TRANSCRIPT OF PROCEEDINGS

NATIONAL COMMISSION

ON

ACQUIRED IMMUNE DEFICIENCY SYNDROME

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Washington, D.C.
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NATIONAL COMMISSION

ON

ACQUIRED IMMUNE DEFICIENCY SYNDROME

Monday, September 18, 1989

9:00 a.m.

Washington, D.C.

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COMMISSIONERS PRESENT:

June Osborn, Chairman

David Rogers, M.D., Vice Chairman

Scott Allen

Diane Ahrens

Harlon Dalton

Eunice Diaz

Donald Goldman

Larry Kessler

Charles Konigsberg

Belinda Mason

J. Roy Rowland

Irwin Pernick [Representing VA]

David Newhall [Representing DOD]

Jim Allen, M.D., [Representing HHS]

STAFF PRESENT:

Maureen Byrnes, Executive Director

Carlton Lee, Chief Liaison Officer

Thomas Brandt, Director of Communications

Jane Silver

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P R O C E E D I N G S

CHAIRMAN OSBORN: Good morning. I'd like to call the meeting to order.

Almost all of the commissioners are here. Through the compliments of the airlines, one or two are unavoidably late but will be joining us shortly.

I welcome those of you who have come to participate in the opening substantive session of the new National Commission on AIDS. I'm June Osborn, Dean of the School of Public Health at the University of Michigan and the Chairman of the Commission.

Dr. David Rodgers is Vice Chairman of the Commission, and I hope as we go you will get to know all of us quite well. I won't take the time right now to introduce everybody, but we hope that this will be a very interactive session and you will get to know a very distinguished group of commissioners as our proceedings develop.

I thought it might be worth opening by telling a bit about the origin of this Commission, some of its distinctive characteristics, and some of the hopes that I at least hold as chairman of the group for

our two year work span, which is the defined life of the Commission.

First of all, a bit of history. The father of the Commission, as we like to say, is Congressman Roy Rowland, who is in fact also a member of the Commission now. Congressman Rowland, who is from Georgia, was, I believe, at the time he wrote the legislation creating this Commission the only physician in either house of Congress and who responded to the express need for a Commission that was broadly representative of national experience and expertise to address the full range of talents this country has to offer to our awful and developing problem with the AIDS and HIV epidemics.

Congressman Rowland's idea ended up as a significant part of the AIDS legislation which was finally passed into law and signed in November of last year and this Commission was therefore created. It is an interesting variation from commissions that you may be familiar with. It is not a Presidential Commission. It is not exactly a Congressional Commission, although perhaps a bit more of that. In point of fact, it is a

hybrid Commission with five of the members having been appointed by the Senate, five by the House, two members at large by the President and then three Cabinet Secretaries as ex officio members of the Commission from the Departments of Health and Human Services, Defense, and Veterans Affairs. So that in point of fact there is a very broad and distinguished representation from the government as well as a broad range of expertise chosen by the President and by the Senate and House.

The need for such a Commission had been indicated both in the earlier report of the Institute of Medicine, National Academy of Sciences, that many of you will be familiar with called "Confronting AIDS." At that time one of the dominant recommendations of that report and its successor report was that a Commission comprised of people with expertise and experience that could be brought to bear on the epidemic was a very crucial need within the activities that respond to the epidemic, and similarly in the Institute of Medicine White Paper recently given to President Bush that was rearticulated.

The Presidential Commission to which we are in a sense a successor did a very impressive piece of work, brought together a set of recommendations which gives this Commission a very strong base on which to begin its work and to assess where we stand and start to look for areas that need special emphasis. Now, the time has moved along but we are very grateful to our predecessor Commission which had a different kind of constitution and different constraints on its function.

One of the things that comes out of this hybrid or different nature of the Commission is that we have a mandate that is not focused strictly on report writing but over the two year lifespan of the Commission invites or asks us in fact to be interactive with Congress, with the Executive as they wish in assessing and reacting to various facets of the epidemic.

With that somewhat broader mandate and the kind of composition of the group, I think that we are in a position to do something that will, I think, be helpful no matter what concrete things we do. It is my hope that this group can contribute to the development

of a compassionate and very convincing national consensus about ways in which the country needs to move as some more hundreds of thousands of people begin to be ill from the HIV epidemic.

Now, that brings up one of the differences also with our predecessor Commission, which began its work at a time when there was quite a lot of argument about how much of an epidemic there was going to be. The argument wasn't carried on very much in expert circles, but publicly it seemed as if there was a concern about whether it was going to be a large one or a small one, or already contained. There was a good deal of uncertainty on that score.

I think in that technical sense the epidemic has matured in a very sad way. We already have an exceptionally large epidemic with over 100,000 people reported ill of AIDS, itself, and we are quite certain that we will have had that number double or triple--double certainly, perhaps even triple--over the lifespan of this Commission. There is an exceptionally large pool of human talent and of Americans to be lost, or at least put at great risk of being lost,

prematurely in their lifespan, and we are, I think, in general agreement that there are in fact over a million people who are now infected and whose futures are jeopardized as this epidemic progresses. So we now have a very large problem, we do not need to argue about whether it is a large problem or not.

Another evolution, as it were, that intensifies our problems as a Commission is the evolution of the drug epidemic, the twin to the HIV epidemic and sometimes, I think, a Siamese twin to the HIV epidemic. There has been recent attention being paid to that--not a lot of attention--paid to the interface between the two epidemics, and that certainly is a critical interface which will in part determine how much longer there need to be commissions of this sort, because it is a driving dynamic of this country's HIV epidemic. So we will certainly need to take advantage of things that have been learned, but also to involve ourselves, I think, in some very important facets of that national problem.

Another very large difference that comes partly from just the number of people involved, but

also from some of the thankful progress that has been, made is the whole set of issues involving care for people with HIV infection and AIDS, cost of care and choice of strategies, including now prophylactic strategies that can significantly defer the onset of serious illness and perhaps even the onset of illness in HIV infected people.

Those are merciful bits of progress coming out of an energetic biomedical research attack on the epidemic, but they instantly present problems of access to care. They intensify existing problems of health care financing and delivery, and will surely drive some of the dynamics of this Commission as we look for ways to be sure that the access to these pieces of progress is as equitable and widespread as can be among those people who need it.

We also need to be communicating the ever increasing firmness with which we are aware of the sharply restricted modes of spread of the virus of AIDS. I think this is something that this Commission can be helpful with in that there has been a residual fear and concern that I think has gotten in the way of

a compassionate societal response to the epidemic, and as the data become ever more overwhelming that casual contact, that interactions in places of business and recreation and so forth, pose no risk to people whose specific behavior does not put them at risk, this is a very necessary piece of comprehension.

Americans, I think, feel that they know a lot about AIDS now, but they need to know that down to the foundations of their soul so that they are in fact free to respond the way they normally would respond to people who are sick and in trouble. We haven't seen as much compassion as we need in an epidemic of this magnitude, and that feature is so strikingly one that is distinctive to Americans that I would like to see that mobilized. It would make everybody's job in the epidemic much easier if we were indeed dealing from a base of compassionate response. So we need to look at ways to enhance and continue efforts in both general public education and then behavior specific education for people whose behavior may put them at risk.

There are a few problems I will point out, although we'll come very quickly to these as the

program progresses. The problem of discrimination against people with HIV infection and AIDS has been a very real one, not one to be argued about, and we will get to learn some more about that. We will want to stay alert to that as we have our hearings and deliberations.

Some of this has come from a very disturbing sense of guilty and innocent victims of the epidemic. I think that that kind of thinking is normally not applied to people who are sick and, as I have often commented, I think that the past and present smokers among us ought to be hopeful that it never does begin to be a habit of people to look at illness in those kinds of terms, because it is both unrewarding in terms of the specific responses needed, and very much away from the kind of compassion that is appropriate.

Secondly, I think we have a problem that must be addressed in terms of public awareness that HIV infection and AIDS are sexually transmitted diseases, not restricted to specific sexual behaviors. There is a variation in efficiency, but sexual behaviors of many sorts are capable of transmitting the virus and that

kind of broad message is necessary to educate our children as well as to, again, diminish some of the sense of special otherness that has been applied to people with HIV infection and AIDS.

As I mentioned, the problem of health care delivery and financing will be intensified greatly for both negative and positive reasons, negative because so many people are going to be becoming ill and in need of care, positive because we now have care to give at a level that we did not before and that's an opportunity that we must find out how to grasp.

We will as a Commission pay some attention to the problems internationally because we are indeed part of a broad human family and must be aware of our role in it. We are the epicenter of a global epidemic, and I say pandemic, and we need to be alert and aware both so that we can find ways to help other countries and nationalities with our experience and also to learn from others.

Finally, in terms of a challenge to the Commission I think that, as I mentioned a bit earlier, the most fundamental challenge will be that of

development of a national consensus. Americans are a compassionate people. They don't walk away from little children who fall down a well and they won't walk away from people who are ill and facing the foreshortening of their productive lives if they understand well the nature of the present problem. We are losing intolerable amounts of both trained and potential talent and we must respond in an appropriate way.

Most notably, at the moment there is something going on that I think we simply must change, and that is because of the discrimination and the misunderstandings about the epidemic, a very large fraction of the 60,000--more than 60,000--families who have lost loved ones in this epidemic so far are having to do their grieving in secret. I think that the Commission should make one of its goals the change in atmosphere that makes that unthinkable process no longer necessary for the people who have been caught in the path of the epidemic to date.

Secondly, I think this Commission faces such an overwhelming set of challenges that we must as a group search out for and address our special energies

to these things that others can't do. Already as chairman of the Commission I'm aware of the pressures to address this or that specific problem, and I am trying to learn a habit of thinking that says is there already a well-constituted group or set of groups addressing that problem? If so, we should remain alert, we should try and keep ourselves educated to progress in that area, but we as a Commission should look for ways that we can specially address the energies of this unusually well-constituted group of experts.

The nature of the Commission and its commissioners allows us a broad latitude in that regard and I think that as today's and tomorrow's discussions progress we'll be searching for those kinds of areas where we can specially make a contribution. It has been worried out loud that this might in fact lead to false expectations with us coming on with a fresh burst of enthusiasm, I hope, and an ambition to make a big change, or at least a difference in such an overwhelming set of problems. I would hope that we will make a difference that will be measurable in

everything that others are trying hard to do, as I mentioned, through compassion and through the infusion of new hope and energy.

In reality we must keep in mind that there is nothing very new about this epidemic except the virus itself and the peculiarly awful set of manifestations that it sometimes provokes. All the rest of the problems that we will be facing are old ones. They have been stalled, they have been met with Band-Aid solutions or they have been ignored up until now, and I think in that context we should all be aware that if we are very good about our work and wise in the solutions, we will be able to make some contributions that go well beyond the very wide confines of the epidemic of HIV and AIDS. Thank you.

This morning, we have asked that we have our deliberations started by somebody who has made a marvelous contribution to the epidemic in essentially every way that I have just been talking about, somebody who has moved national consensus by her very own efforts in a rational way, who has contributed her extraordinary energy and talent to the development of

activist and realistic solutions and who has been very creative in her approaches to the problems that have been coming faster than one can even keep track.

I am delighted that Dr. Mathilde Krim could be with us to inaugurate our deliberations. And let me welcome you, Mathilde.

I didn't give her a very precise assignment because I thought it would be wonderful to hear her thoughts at this juncture in our beginnings, but in an ongoing epidemic of eight years duration now. Thank you.

STATEMENT OF MATHILDE KRIM, PH.D.

AMERICAN FOUNDATION FOR AIDS RESEARCH

DR. KRIM: Thank you very much.

Ms. Chairman and distinguished members of the Commission, I am very honored having the opportunity to be the first to congratulate you on your appointment and to tell you that I believe that each of you can contribute to your work an enormous amount of expertise and experience as well as sincere concern for your fellow Americans, so many of whom are now either suffering from or threatened by AIDS. So first of all I want to thank you for agreeing to accept to become commissioners and agreeing to serve as commissioners.

Your mission is best defined, in my opinion, within the context of the kind of threat the epidemic of HIV infection and AIDS represents for our nation, the kind of resources and capabilities we possess to fight it, and our past accomplishments and failures in confronting it. In 1989 we are still witnessing only the early inroads of a pandemic, a world epidemic, itself the product of the evolutionary process as it has occurred and continues to occur in a family of

human retroviruses.

A viral pandemic is not unprecedented in human history, nor is the fact that a virus can brutally kill. During the lifetime of many people alive today, in 1918 and 1919, a highly pathogenic strain of influenza virus swept the world and killed 20 million human beings. The main difference between the new killer, HIV, and that flu virus is that the flu virus made people sick rapidly and claimed mostly the old and the weak while the young and strong developed immunity against it. Very rapidly, within two years, the influenza virus had no one, or very few, left to infect and its spread was halted and it disappeared from the face of the earth.

HIV, on the other hand, attacks and destroys the very system that should protect us against it and against other infectious agents and neoplastic cells. No one, for all we know, has developed effective and lasting immunity against HIV. No one has become resistant to it. Therefore, we cannot expect the epidemic of HIV infection to be self-limiting. This is a major difference between the previous and this viral

pandemic. Furthermore, because HIV is transmitted sexually and through blood, it infects and dooms mostly young adults in the prime of their lives and their infants, causing extraordinary pain and tragedy and destroying society's most precious human assets.

HIV has another ominous property, it does not cause disease immediately. Clinical symptoms fail, therefore, to alert those who have acquired it, and this for a period we know today to be on average as long as nine years. It leaves ample time for those infected to transmit the virus, totally unwittingly and innocently, to others. This happened most dramatically when HIV first reached our shores, perhaps in the late '60s, and spread silently for over a decade among the people of our coastal urban centers, and in particular among their gay communities.

