenting on the potential hazards or loss that might require someone warned. In California as well as in other states, it is a crime for a physician to tell a sexual partner that their partner is infected. They can also be sued for everything they are worth. This law is preventing any action on ethics on duty to warn except in very courageous people who are willing to gamble everything they have ever worked for to do so. We have also had many, many lectures and guidance for physicians in California where they have just basically been told, you are going to get sued if you do, and you are going to get sued if you do not, and you are better off warning, being a better plaintiff that can be defended than not warning. I have heard from this panel something that I find really difficult to interplay either logically or emotionally. I have heard that it is mainly women who would be involved at this time in duty to warn which is probably true but that being told, particularly if they were told in an improper way might upset them, the conclusion being it is better to let them die in the event that you might have told them in time before they were infected, and bear in mind that 50 percent of the sexual partners of infected people do not necessarily get infected, at least for a long period of time.

I heard the comment that if the duty to warn occurs, that it should be done with emphasis on encouraging sexual activity between that couple. I also heard that they are probably infected anyway so what is the point of warning, and I heard the most illogical thing that I have heard consistently in this epidemic, that because there is no cure, there is no point in warning, and it seems to me that because there is no cure, it is even more important to warn. We are talking about ethics so the thing that I want to, oh, and I might also comment on mentally impaired patients who should not be put with other mentally impaired patients but where duty to warn is not the first response, where chemical castration which in the past was more controversial than any of these issues, is the first line of defense.

Now, it is kind of a buyer beware sexual attitude, even among spouses as a result of these things. I recently learned of a case, a woman who could not be with us here today who fits into this, and I would like your comments on this. She is a woman who had been married for 20 years to a pillar of the community, successful businessman, leader in the religious community, who had been in and out of the hospital for about 8 to 11 months. She was very concerned that there was something dreadfully wrong and wanted second opinions but was not a very

assertive woman. I might add, incidentally, that she had six or seven children. When she finally, 11 months later, got agitated enough to insist from her husband's physician that a second opinion be gotten, her doctor said to her in a rather irritated fashion and an angry way, we do not need a second opinion. We know what your husband has. He has AIDS. The doctor also informed her that he had many bisexual spouses in the condition and that he did not tell her because it was against his ethics.

Now, she was later diagnosed with ARC, and who knows retrospectively when she became infected. A few months previously, she had been asked to donate blood for her daughter who was pregnant and hemorrhaging during birth and not knowing that she was infected herself, she donated the blood. Her husband was aware that his wife's life was at risk, he was aware of the donation, he was aware that he might kill his daughter and this child. So I would like your comments on whether it was ethical to leave her in the dark.

DR. BRENNAN: Just to comment on the confusion, Dr. Crenshaw. I do not think anybody here, especially me is saying that just because it might upset somebody, they should not be warned. The question that we are trying to address is who should do the warning. If you are a physician in a state that has got certain laws and you approach public health authorities because you think someone needs to be warned and the public health authorities cannot do it, and you feel you are ethically bound to warn that other person, as I might in the situation you outlined, I think no matter what the law says, you go ahead and give that person a warning. I am not trying to say in terms of the debate about whether individual physicians should do it or public health agencies, that it should not be done if nobody can do it in a nice way. That is not what I am saying at all. What I am asking is, who will be able to do it in the best fashion possible? terrible.

DR. CRENSHAW: Well, I may have misunderstood, but I heard from I thought at least four of the members of the panel that if someone was unwilling to warn then you worked with then until they were willing and that could be a few months, it could be a year and consequently someone is not warned in the interim. I am glad to hear you say that clearly because that is what I need to hear. I think if someone is infected and having sex with someone else and putting them at risk, I do not have any dilemmas or debates. I think that person should be warned, but I am not hearing that.

DR. BRANDT: I heard just the opposite. I heard a general consensus among this panel that in the instance where you could identify a third party at risk with somebody who was capriciously disregarding their welfare, everyone of us, I think, sees a clear and explicit duty to warn. I do not think there is

any disagreement about it, but there are serious questions about it.

DR. CRENSHAW: Does that automatically include telling a wife?

DR. BRANDT: Automatically. Well, if the patient does not do it.

DR. CRENSHAW: Okay. That I appreciate. I am glad for that clarification because that was not coming across to me.

DR. PRIMM: But if he qualifies with the term capriciously disregarded, what if one is just not telling the other person --

DR. BRANDT: I consider not telling capricious disregard of somebody's welfare.

MR. REAVES: But you also predicate by saying that if the patient does not tell a person, I do not know how you can guarantee that unless you satisfy yourself personally that that warning has been given them.

DR. CRENSHAW: I agree, and the Public Health Department has systems to do that very effectively and without revealing names if it does not happen to be a sexual partner as Kristine Gebbie was explaining a little earlier.

DR. WALSH: But that is the problem. The federal legislation that is before the Congress now. Several of those bills do not permit the physician to tell even the wife. I mean, I do not think that one will get passed, do not misunderstand me, but there are bills down there that will penalize the physician for telling anyone without consent.

MS. LEVINE: That is not my understanding of the Waxman bill which does permit, as an exception --

DR. WALSH: There are 45 bills down there.

MS. LEVINE: Well, that is the main one that is getting the publicity.

DR. SCHAERF: Let me just reassure Dr. Crenshaw as well. I think all of us would follow the guidelines and we would inform one specific individual. Let me just say that I have never needed to do that, and neither has Dr. Clete Di' Giovanni or Dr. Jeff Ackmann at George Washington, and we probably take care of 90 percent of the patients that are HIV infected in the Baltimore-Washington area. I would resist having any legislation that would give you a specific window to do that

because, again, it does not happen the first time you see the patient but maybe in the first week or two it does and it preserves that therapeutic relationship.

DR. CRENSHAW: Well, I am reassured to hear that you are all unanimous that the spouses should be informed one way or another, and I have no disagreement with the approach. As a matter of fact, I think it is the best approach to try to get the sexual partner to either tell themselves or agree or to offer them assistance if they need it as long as what Mr. Reaves say is true, that there is some continuity and follow up so that you know that it is done, and that if a patient refuses that you take over.

CHAIRMAN WATKINS: Dr. Lilly?

DR. LILLY: Just a comment. Quite to the contrary of Dr. Crenshaw, I did hear a good bit that I liked, and one thing that I particularly liked was something that I have been convinced of for a long time now and which Dr. Brandt emphasized, that one of the main criteria that must be applied to the decision as to what policies to impose in society has to be how effective are they in preventing transmission of the disease. I appreciated hearing that because I am not sure that I have heard that before stated so clearly.

DR. BRANDT: Thank you.

CHAIRMAN WATKINS: That completes our questioning of this panel. We appreciate very much the fact that you have come here and been as patient as you have been to go beyond the prescribed hour. Thank you so much and we would like to keep our relationship with you open from now until the end of the Commission's time if there are any other questions we may have. Thank you very much. We stand adjourned until tomorrow morning.

(WHEREUPON THE HEARING WAS RECESSED AT 5:58 P.M. TO RECONVENE THE FOLLOWING MORNING.)