This is why despite the extraordinary and admirable efforts at education undertaken by these communities and their prompt adoption of safer sex practice as soon as they were alerted of the situation, their population continues to be decimated by AIDS. This enormous tragedy is the result of HIV infection

acquired by many gay men many years ago before anyone knew of the existence of the virus. The properties of HIV I just mentioned--its ability to destroy the immune system and to be transmissible sexually by people who feel and appear healthy--are the viral properties that make of this virus an unprecedented and extraordinary threat to the public health.

Another most unfortunate aggravating factor in the epidemic of HIV infection and AIDS is a societal one, and it is in western countries a widespread and culturally sanctioned active dislike of homosexuals, the group of people first identified as being disproportionately afflicted by AIDS in this country.

Starting in 1982, and certainly by 1983, we knew that AIDS was a venereal disease, a disease caused by a blood borne sexually transmissible infectious agent. Although we did not know the specific nature of this agent, we could well surmise that alerting and educating those at risk could either stop or slow the spread of the disease, but little more. No help, financial or otherwise, was extended to gay community groups, some of which were pleading for it as early as

1982 in New York, so that they could be able to undertake educational efforts in their communities. Not only were they left to fend for themselves, but a terrible stigma came to be attached to AIDS, a stigma that stood in the way of even private charitable and educational efforts.

As for drug addicts, who had been identified as soon as the CDC started reporting the results of its AIDS surveillance program as also constituting a major risk group, the fact that they were also despised and that they were unseen and unheard resulted in a general inattention until very recently, even to the fact that they, for the most part a heterosexual population, were going to constitute the channel through which HIV would spread to the majority population.

The early moralistic and self-rightous response by much of our society to the suffering of people with AIDS was not only morally wrong, callous and cruel, but it was most ill-advised and proved fateful. Precious time was lost which doomed countless more lives, lives that could have been spared by swift early educational intervention.

First, in 1983 in France and then in 1984 in the United States, a peculiar virus of a kind not previously suspected of having any major pathogenic role in humans was isolated from the blood of people with AIDS-related symptoms. I cannot resist informing you that this momentous discovery occurred in two labs that pursued basic virological research of a kind that had been funded by the National Cancer Institute in the '60s under a program called the Virus Cancer Program.

This program was terminated in the early '70s because its investigators had been unable to link retroviruses to human cancers as opposed to animal cancers. Researchers working on retroviruses were often derided with the name of "mouse doctors," and the discovery by two "mouse doctors" that AIDS was caused by a retrovirus, HIV, brilliantly exemplifies the value of pure biomedical research to human welfare. Let us therefore never underrate the value of basic research.

Dr. Robert Gallo of the NIH, the American co-discoverer of HIV, and his coworkers were able to grow the new virus in quantity, purify it, and study its components in great detail. They could then also

develop an ELISA test that can, by detecting the presence of antibody to the virus, identify people infected with it. The use of this test in many people with AIDS and in many people who were healthy or suffered from other conditions, readily showed a strong and a unique association between HIV infection and AIDS. This and other studies soon established HIV as the cause of AIDS.

Furthermore, other seroepidemiological studies revealed that many more--perhaps as many as 20 times more--people were infected with HIV than had AIDS. Studies of infected people followed retrospectively and prospectively over a long period of time showed that the vast majority of them, possibly all of them, ultimately convert from an asymptomatic to a symptomatic condition while progressively losing their natural immune defenses and their ability to fight off life threatening opportunistic diseases.

In 1985 and 1986 the use of the ELISA test progressively revealed the full scope of the epidemic of HIV infection in the U.S., and as you heard from your chairman, one million people were estimated at

that time already of being infected.

As the correct use of this and related tests become more widespread in the Third World, the extraordinary dimensions of the world-wide epidemic, the pandemic of HIV infection, are also becoming disturbingly clear. And WHO has estimated that from 5 to 10 million people now are infected throughout the world.

In the United States, from being once largely limited geographically to urban centers on the east and west coast, HIV infection has now spread to every state in the nation. From being largely limited to high-risk groups identified by the CDC, the infection now reaches beyond them to the sexual partners of people belonging to these groups, mostly to women and children. And I'm sure you have some of the figures, such as the fact that one woman out of 20 who is healthy and comes from prenatal care to a hospital center in downtown Brooklyn in New York is found infected with HIV, and that one kid out of five in certain areas of the South Bronx is infected with HIV--I mean teenagers.

And like most infectious diseases, HIV has

made the most rapid inroads among the poor and among the members of minority groups, those least able to afford being sick, and if they should become sick, least able to access and pay for decent medical care.

You have also all heard the national projections for the immediate future--300,000 total cumulative cases of AIDS by 1992, 80,000 new cases of AIDS in 1991, possibly 70,000 orphans, half of them infected or sick with AIDS by 1992, municipal and teaching hospitals collapsing under the added burden, losing their burned-out nurses and doctors and unable to replace them, finding themselves bankrupt because of low reimbursement rates for the expert and costly care required by people with AIDS, unable to discharge AIDS patients to nursing homes or other care facilities better suited for these patients' chronic condition, people with AIDS dying by the thousands in the streets and in shelters for the homeless, totally destitute.

In New York these are realities we are already facing today. Indeed, because people with AIDS are mostly young, many of them have either never acquired health insurance or they have lost it. They

are being forced to let themselves become totally impoverished so as to qualify for Medicaid. In New York an estimated 7,000 of them are now homeless.

What have we done altogether as a nation in the face of this truly horrifying situation? Research funding by the federal government has increased substantially over recent years and the investment has been highly productive, although it is still far from exhausting all research possibilities. I will return to this subject a little later in this talk.

Prevention of HIV infection through education that seeks to reduce risky behavior is one of the two areas where I believe we have failed most abysmally. We failed to start educating members of high-risk groups in 1983. In 1986 Surgeon General C. Everett Koop produced an excellent educational pamphlet that was not distributed. To obtain it it had to be requested. To my knowledge, it was not even translated into Spanish.

A good comprehensive AIDS bill was enacted in 1987, and that same year a Presidential Commission was appointed that produced an excellent and comprehensive

report in June 1988. However, the letter's recommendations were ignored and not even widely debated. Later that year, a good educational pamphlet was released by the PHS, Public Health Service, and mailed to some hundred million households, but none of the advertising techniques at which the private sector is so adept in this country were used to direct attention to it or to reinforce its message. Its impact, which does not appear to have been great, was not evaluated.

Other federal efforts at public education using the medium of television have been noteworthy for their almost total invisibility. Public service advertising campaigns sponsored by the Advertising Council, the American Foundation for AIDS Research and the National AIDS Network suffered a similar fate.

The education of most of the public about AIDS has occurred partially through excellent but local and necessarily limited efforts by gay community groups. Principally it has occurred through sensational tabloid articles and through several broadcasts of fictionalized stories in which the person

with AIDS was usually very far from being a typical AIDS patient. Some of these stories were highly alarmist, others too reassuring. As a result, although widely aware of the existence of AIDS, the public is still confused and most individuals still find it very difficult to apply what little they know to their personal protection. Their personal attitudes and consequent behavior still range from excessive fear to total lack of concern.

Finally, the greatest failure will increasingly occur, unless extraordinary efforts are undertaken immediately, in the care of people with HIV infection and AIDS. We simply do not have a system that delivers whatever medical and supportive care we could and should provide in a cost-effective and efficient manner. We do not have the kind of care institutions or delivery systems and have failed to either develop or use them, that are appropriate for people who are usually young, who are suffering from a chronic, progressively but capriciously worsening and anxiety provoking disease, almost half of whom have no health insurance.

It has often been said that AIDS in many ways dramatically highlights the preexisting defects in our society. The most glaring and central one has for too long a time been, in my opinion, a lack of articulated moral leadership from the highest elected official in this country. In the early years of the epidemic the presidential voice could have immediately silenced the self-rightous, the bigot and the haters. It could have fostered compassion and human solidarity and drawn appropriate attention to the danger before all of us.

It could have encouraged cooperation among federal agencies in support of the NIH's crucial AIDS research efforts, and it could have stopped the dragging of feet and delay tactics of certain federal agencies. It could have reminded all us of the moral supremacy of saving human lives and inspired all of us to rethink our national priorities, which is exactly what we are going to have to do very soon. As a result, we have never had a coordinated national program to fight AIDS.

Now we have a National Commission on AIDS, and yours will have to be the voice that the nation

must hear, there is no more important task before you. You will, of course, and in addition, have to concern yourself with many specific issues and educate the public, the Congress and the Executive Branch of the government on their substance and urgency.

Science is making significant strides in AIDS research. There is little doubt that HIV infection will one day become medically controllable, and it is even likely, in my opinion, that a vaccine will be developed. But such research requires the use of the most advanced methods in molecular biology, immunology, and many other disciplines. It requires state-of-the-art equipment with biohazard protection for laboratory personnel. And it requires highly skilled and specially trained people.

It is imperative that financial support for AIDS research keep pace with all research opportunities and that it should include the AIDS specific training for young investigators, the kinds of intensive, long term training now provided solely and on a modest scale by a private organization, the American Foundation for AIDS Research.

This Commission should not let itself be intimidated by comparisons between levels of funding for biomedical research in AIDS and other diseases. Levels of funding for AIDS cannot be established on the basis of how many people suffer from AIDS today as opposed to people who suffer from cancer or heart disease, for example, but on the basis of how many people will suffer from AIDS within the next 10 or 20 years unless we are very and rapidly successful in our research efforts, and on the basis of who the people suffering from AIDS will be, not for the most part older people, as in the case of cancer and heart disease, but the young, the future of this country, our children and grandchildren.

The Commission will have to work to actively protect AIDS research from being downgraded to research on just another intractable evil, and will have to protect separate AIDS line items in the NIH and ADAMHA budgets from being folded into these agencies' overall budgets.

The Commission will have to insist that the treatment of drug addiction and the treatment of HIV

disease and AIDS, even should they cost $5 billion per year each, must come before bailing out the savings and loan industry or the production of more stealth bombers.

I have no ethical qualms in making this a very strong recommendation. AIDS is lethal, transmissible, and spreading out of control among a resource much more valuable than airplanes, our own youth. Moreover, AIDS research consists of broad-based biological research on a class of viruses that are now being perceived as playing etiologic roles in many chronic degenerative diseases and malignancies.

Such research also concerns itself with a functioning of the immune system and its stimulation and restoration. Nothing could have more relevance to a wide array of human diseases. Strong support for AIDS research will benefit the understanding, prevention and treatment of many presently intractable diseases.

This Commission should also see that a much greater effort be undertaken in research on the diagnosis, prevention and treatment of opportunistic

diseases, the devastating infections and malignancies that are the immediate cause of the death of most people with AIDS. And by the way, such diseases also cause the death of people who receive bone marrow or organ transplants or who are treated with chemotherapy for cancer.

The authority and facilities of the NAID and other federal agencies directing or regulating AIDS research need to be reviewed by this Commission in order to ensure that they are all able to perform their mission in the most effective way possible.

Basic research has resulted in the identification of several families of drugs potentially active against HIV, of which AZT is only one forerunner. The traditional way of conducting clinical research for the evaluation of the safety and efficacy of new drugs is time consuming and very costly. The traditional system will simply not cope with the number of drugs needing to be tested in humans, nor the number of people with HIV disease for whom experimental drugs are the only hope of receiving other than palliative treatment. This Commission should therefore take an

active interest in the many burgeoning community-based clinical trial groups formed by physicians in medical practice who now volunteer their services to the process of drug evaluation. These groups also have a laudable interest in studying and finding solutions to the deadly role of opportunistic microorganisms in people with immune dysfunction.

These groups represent, in my opinion, the kind of new institution we need desperately to provide rapid access to new treatments to people who need them and to accelerate the drug development process. They deserve enthusiastic support as well as all the guidance we can offer them.

In the field of education, this Commission should review the use of federal educational funds by agencies disbursing them, and it should evaluate the cost-effectiveness to date of federally financed education programs. I'm afraid that you may find the results disappointing. In view of the proven effectiveness of many truly community-based educational efforts and in view of the present disparate financial situation of all community-based education and support

organizations, whose private resources are rapidly dwindling and becoming exhausted while their client load is rapidly increasing, this Commission should study ways that will make it possible for federal funds to be channeled more often and more effectively to deserving grass-roots organizations.

The Commission may, by the way, also vehemently protest an amendment to the 1987 comprehensive AIDS bill that prevents federal funding for education and prevention to be given to the one segment of our population that is still suffering most from AIDS and that has fought its spread most admirably and effectively, the gay community organizations.

Finally, this Commission will have to study extensively and make important recommendations to Congress in the area of AIDS care and equity of access to care. Science can solve scientific and technical problems, it cannot solve social, institutional and economic problems. The best drugs, treatments, and vaccines will be worthless unless they are used, and not only by people who can afford astronomical medical bills.

Thirty-seven million Americans, mostly young people, among whom AIDS has caused the most horrible ravages, are at present uninsured. It is no longer possible for many of them to buy insurance at any cost because they carry HIV. Others are losing their insurance because they carry HIV. What is to become of them, particularly in view of the extraordinary cost of the only specific treatment for their condition, AZT, and likely similarly high costs of future medications?

This Commission will have to examine the difficult and unpopular subject in high places of possible abuses of the free-market system by companies producing drugs for AIDS, and the Commission will have to study how one can eliminate such abuses. The stopgap method of special federal financial subsidies for which we have had to plead each year so that states can be reimbursed for buying AZT at its exorbitant market price for very poor people with AIDS is no less absurd and wasteful for having been absolutely necessary. Better and long term solutions must be proposed by this Commission. One of them could, for example, be that the federal government buy certain

costly drugs wholesale directly from the producer and arrange for their distribution, and there are precedents for this way of solving this problem in the National Cancer Institute program.

In the process, this Commission will come to have to consider whether society prefers to pay for the medical care of a totally impoverished and debased population through Medicaid or through seeing a system of universal health coverage instituted that recognizes a right to medical care and does not require that people become destitute in order to qualify for it. It seems to me that it is high time in this respect that this country leave the company of South Africa and join other civilized western countries in guaranteeing decent medical care to all its citizens, irrespective of their ability to pay for it.

This Commission will also have to review, analyze and assess the merit, both in economic terms and from the standpoint of quality of life, of a number of models for the delivery of health care. It is of utmost urgency, not only to the quality of life of people with HIV infection and AIDS, but to the quality

of life of all Americans, that the variety of care institutions needed for proper case management and for cost effective medical, nursing or supportive care delivery to people with HIV infection and AIDS and to people with other chronic diseases be identified and developed for use. The era of endless demonstration projects must come to an end.

This Commission must also be prepared to debunk a number of false issues and misguided ideas that resurface periodically in Congress, state legislatures and the media. I am thinking here of such tiresome perennials as mandatory testing, the reporting to authorities of the names of infected people, or mandatory and indiscriminate contact tracing that are all sure to send most people in true need of testing and counseling and medical care into hiding. This will force such people to lie to everyone around them and guarantee a field day to their virus.

Importantly, for this Commission not to see its efforts wasted and its report simply gather dust on shelves, it will have to have the courage sometimes to do battle with those who appointed it, Congress and the

White House. Good legislation and dollars always make things happen better than just words. This Commission must be willing to decide what is right and to defend its decisions no matter who needs to be confronted, whether the OMB, the FDA, the pharmaceutical or insurance industries, professional organizations and even advocacy groups of different stripes.

Integrity and courage must be your hallmark. No less than the health of the American people and quality of its civilizations are here at stake. Future generations will judge our time by what we did and how we conducted ourselves in the face of AIDS. That we do all we can and the best we can so that we can look one day into the faces of our children and grandchildren without shame is to a large extent now in your hands.

I am confident that the members of this Commission are up to their difficult task. You may rest assured that I and all my colleagues at the American Foundation for AIDS Research stand ready to extend any assistance we can offer you and to answer any call you would place on us.

Thank you.

CHAIRMAN OSBORN: Thanks very much, Dr. Krim. That was a most inspiring start for us and a magnificent blueprint to which we will check repeatedly to be sure that we are on track. I very much appreciate your effort.

DR. KRIM: Thank you

COMMISSIONER ROGERS: Now, may I just add, Dr. Krim, I hope all of you realize what a privilege it was to listen to this remarkable lady. We thank you for being with us today.

CHAIRMAN OSBORN: Next on the morning's agenda we felt it very important that we hear from people who are living with AIDS about the nature of their experience, the nature of their problems, and let them tell us as we start our deliberations things that they feel particularly strongly we must know in order to meet that historic challenge that Dr. Krim has outlined for us.

I believe one of the people who is going to talk to us has not yet arrived, Amelia Williams will probably join us in the process, but we will be hearing from Commissioner Belinda Mason. She will be leading

us in this, and Dr. Lou Katoff, I think, is going to be talking with us, Mr. Dave Johnson, Mr. Willie Bettelyoun, and later Ms. Amelia Williams I hope will be able to join in as we go.

I'm very grateful to Belinda Mason for having organized this opportunity for us, and to the participants for sharing with us their thoughts and experiences.

STATEMENT OF COMMISSIONER BELINDA MASON

COMMISSIONER MASON: I'm sorry this took so long to put together. One of the problems of hearing from people, even, with AIDS and HIV infection about this disease is that we spend an inordinate amount of our time trying to be healthy and so some of us often make these commitments and then we are not able to get to them.

I hope all of you appreciate what an effort this has been for the people who are joining me here today to come. They are remarkable people and I'm glad that we are able to speak to you today. Dr. Krim is always very inspiring to all of us living with this disease. I feel like I'm preaching to the choir in a way, but you all know that she has gone to the mat for us from the very beginning and we are lucky to have people like her with enough backbone to get up and speak the truth even though it might be politically incorrect.

I was really glad when Dr. Osborn asked me a couple of weeks ago to put together this panel of people living with AIDS and HIV disease to bring our

concerns and suggestions to the Commission. I felt an immediate sense of relief and validation. Maybe we are making headway in our struggle to be recognized as part of the solution to AIDS, as partners in the essential work of finding the solution to AIDS, rather than as exclusively the problem ourselves.

But once the relief faded, I was really struck by the responsibility that I had accepted. I wanted so much for you all to hear the truth from the people who really know the truth and it was difficult to find people in such a short time, and I felt that I really was imposing on a lot of people to change plans at the last minute. And that's my apology section, and I will move right along from that.

I know that all of you have been in recent weeks receiving all kinds of stuff in the mail from all kinds of different people who are interested in supporting us. I know Charles and Scott and Don Goldman and I were talking about how recently our mailboxes have just been packed with all kinds of statistics and reports and scientific abstracts and medical models all the time. We need all of this and

it is very important, but I wonder what we as commissioners have read or heard or what we know first-hand of the daily lives and the struggles of people who are living with HIV disease, and their partners and their families.

How many of us in this room count a person with AIDS or HIV among their personal acquaintances? And how can we hope to address the challenges that HIV presents for us unless we understand the complexities of all of its various hosts in the lives that we lead and we all lead.

There is so much that I wanted to be sure that we said today, but an hour is not really enough time. We don't have a lot of time and we don't have any documents to mail that you can read later about us. So I'm hoping that what we will bring to you today are some images that will stay with us after the statistics and the abstracts have lost their meaning for you. I also want all of us to be aware that while we sit here today and talk about what to do about AIDS that dozens of people are ill and dying. Dozens will have died by the time that we adjourn today.

So in recognition of that, I'd like to ask you all to join me in a minute of silence to recognize those who are passing and to honor the pain of their families and partners.

[Moment of silence observed.]

COMMISSIONER MASON: The ones of us here today, we will be talking about the general areas for us of care and treatment, discrimination, and we had hoped to have Amelia Williams join us and talk about women and children's issues, maybe she will come in.

I was speaking to a really close friend of mine about this plan. I tried to divide it up like what was really important to PWAs, what did we really need to bring here that nobody else could bring, what could we say. And I was compulsive about it. I wanted it to be exactly right, and so I divided it up into these areas. But I don't know--and the friend who I spoke about this with, his life has been virtually shattered by this disease. And when I told him about my plan of dividing it up in a neat form and having discrimination, treatment, services all in a little package, he said, "That's all fine and I think the

Commission needs to hear all that, but who is going to speak to the issues of the heart?"

So I decided that what I could do best is tell you some stories that come from the heart of people who for a million different good reasons can't stand up here and be doing it.

My friend told me this. He said, ask them if they can imagine holding the body of their nine month old son while he grows cold in their arms? Ask them if they can imagine what it would be like to put him in a casket yourself because the people at the funeral home won't touch his body? Try and tell them what it is like to send your other son to first grade and wonder when people will find out that he is HIV infected and how many different kinds of ways that they will devise to hate him. Ask them if they can imagine what it is like to watch your son and his mother die and to carry that alone because you can't tell anyone what is really wrong?

As Dr. Osborn said, we have not created the kinds of communities that allow people to process their grief in the normal fashion around AIDS. Where I'm

from in Kentucky if someone is ill with cancer or if they die of cancer, it is okay to say that, to stand up in church and say, "Will you be in prayer for my family, we have lost a son to cancer."

But where I'm from, right now if you stood up in church and said, "I have lost a son from AIDS," you don't know what would happen after, but from the reports that we have all seen from all over the country, we can't count on the appropriate response. And one thing that I'm hoping that we can do, if we don't do another thing, is to make it okay for people to live and to die with AIDS, and make it okay for their families to say what it is about, what the truth is.

And then I think of my friend Suzy, her doctor told her a month ago that DDI was her last hope, but DDI is not going to be ready until October. Now, intellectually I understand this delay, I understand this process, but my heart says that it is immoral for Suzy and the hundreds of other Suzies like her to be held hostage by the treatment delivery system because of bureaucracy or rules or details to be worked out.

It is not fair that hundreds of people should die just because the paperwork hasn't been done.

That I sit among all of you today as a peer is a function of white privilege in this country and the visible expression of the injustice of our system. I am an acceptable person with AIDS. It is the sad truth that those of us with the means and the resources to access treatment and support systems are able to survive and thrive and have the luxury of time and energy to pursue political agendas. It is still the reality in this country that those who can afford to pay for care do better than those who can't. We must learn to practice the justice, freedoms and compassions that we take so much pride in talking about in civics classes and teaching our children about when we tell them what it is to be an American.

Our response to AIDS must take into account how all people with AIDS and HIV live and recognize that we aren't all in San Francisco or New York using systems that are collapsing from the weight of us. Some of us are in Kentucky and Alabama and Missouri and Iowa, still trying to find a doctor willing to treat

us, or a home health care agency that will send the nurse without requiring a baseline antibody test for her.

I can afford to drive 150 miles to the doctor, but as it is in so many other ways in this illness, people like me are the exception and not the rule. All of us here today understand the facts about how AIDS is transmitted. We are sophisticated enough to know that we are not in danger of catching something. But we all have to remember that we are in grave danger of losing something, and that's our humanity. And no matter how many commissions we make or how many reports we give or how many meetings we do, there is never going to be a cure for that. No matter how much money Dr. Krim raises over there at AmFAR, there is not going to be a cure for losing our humanity. We have got to make sure to hang on to what shreds of it that we have left, and I hope that we can provide some leadership in that.

People occasionally ask me about being involved in AIDS work and they say, "Well, what do you all want, really, what is this all about, what do you

want?"

And I have to say that we all want nothing more or nothing less than what all of you take for granted today, a place to live, the right to have a job, decent medical care, and to live our lives out without unreasonable barriers. We are not asking for extras, only to be included in what America already delivers to her privileged people.

I'm 31 this year and my life has been blessed with two healthy children, a six year old daughter, and a son who is almost three. Relatively speaking, I'm not in bad shape and I used to hope that I would be able to live long enough to see my children, with the help of their father, accept and adapt to the inevitability of my death. More lately I've been hoping that when I'm gone they wouldn't continue to be stigmatized by the shadow thrown by my public life.

But compassion is not going to happen because of a report that we make or an edict that somebody in Washington delivers. It will begin in the small towns in the quiet country throughout America when people understand that people living with AIDS and HIV are

just like us because they are us. I don't have any answers for the Commission, but I do have the great hope that we are beginning to ask the right kinds of questions.

I would like to hear from Dave Johnson next about treatment issues.

STATEMENT OF MR. DAVE JOHNSON

MR. JOHNSON: Thank you very much.

My name is Dave Johnson and I currently work as the AIDS coordinator for the City of Los Angeles, but I'm not here today speaking on behalf of the City of Los Angeles, but rather on behalf of myself and my own experiences, both as a person with AIDS-related complex and also as a gay man, because much of what I have experienced as a person with AIDS-related complex is inseparable from the fact that I am a gay man.

Part of what I want to set up for you today is a little bit of the history that leads to the environment of distrust which I think we must face exists between the government and the health care system and many of the communities affected by AIDS. Most of us who are not acceptable people with AIDS come from communities which traditionally have known that we are not high on the list of society's priorities for care or for civil rights, whether we are gay people, people of color, or, very frequently, both.

But I think there is something in the mythology with which those of us who grew up in the

television age were invested that believes that when people get sick the prodigal gets to come home and no one rejects sick people. To our great dismay, when we got sick we found that precisely the opposite was true. I think some of us really believed that AIDS might break through the barriers of racism and homophobia and cause people to care at some basic and fundamental level. And in many heroic individual cases that has been true, but in general the responses that we have gotten from the federal government have been a long and brutal and frustrating decade of neglect and of denial and often of outright prejudice.

First there was the terrible silence, as Dr. Krim quite eloquently pointed out. For the first three years of this epidemic in the mainstream media and in the Halls of Congress and the White House it didn't exist, and a thousand people died in those first few years, and many hundreds of thousands became infected who didn't need to.

Then we moved into the period where the great debate was and to some extent still is, will this or wouldn't it really affect the general population, as if

that is the basis upon which we should decide whether the potential death of a million and a half Americans is important. Now we are moving into a third phase and that is the debate over aren't we really doing enough about AIDS, and what do these people want?

All three of those events in the public consciousness have communicated a very simple bottom-line message to those of us who are not acceptable people with AIDS, and that is that ultimately your government doesn't really care about you and your lives are worth less than the lives of other people.

Let me translate that for a moment into my own direct personal experience. When my lover of many years, Lonnie Richards, was first sick and later diagnosed with AIDS, there were some realities in our lives that are certainly not what one expects to have happen in the face of a dangerous and potentially fatal illness.

First of all, we found at that time that the only services available to us were the services that our own community had created out of nothing and was

struggling to finance out of walk-a-thons and fund raisers in bars and individual contributions of what people could afford, and usually beyond what people could afford.

The second thing that we found was that we could not tell his employer what was going on. We could not, until very late, tell his family what was going on, that we were in great danger if we were honest with anyone beyond our own physician of losing everything we had.

And finally, we found, to our great dismay, that it was not possible to participate in clinical research. A lot has been discussed about why simple clinical research is not adequate to prolong the lives of people with AIDS, and one of the issues that doesn't get mentioned very often is the very limited scope of clinical research.

The best way I can think of to sum that up is by telling you that in September of 1985, having never participated in any clinical drug trial, not for lack of trying, but for lack of eligibility, Lonnie went to the University of Southern California Medical Center to

attempt one more time to qualify for a drug trial. It was a drug trial that was going to accept eight people in a county with nearly 2,000 cases of AIDS. Lonnie didn't qualify. He died four months later. The drug trial was for something that was at the time called Compound S and is now called AZT.

We are now, as people who have been on the front lines for a long time, coming before another governmental process and we have a lot of experience at coming before governmental processes. One of the things that has evolved in response to the lack of trust based on the history is a desire for something which we in the PWA community have tended to call empowerment. What that means, as distinct from inclusion, is very important to note. Inclusion is where some "we" listen to some "them." Empowerment is where you change the definition of "we."

I am very pleased to see that the composition of this Commission, versus government processes in the past, begins to change the definition of "we," but I would like to propose that in the ultimate partnership that creates the solution to AIDS that the definition

of "we" be fundamentally changed by doing a number of specific things.

First of all, hear us, hear us on an ongoing basis and use the expertise that we have gained from years on the front lines. We in the PWA community, and certainly we in the gay community, invented AIDS services and education with our bare hands out of nothing, on the front lines by ourselves. We understand how to reach our communities. All of the communities affected by AIDS are the best experts on how to reach their own communities. There is one principle that is fundamental to AIDS services and education. It is that the best programs are those developed by and for the affected communities and that the role of government in AIDS services and education is to promptly provide resources to those communities to do what they know how to do best.

Another concrete thing that you can do is to, of course, implement the recommendations of the previous Commission which, as Dr. Krim pointed out, were largely ignored, in particular, the anti-discrimination recommendations. There can be no

single act the government, I can imagine, could take that would do more to breach the terrible barrier of mistrust so crucial to the effectiveness of education and treatment efforts than to guarantee at the federal level that persons with AIDS will not be subject to discrimination in housing, in employment, in insurance, in general.

Secondly, it is crucial that we support an accelerated drug trial process. A great deal of progress has been made in this area, progress like the implementation of the parallel track, progress like the general acceleration of the drug approval process, and I think more fundamentally, a recognition that in a life-threatening illness clinical research has two missions, one is research and another equally important is early emergency treatment to people who will be dead if we wait for five to seven years of clinical trials.

We are finding ways to merge those two missions without jeopardizing the scientific integrity of clinical research, and the way we are doing that is by a partnership between the Public Health Service, clinical physicians, and people living with AIDS.

I hope you will be hearing a great deal from some of the people on the front lines of that effort, and in particular, Mr. Martin Delaney of Project Inform, who recently staged a protocol for Compound Q which, to my way of thinking, conclusively proved that in four months with a well-designed trial without a placebo you can answer fundamentally important questions about whether to use an available drug to treat people. Given the fact that even in the context of parallel track a phase one trial still can take 12 to 18 months, I hope you will look very seriously at what I believe Mr. Delaney and company have proven there.

Another thing I would like to emphasize is the critical need to get prophylactic treatment to millions of people who not only need it and often can't access it, but just as importantly are often in denial and ignorance about the fact that they need it, and we are running out of time fast on this issue.

The People With AIDS coalition in Los Angeles 18 months ago changed its position on testing and urged that people voluntarily and anonymously take the

antibody test and begin early treatment against HIV infection. We face two important barriers in implementing this, and I must emphasize that if we don't implement this, we are in the last year or two to implement this. People are going at the rate of 150 to 200 a day beyond that point of no return. It is not just that 150 people are dying of AIDS every day, it is that 150 to 200 people are passing every day the point beyond which such prophylaxis has any hope of retarding their disease process. The two barriers we face are, one, the denial and ignorance within the affected communities, and second, the lack of access to this prophylactic care for most people living with HIV.

We have called in the PWA coalition in Los Angeles for the implementation of as massive an education program in the area of early intervention as was mounted for safer sex a number of years ago. As yet, no federal dollars, no state dollars and no local dollars exist for such efforts. We are at the same point with such efforts that we were with safer sex efforts in 1983. We are running off leaflets, a few thousand at a time, and passing them out by ourselves

in bars. That's how we are trying to save a million and a half lives. We urgently need dollars to educate our communities about early intervention and treatment.

But it is important that we also recognize the reality that without a great deal of money we are not going to be able to get early treatment to most people. And this is not--it is one thing to talk about this where the issue is ignorance and denial, it is another thing to talk about this where the issue has been an ongoing fundamental lack of access to any kind of preventive health care. It is important to note that in the State of California's Office of AIDS report on the needs of minority persons with AIDS in California, they noted that at Bayview Hunter's Point, which serves the largely African American population, 67 percent of their clients with AIDS had first sought treatment in an emergency room.

Now, that should dramatize to you the level of availability of preventive ongoing clinical care. We are not talking about people who merely need to go see their doctor, we are talking about many populations for which the concept of "their doctor" has never been

a relevant reality.

And we need at last to ensure that the federal government does not abandon its responsibility to get into the areas of AIDS services and AIDS treatment. An alarming message was sent recently that the government is only going to worry about prevention, which again says to us, only about the people that aren't sick yet that we really care about. The reality is that millions of people in this country need education and need treatment and need supportive services, and the Federal Government will have to be a partner in that. Just looking at the cost realities, people are talking a lot about how frightened they are about $5 billion for AZT. Do they have any idea what it will cost if all the people who need AZT today progress to AIDS in the next three years and become presumptively eligible for Medicaid? It could bankrupt HCFA.

It is critical that we look to what we need to do now to prevent that kind of a catastrophe. But ultimately I would echo what Belinda said, and that is look upon us certainly not as victims and not as

classified into guilty victims and innocent victims, but as partners, as people with faces. We are the general population. We are anxious to work with you, to merge your expertise with ours, to create together with you the leadership at the federal level that, as Dr. Krim pointed out, has never been there, to create in partnership with you an appropriate response from this country. I'm reminded of the fact that when 28 members of the American Legion became ill in Philadelphia it was the lead story immediately on all three networks for a week, and that this epidemic, far more catastrophic, took three years to make the nightly news.

We need to create an awareness in this country that the only important reality is that a million and a half Americans are desperately ill and that the government needs to marshal its resources to prevent further infection, to treat those who are ill, and to care for those who are ill.

Ultimately, your opportunity here today is to be healers. In a time of death and despair and, worst of all, of terrible apathy, cutting through a morass of

racism, sexism, homophobia and scapegoating, you have a responsibility and an opportunity to have the courage to join with us on the front lines and be the healers, be the ones who ultimately create and implement a solution to this epidemic. Thank you.

CHAIRMAN OSBORN: Thank you very much for your eloquent comments and thought provoking comments.

I think in the interest of being sure that we hear from all of the people who have made the effort to come, I want to keep going with the panel that is here. I know the commissioners want to ask some questions, and we'll try and do that, but perhaps at the end of everyone's chance to tell us what they want first. So if you would proceed, please.

COMMISSIONER MASON: Could we hear from you, Dr. Katoff, about services.

STATEMENT OF LOU KATOFF, PH.D.

DR. KATOFF: My understanding is that I was invited both as I think--I think I now qualify as a long term survivor of AIDS and as a long term survivor of service provision.

Three years ago I was diagnosed with pneumocystis pneumonia and with AIDS. At that time I knew the research on survival and I knew there were no--in the summer of '86 there were no approved or, in fact, I don't think there really were any unapproved treatments available.

I and everyone around me assumed that I had only months to live, that I would be unable to work, to exercise, to travel, to plan for a future. Three years later I still work 50, 60 hours a week. I still run five miles a few days a week. I moved to a new apartment. It occurred to me that I have attended four international conferences, which certainly indicates stamina.

My point is that AIDS can be viewed as a chronic illness and that we don't know how long someone diagnosed in 1989 is going to survive. That

uncertainty about the future, an incredible ambiguity, is very difficult to live with personally. It is very difficult for the people who care about me and who work with me to live with. It is very difficult for you to live with, but in terms of your planning and your forecasting, that has to be taken into account.

I have to live my life, as difficult as it is, planning on being around for a while. I work at Gay Men's Health Crisis, and have for, I guess, about three years. I direct a staff of 50--a paid staff of 50--and a voluntary force of about 1,000. This year we'll provide direct services to 4,000 people with AIDS in New York City. Each week we will run 50 therapy groups, serve probably 800 meals, in a year 600 to 800 people will receive buddy services, 2,000 will receive counseling and advocacy about entitlements. Every client will receive a book that we have put together on resources in New York City, which you will be receiving I guess sometime today. We brought some materials for you.

GMHC is one of the larger community-based organizations that relies on volunteers, but there are

probably 2,000 other new community groups providing the same essential support services. People with AIDS need more than acute medical care. Voluntary groups and public institutions must be organized to provide the necessary support, the necessary advocacy and the necessary educational services to people with HIV illness.

The voluntary groups, the thousand points of light, or 10,000 points of light, have done a remarkable job. People have demonstrated enormous compassion, nobility and courage and persistence from large cities to rural areas.

However, state and local, and certainly federal government, have often neglected their side of what must be a partnership. Voluntary organizations can provide economical care, compassionate care, culturally sensitive care, but only with financial support and the real commitment of local and state governments to needed capital expenses and operating expenses. Volunteers can do grocery shopping, they can cook meals, they can organize AIDS walks, but they can't build nursing homes and they can't build

community health centers.

Housing options are desperately needed. Increases in community health care, long term care options, increased drug treatment, education of employers and health care providers, community-based research initiatives that have already been referred to, all of these services are desperately needed and will have to be supported by public dollars.

The absence of housing, community health care, drug treatment, long term care, only increases the cost of AIDS through lengthier hospitalizations, more frequent use of emergency rooms, and preventable spread of infection.

In conclusion, allowing people with AIDS and other disabilities to work saves money and has both, obviously, financial and less tangible, more human rewards. I and other people with AIDS and HIV illness can make a vital contribution of talents and experience and energy. We need the Americans with Disabilities Act. We need changes in Medicaid regulations so that individuals can risk going back to work. We need a reduction in public fear of casual transmission.

But, as has been stated before, what we also need and what I think this Commission can be important in is we need to confront the fear and hatred of homosexuality and drug users, as well as the racism that has got in the way of a compassionate response to this epidemic. Thank you.

COMMISSIONER MASON: Thank you. Now we are going to hear from Willie about discrimination and human rights issues.

STATEMENT OF WILLIE BETTELYOUN

MR. BETTELYOUN: If you would bear with me, I would like to greet you in my native tongue, which is Rosebud Sioux.

[Comments made in Rosebud Sioux.]

It is in the spirit of friendship that I come here from the Rosebud Sioux tribe in South Dakota to tell you some things about my life, which is culturally not acceptable. People in my case, my tribe, in my extended family, when it is their time to die they go into retreat, and I have done the opposite, I have come forward.

If I sound today choppy or disoriented, it is I am sick again. I had fought to keep this sickness off, but it came back. This may be it, or it may not be. That's one of the parts of AIDS that I wasn't taught at U.C. Berkeley during graduate studies, or at San Francisco General when I interned in the AIDS ward. To be Indian and have AIDS is very different from what I hear here today, my needs are different, my outlook is different.

I am Indian so we see it this way. I say

"we," we are Indian, because of the extended family complex in relating to AIDS. In the beginning when I contracted the disease and experienced my first of two opportunistic infections I had utilized the Indian Health Service. Given the Rosebud Reservation and the amount of miles and terrain of our reservation, that was the only outlet that I had for medical assistance.

There are three groups within the Indian Health Service; those that advocate public notification of everybody for those who have AIDS, those who would like to keep it private, because it is a doctor/patient issue, and those that remain neutral. And my hospital was the same. A number of doctors publicly released that I carried the virus, or I did have AIDS. Within a period of two working days I was asked to resign by our tribal chairman because I did have AIDS, I was going to infect those people in my office.

During that time just dealing with the trauma of being recently informed that I had AIDS, I had no one to go to. There was no support system, no support group, no advocate. Everybody was afraid for their job. This was new. I was their first

reservation-based and developed AIDS person.

I was subsequently offered a considerable amount of money if I would resign. I was offered contracts--because I wrote federal proposals--by our tribal chairman and my supervisors if I would leave quietly. During this time I had contacted the State Health office. I was told by them when they did their investigation because it was a communicable disease that any time I needed them just give them a call. I was given a card, a number. I was given a telephone number to call. They would be there, they would always be there.

I called them three different times saying I need some help and I need it now, I'm being forced to resign. I may be given what is called an exclusion order on our reservation at any time at the whim of the tribal chairman or the council. They can publicly serve you with a subpoena and a writ and they escort you off the reservation. You cannot get back on.

So I asked State Health to help. I asked the Director of State Health to help. No one was there. Even though it was their job and they stated they would

be there, they weren't. I couldn't go back to Indian Health Service because it was too disruptive. There was no, like I said, support groups, no social worker, nobody, so I retreated even further into my community. But even that was wrong. I had people coming to my door wanting to beat me up, they didn't want AIDS in their community, even though these were my relatives. Indian ways, these are my brothers and sisters. But because I had AIDS I was no longer human. I was a disease, I no longer had feelings, I no longer was given the opportunity to plan, to have goals, to contribute.

So I sought out the church in our reservation. I literally ran down a street waving my arms, trying to flag down a priest because I needed to talk to a priest. And again, because I had AIDS, no one wanted to talk to me.

I went from Catholics to Protestants to Lutherans, all the way down the line, no one was there. So I decided I would do it myself. If I went totally public then no one could hurt me any more, no one could hurt my family. The more public I was, the less there

was to throw back at me. But even that didn't work.

The paranoia of our area Health Service director made my life--him and his staff--very difficult. They continually monitor who I talk to, where I go, my talking here today. They have interfered with my legal battles, they have offered bribes; people come back to tell me, to make confessions, if you would. The prime witness in my case against the Indian Health Service and the United States Government was recently offered a home worth $65,000 if she would not give a deposition, if she would not appear in court. And this was by our area director of Indian Health Service in Aberdeen.

I continually receive verbal abuse, physical abuse. It means nothing to you maybe, but for me it is very overwhelming because I have to deal with the physical aspects, the spiritual aspects. When I reach out for help, all I get is either a fist coming back or a slap of the hand.

My family has asked for help. They have gone to all the services that are supposedly there, the State Welfare, the Tribal Welfare, the Mental Health

Services. No one is equipped in our area to deal with what I have. So that makes life very difficult for them. They have forgot to realize that they would carry the virus as much as I do.

In our efforts to educate ourselves as a family and now maybe as a community, now that some of the hysteria has passed, we have sought the media. We looked at all the pamphlets that are printed, researched as a family, as units, trying to find something that would help, and at this point nothing does. Maybe it is an individual thing, maybe it is culturally specific, I don't know any more. In the beginning when I did go to speak to colleges, hospitals, universities, I had definite things to say. I was even, in the beginning, idealistic and naive.

Now that this may be the last, I have really come up with nothing, and I thought there would be something at the end here, in a month or two, I don't know. I needed something, something to sum it up, somebody to explain back to me who was in the position of authority and who knew. What did I do that was wrong, who do I confess to?

If I could leave you with something, it would be a recommendation that when you do develop whatever you are going to develop, make it culturally specific. What is printed now really doesn't apply in my area. It, in fact, does the opposite. It stigmatizes and creates hysteria.

If you could gear your educational or political efforts that are based on traditional aspects of teaching in Indian culture and Indian politics and Indian religion, it would break down the barriers for those who come after me. And there are estimated on my reservation 200 to follow me today. It would make their way easier. If I made their way easier, through you or through your efforts to help them, then maybe when the last day comes or whatever, I can look back and say, "Well at least I tried, at least there was something there, there was something to hold on to."

When I leave here today I will remember there was a lot of things I should have told you, there was a lot of things that I should have left with you that would have sparked in you the right attitude, the right effort to end discrimination. But it was--I guess,

maybe if you can go back to the videos, HBO had a good show on, it was just a regular kid, an AIDS story, and in that movie, which was very similar to what happened to me, he says, "I wasn't a criminal, all I carried was a virus."

If you would keep that in mind in relation to me and those that follow me, maybe then I have done some good.

I thank you.

COMMISSIONER MASON: Thank you Willie.

I don't think Amelia Williams has come in. The fact that she is not here is really eloquent, I think, and it is not--doesn't have much to do with who she is but the kind of woman that she is.

We just had a really difficult time trying to identify an HIV infected woman of color with HIV infected children to speak on behalf of the pediatric population. As I have traveled these months and spoke about AIDS, it seems that the people that I hear who speak for the children are seldom their mothers, and I think to a large extent when we talk about pediatric AIDS we forget that it has a beginning in maternal

AIDS.

So there are all kinds of issues that women who are HIV infected and have HIV infected children who are dealing with that are--I can't even begin to speak to and I won't attempt to. But just bear in mind that this is the most disenfranchised of the disenfranchised populations that we are talking about here.

I don't know if you all have some questions or if there is some time.

CHAIRMAN OSBORN: There is time, and why don't we see if there are some of the commissioners who would like to ask questions. Congressman Rowland?

REPRESENTATIVE ROWLAND: Dr. Krim is still in the audience. I have a question I would like to ask her if she can come back to the table.

I thank all of you for being here this morning to testify, too. We appreciate it very much.

Dr. Krim, you being a research scientist, what are your thoughts about the coordination of efforts between the public sector like NIH, DOD, the VA and the private sector?

How well is that coordinated now? Is there

duplication of effort? And what suggestions might you have for improving research efforts?

DR. KRIM: The answer is that there is no formal coordination, and in fact that is one of the things lacking very much, is communication and coordination of efforts between industrial research and academic research.

The Institute of Medicine has addressed this situation and has convened a number of meetings, some resulted I think last year--or two years ago--in a very good report. And there is a new series of meetings starting now on different aspects of the epidemic and the role of research. And these meetings make an effort to bring together researchers representing academia, government and industry. But this is all there is, to my knowledge.

CHAIRMAN OSBORN: I think it would be helpful to comment that the Institute of Medicine has made considerable efforts to coordinate with the new Commission involving us in that series of meetings so that we will be able to tap into the developing dialogue as it goes and perhaps influence it as needed.

DR. KRIM: Your question is very important because there are things that should be coordinated, not just plans and communications, but actual projects. There are certain parts of the work needed to be done in the development of preparations for vaccines, or even drug development, that are better done in industrial labs that have certain facilities and certain pieces of equipment and certain expertise that do not exist very often in academia, for example, or in government labs.

And it is not only a question of coordination, it is a question of cooperation. There are certain projects that should be done by industry, government and academia together and there should be teams of scientists working and following certain developments and doing certain jobs, once in academia, once in an industrial lab, and then back in academia and so forth. This does not occur right now.

REPRESENTATIVE ROWLAND: What would you say to this Commission, the recommendations that we should make to the Administration and the Congress about how to improve the relationship in various research

activities?

DR. KRIM: Well, just recognizing its need is important, and illustrating it. That is very important in itself. And then, of course, under the auspices of a Commission such as this, or government officials or an institution such as the Institute of Medicine, with a little assistance, you know, the Institute of Medicine is in need of raising monies to pay for its roundtable conferences and its workshops and so forth.

Maybe some help for the Institute of Medicine, financial help, would make it possible for them to do much more intensive work and, as for the actual implementation of joint coordinated efforts, that perhaps, too, requires some funding on the part of government to support the research itself. Maybe industry will contribute its part, but perhaps academia will be in need of additional support. I don't know, one has to really examine specific situations in great detail.

REPRESENTATIVE ROWLAND: Thank you. Thank you Madam Chairman.

CHAIRMAN OSBORN: Harlon Dalton, please.

COMMISSIONER DALTON: Yes. I just wanted actually to speak to Willie Bettelyoun. I mean, you clearly at the end were sort of struggling, wanting to figure out what to say to us, and I wanted to tell you not to worry, you said an awful lot.

Sometimes it is a phrase, sometimes it is more than that, but there was one line that you said that really sort of struck me. You said, in describing your situation on the reservation and members of your family who were not as supportive as you had a right to deserve, expect, you said, "I was no longer human, I was a disease."

And that, to me. so powerfully captures a lot of what you came to tell us today, so you did it. And if spirit can help deal with disease, which I believe it can, I think you are going to beat it this time, too. But I just wanted to thank you.

CHAIRMAN OSBORN: Thank you. Larry?

COMMISSIONER KESSLER: Dr. Katoff, you described your staff and the number of volunteers and the number of clients that you are serving.

Can you give us an idea of what kind of

federal help you have now in terms of your budget and how much of your budget is state funded and private sources and so on?

DR. KATOFF: GMHC has been moderately fortunate in terms of receiving funds from the State Health Department, particularly in terms of client services. And I think the state provides about 50 percent of our operating dollars for client services, and provides some funds for a hotline. We receive actually at this point, and I think for the last couple of years--I think out of our $10 million budget, I think this year we will receive 60,000 from--or 80,000 from the federal government through the Public Health Service, through HRSA, but just 60,000 out of 10 million.

COMMISSIONER KESSLER: Have you taken the time at all over the course of the years to put a value on all the incredible number of volunteer hours?

DR. KATOFF: We have done that. I don't have that at hand. Again, we have probably had about 10,000 volunteers providing probably--we consider someone a volunteer if they are giving us eight hours a week of

their time, and that's been since 1982 and we have served about 8,000 people with AIDS and with ARC. Our hotline handles about 5,000 calls a month, again all with volunteers. I wish I did have those numbers, I'm sorry.

COMMISSIONER KESSLER: Well, apparently, it is significant. Thank you.

CHAIRMAN OSBORN: Thank you. Dr. Rodgers?

COMMISSIONER ROGERS: I simply wanted to indicate how profoundly moved I was by the courage of the four of you in coming before us. I heard the word "empowerment," I heard the words "Please be partners with us."

I think I heard, if you could do nothing other than simply change the kinds of attitudinal mindset that have so hampered our work on AIDS, that that would be a contribution.

I think I can assure you, as at least one commissioner, that you have given me the text for our two year effort here and I wanted to thank all of you for being here.

CHAIRMAN OSBORN: Don Goldman.

COMMISSIONER GOLDMAN: The question is really addressed to all of you. A number of you mentioned with favor the recommendations of the former President's Commission and indicated that regrettably many of its recommendations had been ignored. I was wondering if each of you might be able to identify--in no particular order, you can go left to right starting with Dr. Krim--perhaps three or four of the recommendations of the President's Commission that you feel are most important and that have been ignored.

DR. KRIM: Well, the first one that comes to mind, because somebody else mentioned it and I agree with what was said, that legislation prohibiting discrimination against people with AIDS or HIV infected or perceived to be so infected or associated with them, et cetera was the first order of business and that was very clearly said in the President's Commission recommendation, and this is an issue that was not taken up by the previous Administration.

Now we have new legislation before Congress that would include people with HIV infection and protect them against discrimination on the basis of

handicap, so that kind of legislation may do some of what we would like to see happen. But that was initiated in Congress. This Administration is in support of the ADA bill, but the previous Administration did not respond at all to this very important recommendation of the Commission.

COMMISSIONER GOLDMAN: Are there any other major items of the President's Commission that you would like to identify now?

DR. KRIM: There are 600 recommendations and very few, if any, were followed, so I am sure we could come up with something. Right now I can't say anything specific.

COMMISSIONER GOLDMAN: Would any other members like to respond in terms of what recommendations they think are appropriate?

DR. KATOFF: I think certainly the Commission's report highlighted this, but I think certainly the studies released on anti-retroviral therapies in the last couple of months point out--and the research on prophylactic treatments--point out the need for early intervention. The only way early

intervention is going to happen is a massive increase in community health care.

We recognize the cost. I mean, each of the panelists has highlighted the cost of neglecting early intervention. It is time to get serious about the financing of early intervention, and that seems to be one of the most important things the Commission needs to look at in terms of what kind of funding streams will exist in the next few years for prophylactic treatments and for retroviral treatments and the other treatments that are necessary.

MR. JOHNSON: I would just echo on the linkage between the anti-discrimination recommendations and early intervention and treatment. In the context of the atmosphere of distrust that has evolved, you really can't expect people to come forward to be tested unless they know their civil rights are going to be protected. Very often people, especially now with the media attention focused on the availability and effectiveness of early intervention, are literally faced with a choice between their health and their civil rights. And if we don't have the

anti-discrimination protection, we are not going to be able to get people to come forward and test and treat, and if we don't do that then we are going to have literally hundreds of thousands of cases of AIDS that in the context of present medical technology may be entirely avoidable.

I am not sure specifically what the Commission or the previous Commission said on these other two areas, but certainly the need for effective coordination of federal efforts and also, I think, the need for ongoing federal dollars--the $60,000 that was mentioned to GMHC from HRSA, HRSA's dollars are demonstration dollars, and as Dr. Krim pointed out, we really have to move past the concept of just HRSA. And my sense is that HRSA really wants to fund services but is tied to having to fund two and three year demonstration projects which run out and then have no funding, and CDC is only able to fund prevention and CDC has not funded early intervention education. So really in terms of ongoing services the federal dollars just aren't there.

DR. KRIM: Mr. Goldman, can I add that on

reflection every one of the recommendations we made here today all of us, could reflect something that was also recommended in the report of the previous Commission. Nothing of what we said today is entirely new, it is all there. I could not list by number or phrase or be precisely in the right words the recommendations as made by the previous Commission, but the content is very much the same as what you heard here today in different areas, research, services, care, education, et cetera.

CHAIRMAN OSBORN: Eunice Diaz?

COMMISSIONER DIAZ: Two brief questions, one for Dr. Krim and one for Belinda.

Dr. Krim, you had some very interesting statements to make about the national media campaign focusing on education to the larger population. Many of us are concerned because of the great amount of expenditure involved in that media campaign. If you had to tell us one or two corrective or, how shall we say, positive actions that could put that campaign back on track, what would those be from your perspective?

DR. KRIM: Well, there are two campaigns that

are ready and supposedly ongoing. One has been financed by the Centers for Disease Control with federal money. The other one is a campaign contributed at no cost by an advertising company for the Advertising Council, and the American Foundation for AIDS Research and the National AIDS Network were advisors on the contents of this campaign.

Both--I think that the Centers for Disease Control bought time on--and I'm not too sure to what extent it was time bought or time requested, you know, as a public service. In the case of the Advertising Council campaign, we didn't buy time. The Advertising Council sponsors campaigns and request that networks and television stations show their ads as a public service.

I know that I personally never saw one of these PSAs because they are shown at three o'clock in the morning and not in prime time. And this is what is so disappointing, because so much effort goes into preparing one of these advertising campaigns, it is so important that the public hears the messages, and the public doesn't. We don't see them. You know, it is an

empty gesture in a way, and it is very disappointing that the networks don't take their responsibility in the public education more seriously.

COMMISSIONER DIAZ: My question to Belinda, as the President of the National Association of Persons With AIDS, as well as other coalitions represented in the panel here, do you have any ideas as to how you feel your input could be ongoing and as important and valuable to us as it has been today throughout the remaining work of our Commission?

COMMISSIONER MASON: Well, I like what Dave Johnson said about the fact that we have been on the front lines, the National Association of People With AIDS, Project Inform, Gay Men's Health Crisis, many of these people have been on the front lines for a long time, so I hope that we will kind of institutionalize in that process some way to hear from people on the front on a real regular basis and not just at the pomp and circumstance day, but maybe later at more, you know, of the circumstance and less of the pomp day.

So I'm hoping that we'll be able to have some kind of regularity in hearing from us, because there

are a lot of things that I wanted you all to be able to hear, but not a whole lot of time. And I couldn't just say them all today, or I couldn't get other people to say them. And so I hope that we have a mechanism that will assure that we can come before you again and that we can address some of these things that are so glaringly absent from the panel today.

CHAIRMAN OSBORN: Well, to the extent that there was pomp this morning, I want to thank all of you for having contributed greatly to it. It really distinguished the morning in the quality of your input. I'm afraid I need to have us break now because the schedule drives us a bit, and we also want to get a brief chance to say hello and thank you in person.

So if we would take now a 15 minute break and then reconvene.

[Brief recess.]

CHAIRMAN OSBORN: I'm very pleased to have the opportunity to introduce Dr. C. Everett Koop to speak with us now. When I thought about how we could inspire ourselves to better things than even this group would ordinarily achieve, one of the first thoughts

that came to mind for me, as it does to most Americans, would be to see if we could impose on Dr. Koop's schedule. I need not say much about that except to thank him personally and on behalf of the Commission for the extraordinary leadership he has given us during what I hope will be the most difficult time when he was alone some of the time and having to do that rather solo.

We want to pick up some of the momentum of your contribution, Dr. Koop, and would appreciate any comments you have for us as we begin our work.

Thanks so much for coming.

STATEMENT OF C. EVERETT KOOP, M.D.

FORMER U.S. SURGEON GENERAL

DR. KOOP: Thank you, Dr. Osborn. I have not come with any prepared comments so I will be speaking off the top of my head, but hopefully also from the depths of my heart about this subject.

I for one welcome you to this position, you and all of you, because we sorely need this kind of a Commission in this country. I have nothing but the greatest respect for the work that Admiral Watkins did on the Commission that he chaired. I think he did the kind of work I would have expected from him, having worked with him for two years previously on his Commission on Excellence.

But I think we all agree that the impact of what he said and he did has not been felt by mainstream America. You know it and I know it and we know he was right, but there has nothing happened. So that my greatest concern about the work of this Commission is that you transform what you hear and what you decide into some mechanism that reaches the people that it is intended to reach. And I have to be very frank about

this and say that that means that the Executive Branch of this government has to recognize that although AIDS may not be the most important health problem that this nation faces, it is the most mysterious and has the greatest potential for seeing us lose not only a battle in health, but see our social contract disrupted.

I have the feeling that if you got the best think tanks in Washington together and said, "Sit down and devise for us a disease that will have the greatest possible impact upon this country for 50 years," they could not have come up with anything better than AIDS, because it has something in it that is deleterious to every member of this society.

And when I wrote in the report on AIDS that the President requested of me in 1986 that the day would come when this epidemic would impact upon every citizen in America, I was thinking of the fact that they would find times when health care was not what they wanted, they would find times when social intercourse with other parts of the society were difficult to have, and that eventually they would all be forced to pay for it in some form, either by taxes

or voluntarily contributions. I think that day is here.

I don't think there is much that I could or should say about the disease itself, how it is transmitted, but to talk a little bit about those things that people find difficult to talk about. I think that because AIDS is transmitted the way it is and because most people get AIDS by doing things that other people do not do and don't approve of other people doing, that you start off with a situation that is very difficult to overcome.

Even today in some parts of the country there are people who are bashing homosexuals, who are bashing IV drug abusers, who are keeping children out of school. And that's very discouraging to me because I think that the educational effort that was made by the government was really a superb one, that it was far-reaching, and that anybody who really wants to understand, anyone who is intelligent enough to bash a homosexual, anybody who is intelligent enough to keep a child out of school, is intelligent enough to read what has been written and to listen to what has been said,

and they choose not to.

I think if you recognize, therefore, that there is a certain mean-spiritedness among a section of our society that will not respond just to a message about risk, a message about society, about improving relationships with one's fellow man, then I think you will have recognized one of the problems that we have with AIDS, and I think your obligation and your opportunity is to prevent that soreness in America from spreading to other people who at the moment might be considered neutral.

Another aspect of AIDS that bothers me, other than disease itself, is that because of the disproportionate number of blacks and Hispanics that have this disease. I already encounter as I travel around the country the fact that people are saying, "It is their problem and not ours."

Initially they said "It is their problem and not ours," and they meant homosexuals, bisexual men and drug abusers. Now when they say "It is their problem and not ours," they have added to that blacks and Hispanics. And because many blacks and Hispanics are

persons with AIDS and because many of them are IV drug abusers and live in ghettos where they have had very few choices to make and have made the poor ones, it is also a disease that is becoming associated with poverty. So when we say "them," it also means the poor.

And AIDS, if you think about it, affected people initially who always found themselves outside the mainstream of medical care in this country. Fifteen years ago the homosexuals elected to go to physicians who better understood their lifestyle. Certainly drug abusers had never been part of mainstream health care in America. Certainly the prostitutes have not been. So we started off with a group of people already isolated from what we have to offer in mainstream medical care, and the presence of AIDS now makes that isolation even worse.

We have got to do all that we can to bring those people back into the mainstream of health care in this country and to make them feel welcome and to treat them as though they were any other member of society.

I think this raises another problem, and that

is that when I say things like that in public, old time public health officers say Amen, that's what we believe too. But there is a new breed of public health person today who came into public health because of AIDS, and that kind of person would love to see AIDS separated from the mainstream of health care. And I think that would be disastrous and I think that's another issue that you would be well-advised to address.

I have talked to people who think that there ought to be a city Department of Public Health and a city Department of AIDS. That is ridiculous. And the more we separate these and the more we isolate the AIDS problem from society, the worse it will be to deal with.

But I want to assure you that I do have hope for the American people. I have dealt with them--at a distance--but nevertheless as sort of my patients for the last eight years, and they do respond in a remarkable way. And the American people I think are kind and generous to a fault. They are perfectly willing to give voluntarily to all sorts of causes. They are perfectly content, in a sense, to pay taxes

for things that have to do with public health, such as maternal and child health, the rehabilitation of drug addicts, the rehabilitation of alcoholics.

But there is a common denominator to all of these things that the American people expect, and that is redemption. When they offer something to maternal and child health, they expect to see a lower death rate among newborns. They expect to see an increase in the birth weight of babies. They expect to see a lowered mortality in women, and they expect the whole thing to work better, and that's what the effort is. When they put their money into the rehabilitation of alcoholics, they expect to see some redemption there and people returned to society.

The difficulty with AIDS is that because it is a fatal disease, because we have been so frank in our discussions with the public about the time it will take to develop a vaccine, because we have been so frank with the public about the therapeutics we have being merely palliative rather than curative, I think there is a kind of depression among most people in America about what AIDS is all about. And therefore

they see no redemption and they wonder whether the effort that you are making, the effort that I made, the effort that society and science is trying to make today, is really worthwhile.

And when a society begins to think that about a disease that plagues them, I think we have a tremendous opportunity to try to disabuse them of these improper thoughts. So I would also suggest that you place that kind of thinking on your agenda to see what could be done in the future.

And finally, so that there might be opportunity for you to ask me some questions if you wish, I would like to say something about adolescents. Most of you know that I spent my entire life with children before coming to Washington, and that even after I got here I spent a lot of time doing things that pertain to children. I think I understand adolescents fairly well. I'm sure you all know most of the same things that I do.

They are individuals that we rely on for the future and therefore in whom we have a great stake, but as charming as they are, we recognize that they

consider themselves to be immortal, that they love to take risks, that they think any health message is for somebody else, and they turn their ears off if you start a sentence with the word "don't."

Now, with that as a situation for young people, you have to transfer those thoughts to what might happen to them in reference to AIDS. One of the reasons that I was eager to do what President Reagan asked me to do and report to the American people in 1986 was that it was becoming increasingly evident that with most persons with AIDS being in their young 20's and with the incubation period being as long as it is, that the teenage years were the years in which an awful lot of transmission of this virus was taking place. And therefore, I do think that one of our greatest targets for education aimed at the change in behavior is the teenage population.

Now, I think you would have to admit that in general we have failed at that. I don't think that there was ever a time in history when explicit messages about the avoidance of sexual contact were made more clear on television, radio, magazines, newspapers,

public events, in schools, than in 1986 and '87. And yet we know that at the end of 1987 the Centers for Disease Control told us that the incidence, the new cases of infectious syphilis and penicillin resistant gonorrhea had mounted at a more rapid rate than any time in the past 16 years. We know that year there were 1.2 million teenage pregnancies, so we know that sexual activity is rampant and that people of the age group I'm talking about are not listening to us.

Therefore, I have two conclusions that I draw from that. One is our message has not been the right one, and two, that we might not be starting early enough. I got in lots of trouble, as you remember, by suggesting that we improve and start at an earlier age the problem of sexually educating our children. I still believe in that very firmly. That is a parent's responsibility. They should be joining with and not fighting the schools in getting this done and getting it done properly. I do believe if we taught sexuality in kind, loving, compassionate, caring ways in a family context, that we could raise a generation of teenagers to be less sexually active than the ones we have today.

But secondly, I think we have to remember that the fear of the consequences of behavior has not ever been enough to turn a teenager's mind, and I think we have to go back to old fashioned morality and expand it beyond just the transmission of sexually transmitted disease and make clear to young people that it has been proven over many generations that the postponement of sexual activity not only prevents the diseases that we are talking about, but makes for better lives, makes for better marriages, makes for better families, and after all, it is the deterioration of the family that got us in the situation we are now.

I'll pause there and if you have any questions, I will try to answer them.

CHAIRMAN OSBORN: Thank you very much.

Are there questions from the Commissioners? Dr. Konigsberg?

COMMISSIONER KONIGSBERG: Dr. Koop, I know I speak for many, many state and local health officials in admiration of the leadership that you brought, I think, to not only the AIDS issue but many other very pressing public health issues. I was particularly

interested in the comment that you made, the, quote, new breed of public health officials that were looking to, in effect, divorce AIDS from the mainstream of public health response, and I guess I have two or three questions.

One is if you could explore that a little bit with me, and also maybe reflect a bit on how you see, in general, state and local health departments' ability to respond to this epidemic. That has been debated a good bit, as I think we all know. And then any recommendations that you have with respect to what we need to do as far as state and local public health responses.

DR. KOOP: Well, I'll answer your second question first, sir, and say that I have nothing but admiration for the way most municipal, county and state departments of health have handled the AIDS problem. My only criticism would come to those communities--and there are still some--who say this is not our problem. And if you remember, one of the major recommendations I made to communities when I wrote the report for President Reagan in 1986 was that you have to prepare

for AIDS when you don't think it is going to affect your community and then you might be ready when it comes.

As far as the divergence among public health people, perhaps I could answer that with an anecdote. I spoke at a large meeting in Boston that attracted only New Englander's, and I was asked to give the keynote speech, and I started off perhaps by alienating my audience by saying, "There are more people in this audience concerned about working on AIDS patients than there are patients with AIDS in all of New England."

And I think that set the stage for the fact that there is a very welcome and laudable effort on the part of society to rally around those who are in danger of this disease and in danger of getting it.

And then I went on and I developed at some length the thesis I just mentioned here very briefly, that we have got to mainstream these people and you can't separate one disease from all the others and expect it to work from a public health point of view.

I divided that audience pretty much down the middle. I learned most about what the reaction was by

watching television that night. And if you were over 55 and were answering something for Channel 5, you said, "Koop was right on."

But if you were 35 and you had started in your public health career with AIDS, you said, "No, AIDS is so different than anything else we've ever had that we need people who are specially trained and not afraid of it and understand all about social implications," and so on.

So, I don't want to overemphasize that point, but I think we have to fight every time that we can not to let AIDS take over as a separate entity and separate itself from the other efforts we make.

CHAIRMAN OSBORN: Mr. Goldman.

COMMISSIONER GOLDMAN: Dr. Koop, this is not going to be a question necessarily about AIDS, although obviously it is in the context. The major general purpose of the Commission as set forth in the act is to promote the development of a national consensus on policy concerning Acquired Immune Deficiency Syndrome. You have certainly had a lot of experience in the area of attempting to develop national consensus in a number

of difference areas.

I was wondering if you could give us any insight into how we deal with the issues of promoting a national consensus, particularly in the context of a disease which has the kind of potential for divisiveness that the disease itself presents, as you indicated.

DR. KOOP: Well, it is hard to put it in a few words, but I think in a sense an awful lot of public health comes down to the word "risk," R I S K. And we have to understand risk, and that is risk assessment. And then people in public health have to try to take care of that, and that is risk management. But between those two is risk communication.

And I think that's the place where we probably have been most lax, because risk communication is two-way, very important for the consensus development that you are talking about. So that in addition to talking and promulgating, I think this Commission has to listen to what people say, but that doesn't mean that they are right and it doesn't that mean that what you say next can't help in that dialogue

to disabuse them of some of the mythology that goes with this business.

And I think another thing that is extraordinarily important is--and I have learned this and I think if are you an astute observer of what happened to me in Washington--is that nothing succeeds like success and that sometimes the credibility of the messenger is more important than the credibility of the message. The difficulty is how do you make the messenger credible. And you do that by being so honest and having so much integrity that you never make a statement that can be ridiculed by the press.

So that I think in this risk communication business, you are walking a veritable tightrope. You never can say anything that can be taken amiss by the audience where a different shade of meaning can be put on it, and so that I would urge very strongly that any official communiques that emanate from this august body be very carefully thought out and checked and checked and checked. I hate clearance processes, but this is one place where it is necessary.

I have come to the end of my time, Madam

Chairman.

CHAIRMAN OSBORN: Thank you very much. Dr. Rogers I think wants to thank you as well.

COMMISSIONER ROGERS: I do want to thank you, Dr. Koop. May I give you one more question, please?

DR. KOOP: Sure.

COMMISSIONER ROGERS: You talked about the credibility of the messenger rather than the message. You talked about some of the mean-spiritedness, which I was pleased to hear you say you feel is a distinct minority, not the majority.

DR. KOOP: Absolutely.

COMMISSIONER ROGERS: I would have said a great deal of your effectiveness was because you as a national leader said here is the way we should treat people who are sick with this type of disease and they should have the same kinds of understanding and compassion and medical care that we give to one and all. I think one of my feelings--and I just simply want to check this with you--is if we could get more consistently that kind of statement from our leaders at all levels, though we might not change the

mean-spiritedness of some, I think we might profoundly change the way this nation would deal with the problem, both financially and humanely.

DR. KOOP: I agree with that. I think that you could isolate the mean-spirited people in this country and that the rest of society would treat them with the same repugnance that those people treat persons with AIDS, and I think that should be your goal, and I think it is achievable.

CHAIRMAN OSBORN: Dr. Koop, thank you very much for that wonderful final encapsulation of your message. I for one was very leased to read that you had said that you intended to keep inspiring Americans as you have been doing in every way you could find. I hope you will keep feeding us your input as you see us doing things that could be done better, or cheer for us, I guess, if we are doing things along a direction that you see as appropriate. We very much appreciate you taking the trouble to talk with us today.

Thank you.

DR. KOOP: Thank you very much.

CHAIRMAN OSBORN: Our next witness will be

Jeanne McGuire, who will be speaking on behalf of the National Organizations Responding to AIDS, the acronym NORA that some of you are familiar with. And I think Chai Feldblum will also be speaking with us.

STATEMENT OF JEAN MCGUIRE

NATIONAL ORGANIZATIONS RESPONDING TO AIDS [NORA]

MS. MCGUIRE: Thank you. This was a run up the steps and I'm still out of breath.

I'm Jean McGuire, I'm director of the AIDS Action Council. I'm here today in my capacity as chair of the National Organizations Responding to AIDS, and I'm very appreciative of the invitation that was extended to Chai Feldblum and myself to represent the interests of that broad coalition.

We are very clear that the importance of your meeting today, a meeting that we have long awaited, is that you will help us and help so many other people around the country struggling with the challenges of this epidemic to bring to fruition the blueprint of the Presidential Commission, and we look forward to engaging in that effort collaboratively.

One of the things that was not in place but was certainly starting to emerge at the time that the Presidential Commission did its work was the National Organizations Responding to AIDS, a coalition that now numbers over 150 national organizations that in some

way are involved in a very real response, a very real effort through their constituency groups to mold our nation's front line efforts to the epidemic.

Many of you have already been in receipt of information about the coalition, but I would just note for the record here today that we truly do represent, and in growing numbers each day, the diversities of the interests that have been brought to bear, the interests of the health care providers, the psychological, educational counseling service professions, churches, labor and industry, minority groups, and many, many others.

The coalition has been particularly important to the political process here in Washington in the course of the last year because of our ability through its diversity to offer to members of Congress a representation of the issues that is solidly based in a public health approach to the challenges and in a compassionate approach to some of the tougher questions.

Increasingly the organization, through its structure, is providing substantive input to the larger

policy issues, not just those that emerge in particular bills or during Floor debates, and through a targeted task force structure we do examine very closely the issues of research, prevention, care, pediatric concerns, anti-discrimination, prevention.

You have already seen some examples of our policy input in terms of the transition document that we offered to the Bush Administration to frame the discussions for this current year and for the beginning of the Commission's efforts. The overarching goals that we discussed during that document are the concerns about anti-discrimination and health care financing which in many respects are represented by Chai's and my presence here today, her in her role as chairing the Civil Rights Task Force, and my role as representing the rest of the programmatic issues we address.

I have also brought for you today to be distributed the legislative goals that this coalition put together to frame the Congressional discussions this year. You will see that they are very comprehensive, very diverse, very programmatically oriented, maybe not looking to broader policy issues as

much as looking to programmatic improvements and resource allocations. We hope that they will be something that will help inform some of the arenas that you should be looking into, likewise.

We are also moving forward to develop concept papers and establish appropriate forms for policy discussion. This is something we would like to do collaboratively with you. I think that the substantive information that you have from us frames for you a lot of what the coalition's interests are at this point. I guess I'd like to talk a little bit about our expectations of you, and the first one is that I hope that you will see us as a resource and you will use us in that accord.

The second one is that I want us collaboratively to be about the business of realizing the problems of the Presidential Commission. It is a blueprint and in many areas that is all it is, and in some of the most difficult areas, like health care financing, it isn't even that.

So we have a challenge ahead of us in terms of more fully describing the issues that were put

forward there and, looking down the road, to appropriate monies for implementation. In that regard, my hope is that you will help us focus on those areas in most need of the prestige and the credibility that your deliberations can bring. And I am concerned that you make conservative choices, that you not focus your energy on arenas that are likely to be being sufficiently addressed elsewhere.

I would suggest, for example, that in the research arena, while I expect this Commission to watch all of the activities that are emerging, we have been able to help structure a number of very viable avenues for information, everything from the parallel track discussion groups that are currently underway through the Lasagna Commission. You should certainly track and be aware and concerned about those efforts. I'm not sure they require your immediate scrutiny right now.

However, I do think there are other areas that are not receiving and have not been so easily embraced for federal oversight. And I would say that the first one is in the arena of targeted concerns regarding prevention efforts. It is with some degree

of embarrassment that I look at what it is we are producing from a federal government point of view in terms of a prevention agenda, as well as prevention materials, and you are well aware of the fact--and I will return to it later in this discussion--that there have been many efforts on behalf of our federal government to limit the effectiveness of our efforts on the front lines by virtue of moralizing around the agenda of what is the meaning of the issues that we face in this epidemic.

It is increasingly important that we be circumspect about our prevention efforts, that we be targeted about the resource allocation, and it is something that I believe that this body here can speak to effectively.

In addition, it is particularly important that we look both at the continuing intervention with the gay community where much has been done on their own accord, much still needs to happen, but look with even more scrutiny at what is happening with women, with minorities, with adolescents, a very hidden part of this epidemic. And what is it that we are or aren't

doing that is affecting the ability for the front lines to be more effective in the behavior change that we know needs to happen? It is time to take much more scrutiny of those efforts than we have in the past.

I think though that when I look to you in terms of what are the major issues that we face, what we need the most help with is framing the health care financing discussion. And I think when we discuss framing it, we talk about both framing the components that are appropriately a part of describing health care interventions and financing strategies relevant to them, taking a tough look at the relative roles of different levels of government and the private sector's involvement. And then, confronting what I think is the hardest agenda in terms of describing health care financing issues in the context of this epidemic, and that is the equity issues.

There are no two ways about the fact that from a political perspective describing health care financing interventions that can most immediately address the concerns of HIV and AIDS, raises serious issues about equity in terms of other populations. And

one of the things we cannot afford to have evolve any more than it already has through some elements of the media is a discussion about AIDS versus poverty, AIDS versus women, AIDS versus children, it goes on from there.

AIDS is a disease of poverty and it is something that people experience poverty through, and I think that what we need to do in terms of making a targeted response for the challenges of articulating the health care financing concerns is recognize that in the best of circumstances we are still going to have some unresolved equity issues. But I would put forward to you that I think that the impact of this disease on the poverty health structures of this country dictates that we in fact put in place targeted AIDS health care financing improvements so that we at least alleviate the burden on our overburdened health structure. That may not be a full response to the equity challenges the politicians will then face, but I think it is a part of framing why you should look at both AIDS specific and system generic improvements to the health care financing structures of this country.

We simply cannot wait for some of the improvements that will come through general system reform, but if we do well some of the things that HIV demands, we will provide a benchmark for future improvements for all of those who are at risk in terms of being underserved with their health care support and health care financing.

Finally, even though I know I have asked you to be conservative about the issues that you choose to focus your energies on, I am also going to ask you to be broad-minded in terms of looking at the issues that emerge and will require people of your stature responding to them, regardless of whether or not they represent a targeted effort of one of your task forces.

As you know, in the debates--in the sometimes not too well framed debates--of our Congressional activities, and sometimes of the media, we have discussions emerge regarding responses to HIV that are driven far less by public health and humane concerns than we would like to see them be. Some of those are likely to emerge during the course of the appropriations process on the Senate side this week.

I have brought for your review a package of information that we have prepared for the Senate to take a look at some of these tough issues that we think may emerge during the debate that shouldn't be discussed on the Senate Floor, probably are best resolved almost universally within the context of state policy decision-making, and to the extent that our Congress chooses to look at it, should happen through the deliberative process of authorizing committees.

The issues run the gamut from contact tracing concerns through the mandatory testing of prisoners. All of them speak to the needs that are sometimes felt to take a moral stand on this epidemic. To the extent that these issues do not claim a particular part of your time--and I'm not sure that they should, I do think that much of what we are talking about here are issues of states evolving and monitoring that process--but to the extent that they may not, I still urge you to be with us in articulating a sane response to those challenges as they emerge.

I think that this is an appropriate point for me to turn over to Chai Feldblum, because this is the

point at which we start walking from just the programmatic considerations into the broader policy issues that tend to frame the rights concerns of the people that are affected by this virus. Chai Feldblum has led the way in NORA with her chairing of the Civil Rights Task Force, along with others, and with her particularly good work during the passage of the Americans with Disabilities Act, and I am pleased to introduce her now.

STATEMENT OF CHAI FELDBLUM, ACLU

CHAIRMAN, CIVIL RIGHTS TASK FORCE, [NORA]

MS. FELDBLUM: Thank you. I'm Chai Feldblum. I'm a legislative counsel for the American Civil Liberties Union's AIDS project, and I am also, as Jean said, one of the co-chairs of the Civil Rights Task Force of NORA.

What I am going to talk to you about today is the legal issues concerning AIDS, specifically nondiscrimination issues, although at the end I think I'll touch on a few others.

As you all know, the Presidential Commission identified nondiscrimination protection as a committee issue in terms of addressing the AIDS epidemic. And I know because of looking at all of you and knowing your previous involvement in this issue you also know that every report, every Commission, every group that has looked at this has identified nondiscrimination protection as important.

But what I want to do is talk a bit about what has happened over the past two years in Washington legislatively where we have been in nondiscrimination

issues and sort of let you know where we are now, because I think that there is definitely a role for this Commission to play in terms of actually finally achieving in this country true anti-discrimination protection.

As you know, in 1964 Congress passed sweeping civil rights protection in employment and public accommodations for people on the basis of race, religion, national origin, sex, no discrimination allowed in those areas. It wasn't until 1973 that Congress got around to saying well, maybe we should have some of these protections for people who are discriminated against on the basis of disability. But when they passed it in 1973, they passed it as part of the Rehabilitation Act of 1973. It really gives you a sense of where disability was at the time. People with disabilities were still seen as people who just needed to be helped. You know, people had to be rehabilitated.

A section of that bill also included what is called--and I'm sure all you know it--Section 504 of the Rehabilitation Act of 1973, which said that

entities that got federal funds, either if they were federal contractors or they got federal funds in some way, those entities couldn't discriminate against people with handicaps.

And then the law didn't describe the different handicaps. It basically said a year later when Congress came back and sort of expanded the definition of handicap, basically said anyone with a physical, mental impairment that substantially limits them in some way should not be discriminated against on the basis of that disability if they are otherwise qualified to do the job.

Obviously, you don't have to hire a blind bus driver to drive a bus, but if someone is able to do a job and their disability doesn't stop them, anyone who gets federal funds cannot discriminate against that individual, in all types of areas.

That was a critical law for people with AIDS and HIV infection, because people with AIDS and HIV infection have impairments of their system which keeps them completely qualified to do jobs, to go into restaurants, to do all types of things, but they often

get discriminated against. So the law was critical in terms of entities that got federal funds.

Again, as many of you may know, there was a Supreme Court case, School Board of Nassau County versus Arline, in which it was questioned whether contagious diseases were covered under this act. The Supreme Court said yes, they are covered, and just like any other disability, someone with a contagious disease has to be qualified, which means they can't pose a significant risk of transmitting the infection to others, if they have some sort infectious disease.

Well, the response on the Hill has basically sort of framed the work that the NORA coalition and lots of other coalitions has done since that time, and it is basically a two-front battle. One is an effort to keep Section 504 strong, to keep those protections in place. And second is to go beyond the protections of Section 504.

The first battle came about about two years ago when Congress passed the Civil Rights Restoration Act, which basically was dealing with some of the provisions of Section 504 and some of the response of

members of Congress to the Arline decision, which had just come down about six months before, was sort of to create a lot of panic and hysteria, the type of panic and hysteria that I really hope that by the time you work on your Commission has really decreased, but I can assure you has not gone away.

The response to that sort of hysteria was to try to exclude people with AIDS completely from the protection of Section 504. And in response, through discussion, what came forward was putting into the law clearly the law of Section 504, which says, "Someone who poses a direct threat to the health or safety of others." In other words, if they have a contagious disease, there is a significant risk of transmitting the disease, those people are not covered under the law, just as they never were under Section 504.

Well, that was the compromise that was worked out in the Civil Rights Restoration Act, and that really set the stage for the next main piece of legislation that Congress dealt with in this area, which was the Fair Housing Amendments Act of 1988. This was a critical piece of legislation, because for

the first time it moved protection for people with disabilities beyond federal funds. In other words, private individuals who rented or sold buildings, apartments, could not discriminate against people with disabilities, including people with AIDS and HIV infection.

Now, I'll tell you, when bills come forward to protect people on the basis of disability it is very clear to Congress that that also includes people with AIDS and HIV infection, as it should, but the response is often an effort to exclude those individuals from protection.

And the same effort was made during the Fair Housing Amendments Act in committee, on the Floor, to exclude people with AIDS and HIV. And again the response was to make it clear that anyone who posed a direct threat to the health or safety of others was not covered, but obviously, people with AIDS and HIV infection as a group remain covered.

I mean, I give you this basically to set the stage for what we have right now, which is the Americans with Disabilities Act. The Fair Housing

Amendments Act went simply to housing. I mean, it came up because that bill was already--that law was already being amended for other purposes.

The next major step forward is to get protection for people with disabilities in the rest of the private sector, in the employment area, in public accommodations, which means all types of businesses, restaurants, doctor's offices, pharmacists, et cetera.

That bill, as many of you may know, passed the Senate about two weeks ago and is now moving over to the House side. The bill is of critical importance for people with AIDS and HIV infection. It is a bill that really reflects the way coalitions have worked. The NORA coalition has worked very closely with the coalition of disability groups in terms of drafting the legislation so that the legislation reflects the needs of the people to be served, as well as working with the coalition, both coalitions, to stop any adverse amendments to the bill.

I basically want to say just two things about the bill. I'm assuming that as you go through your work you will be getting more than enough paper, I'm

sure. I'm sure you already have more than enough paper, but you will get descriptions of the bill, et cetera.

There are two main points that I want to make about it. It basically tracks the protections of Section 504. In other words, identifies, builds on 15 years of history that we have on a law that has protected people with disabilities, and extends it to the private sector. So, for example, it says you can't discriminate against someone who has AIDS or HIV. You can't say, I'm not going to hire you because I don't like the way you look, I don't like that you have this disease, I don't like that you are going to cost me money, whatever. You can't just sort of do a blatant discrimination.

The other piece that it has, we found in terms of the litigation in this area that problems that people had were either straight out discrimination in terms of employment, or times when employers would try to test current employees on the job to see if they were HIV infected. And the bill, as I said, tracks the Section 504 protections, makes it clear that you cannot

simply discriminate against someone by not offering the job, and you can also not test someone on the job until it is job related. It tracks Section 504 in terms of general testing provisions, which is that employees are allowed to give medical examinations to all applicants before the applicants come on the job. They have to first make a conditional offer of employment to the individual, then they can do whatever medical examination, as long as they do it to all applicants, that results are kept confidential and that they use the results and that they use the results of the medical examination only in a way allowed under the act.

In other words, if you test someone and you find that they have some disability that makes them not qualified for the job, then you can withdraw that conditional job offer. As I say, in terms of AIDS and HIV infection, people, as someone said, are qualified for everything except maybe legalized prostitution, for which there is not a lot in this country at this point.

So that the bill, in terms of the employment area is critical, and then, in addition, in the public

accommodations area. The bill, again, sort of has the same perspective of prohibiting outright discrimination in a restaurant, in a doctor's office, in the pharmacist's office, et cetera.

I would imagine that one could still see efforts to try to exclude people with AIDS and HIV infection from the bill, although I will tell you that I think there is a greater understanding in the country overall and in Congress. Certainly this Administration has been very strong in saying that protection needs to be granted to all people with disabilities, as well as people with AIDS and HIV infection. And so I think that there is a greater understanding of the need to provide that protection.

However, the job is never done until the job is done, and this bill still has to go through the House of Representatives. And I think that any work that the Commission can do in terms of learning more about the bill, as Jean said, the NORA coalition definitely stands as a resource for the Commission in terms of going through any details of the bill. But any work that the Commission can do to help make that

bill a reality, I think will definitely set you in a very good step in terms of implementing the President's Commission report, since that was one of the main recommendations of the report.

I would also say that in terms of some of the history of the different bills that have happened, the Civil Rights Restoration Act, the Fair Housing Amendments Act, there is also a document that I prepared for AIDS Action Council which we'll make available to the Commission and can be reproduced for you.

As I said, basically, the nondiscrimination issues are the key issues at this point for the NORA coalition, I think in general, in terms of people working on the AIDS issue. There are some other issues that are probably worth looking at, and I'm not going to go into detail on them, but again, I'm willing to serve as a resource on them. There are immigration issues that I think are worth looking at. The Administration a few months ago came out with a much better policy in terms of visitors who are HIV infected, a good waiver policy on that, but it is sort

of an interim, and I think that bears looking at.

You might be interested in knowing that the American Bar Association at its annual conference in Hawaii--thank God, so I was able to go to Hawaii--passed about 60 resolutions regarding AIDS, and there were some on immigration as well.

I think immigration is one area that needs to be looked at. I think you are going to have put before you issues of reporting and partner notification. These are issues that on the Hill have almost been dealt with with an axe. In other words, we get an amendment to just have mandatory reporting, or mandatory partner notification without any sort of subtlety to it. And the response has often been to simply let, from our part--to let the states decide on a state by state basis. I think that there are issues in terms of legal issues, in terms of partner notification and duty to warn, that the Commission might want to look at in terms of developing some more nuanced responses. I think we have had some very good responses in the public health community on this and, as I said, sort of more axe type approaches by

Congress.

But I think immigration and reporting are issues that you may want to look at, as well as the nondiscrimination. But as I said, the main issue before the coalition at this point is getting the Americans with Disabilities Act passed as soon as possible, and any help that can be provided would certainly be appreciated. Thank you.

CHAIRMAN OSBORN: Thank you very much. I think you are aware that the Commission did in fact endorse a statement urging the passage of that bill two weeks ago when the issue was before the Senate, and this was a unanimous stance of those commissioners involved in a conference call, so that the urgency you feel, we have already said we share about that important legislation.

I would like to invite commissioners to ask questions if they have them. Dr. Rodgers.

COMMISSIONER ROGERS: Ms. Feldblum, this may be bowling a ball right down your alley here, but I sense one of the things you are saying is the number one issue this Commission ought to be firm on is the

anti-discrimination issue, that other things would follow logically from that. If you had one thing you would like to see this Commission do, is that it?

MS. FELDBLUM: Yes. I think definitely the highest priority is definitely the nondiscrimination protection, and as I said, although we certainly are on our way, that is not going to be established until it is in place.

Now, I would like to say, once you pass a nondiscrimination law, that is always only the first step. I mean, I will tell you as a lawyer, clients really don't want to go through paces, you know, go through court. They would much rather have a complete change in attitude in the country so that they don't even have to deal in the first place with having their employer fire them, or having the restaurant kick them out. So I would say yes, number one, as a lawyer, we need the federal law in place to provide the protection. But number two, just as equally as a lawyer, if this Commission can help to change some attitudes so that there is less work for lawyers, I personally would be very happy.

CHAIRMAN OSBORN: Harlon.

COMMISSIONER DALTON: Yes. My questions actually are for Jean McGuire. I gather from your comment about coming up the stairs, that you weren't here for the earlier testimony this morning.

MS. MCGUIRE: I regret that I wasn't.

COMMISSIONER DALTON: Well, I was struck by what seemed like a couple of points of tension between what you had to say and what some earlier speakers had to say, and so I wanted to give you a chance to speak to that.

When you were urging the Commission to proceed, in a sense, conservatively in our selection of things to put on our plate, the example you chose had to do with all the action around drug trials and the like, and treatment, different approaches to treatment.

And I think you indicated, quite correctly, that there are lots of people looking at those issues and that we should sort of essentially keep an eye on what is going on.

But I was struck that Dr. Krim in her remarks this morning had, among other specific recommendations,

suggested that we in fact look favorably upon weighing in on the side of a real catholicity of approaches to testing out new drugs, and in particular, the kind of community-based effort represented by the San Francisco doctors around Compound Q. Similarly, Dave Johnson, in the PWA panel, suggested that we bring in Martin Delaney from Project Inform to talk about a lot of their efforts.

So it seems to me we are going to hear a lot about this and about the role the Commission ought to play, and I just wanted to have you just get a chance to speak to that.

The second, I think, point of tension had to do with your suggestions--and this is maybe a non-point of tension--that in the area of health care finance, I think you quite rightly invited us to pay a lot of attention to that issue, which was not dealt with by the prior Commission. But you suggested that we opt for an AIDS specific approach to financing reforms rather than a more global health area approach.

That happened to follow after Dr. Koop's suggestions that there is a new breed of public--you

are certainly under 55, which is his dividing line--but in any event, public health types who believe in sort of separating out AIDS from the mainstream.

Now, I'm not sure that you that you were necessarily offering up a general belief about mainstreaming versus--but I wanted to give you a chance to speak to that.

MS. MCGUIRE: Thank you, I appreciate the opportunity to speak to both issues. I'd like you to take on everything you can, and I'd like you to spend time looking at the very tough issues that surround research development. I think the reality is you are going to have to end up making some choices, and I think in that regard you could be well informed by the efforts of Dr. Krim and her leadership in research action, Martin Delaney, and many others.

But there are bodies in place that are looking in both, and I guess my challenge to you is I would hope you could invest some trust in some of those bodies so you could look then at the summative pieces of their deliberations and certainly weigh in. I mean absolutely, one thing that I feel like I neglected--and

15 minutes is tough--is to reinforce that throughout, whether it is research or it is prevention or it is care, the community-based need, the need for community-based response to this epidemic keeps being revisited to us through very diverse arenas.

So whether it is in research or prevention or care, I want that to be a guiding force for you. But I think that we need you to be able to truly deliberate around some issues that people aren't touching, and in that regard, I think you should bring in people from these various other panels, see if you can feel comfortable that the process that is moving forward there is one you can lend an imprimatur to, and speak to with some authority, but not to reduplicate things.

And so it is--I felt risky pointing out research because I felt it would indicate some lessening of my support of that as an important arena. Absolutely not. That is our hope. But the other places that are so much harder, nobody is touching, or not touching enough.

In that regard, in the health care financing arena, I do want to be clear. My discussion was not a

mainstreaming versus segregating one, because frankly, I believe that the critical juncture that we are at of the epidemic, especially in terms of the increasing numbers, speaks very specifically to us about the fact that AIDS specific entities are not going to be able to sustain the totality of the impact of care requirements. We must infuse into our generic public health--poverty and other health structures--broadly based and appropriate services to people with HIV infection.

I am at the same time telling you though, that we cannot--many of you have also worked on Medicaid reform, either at the state level or at the federal level for years, you know how slowly those wheels turn. The poverty health structures in many of our communities, and it is not just New York City, it is a whole host after that, New Haven, Connecticut, Miami, I mean, we can go on from there.

They can't wait for that wheel to turn. And it makes framing the debate very hard, and I think I'm asking you to be a part of framing a hard debate. I think it involves an assessment of the appropriateness

of aspects of impact aid in targeting areas on the basis of incidence factors, but I think it also--it would be nice if that would take care of what it is we face. It won't, because impact aid, like any type of block granted structures, it will be underfunded and somewhat inadequate and inefficient in its distribution of resources, which means looking at qualifications in terms of the disability determination process--for Medicaid in particular, perhaps for Social Security, especially with the advent of early interventions--is a choice to look at something that is inequitable in its very nature, but probably necessary in terms of the time frame that you have to work with.

Simply put, if we had started earlier on this--you all weren't around to be indicted in this regard--maybe we would have been further along and could have relied on systemic answers. Ultimately the best ones will be the ones that reframe the system as a whole. But I'm not convinced that you can tell communities out there that that time is available.

CHAIRMAN OSBORN: Larry Kessler.

COMMISSIONER KESSLER: Chai, I have a

question. In light of the fact that discrimination laws do not necessarily stop discrimination, and also that many of the people with AIDS and HIV disease have been reluctant to file cases and so on, what risk do you see developing in terms of the issue of preemployment testing for HIV, if that becomes a condition of this bill?

MS. FELDBLUM: This is a good question in terms of the realities of the world. At the moment we have not been having problems or cases of sort of mass preemployment screening. I mean, that is just not going on at this point. In fact, that is another thing the American Bar Association, in a White Paper that was prepared on this issue, basically recommended to employers that they were going to be walking themselves into more legal problems than they wanted if they would sort of do mass screening before employment, because assuming you had a nondiscrimination law, you wouldn't be able to use that information. Then you would just sort of have that information hanging out somewhere and you could be exposed to all sorts of different liabilities.

But at the moment, employers are not doing that type of testing. Now, it is true, as I explained under this law, that there would be no prohibition on doing preemployment testing as long as it was done to every single person who applied, that the results were kept completely confidential, and that they were not used in any discriminatory fashion.

I would hope that based on the same reasons why the American Bar Association, even before this bill has passed, is recommending to employers not to test, I mean, I would think that those same reasons would still apply and that you would not necessarily find employers doing mass employment screening just for employment purposes, you know, just to find out whether someone is HIV positive and then not hire them.

I do think that there is an insurance issue problem here which feeds right back into what Jean has said, which is that right now what we are finding in the insurance arena is that people who try to get private health insurance, most insurance companies are ready or are planning to require people to be tested and show that they are HIV negative, and if they were

HIV positive, they get denied insurance.

That has not been happening yet at any systematic level on the group health insurance level. It is not at all impossible that as the care issues continue to grow and they are not dealt with, that is, there is no system in place to provide that care and financing, you will be running into testing for insurance issues problems. And this bill, the Americans with Disabilities Act, specifically because of the realities of the situation, does not affect how insurance companies do their underwriting, so that insurance companies can continue to discriminate.

I think that this issue of preemployment testing feeds right into the issue of providing the insurance in some form, if it is going to be a combination of private insurance companies and government working together to provide that care, that the testing issues are going to feed right into the care issues.

CHAIRMAN OSBORN: Let me get Dr. Konigsberg to ask the last question, because then we will need to break for lunch in order to stay roughly with our

schedule this afternoon.

COMMISSIONER KONIGSBERG: Thank you, Dr. Osborn. I will make it brief.

I would like to come back, Jean, to the question of the, I guess for lack of a better term, the public health control issues, specifically the reporting and the partner notification, those other issues, because I'm a little bit unclear as to what your message was. I may have heard maybe a different message from the two of you.

One of the things that characterizes our public health system in this country is the fact that for the most part public health has been delegated to the states, yet our country has changed and AIDS clearly is--and HIV--clearly is a national issue, we do not have a national consensus on those issues. So could you clarify as to did you mean to say that we should address those, or are you saying that we should leave that to the states? That is really what I'm after.

MS. MCGUIRE: I guess there are two ways of kind of parsing that question. And again, within a

limited time frame I recognize that some confusion could have ensued, and I'll take the responsibility for that, and I think they have to do with how are you going to function and what are the things that you are going to be speaking to. I think there is a lot of a sense of a need to have policy with a big "P" spoken to in terms of how do we frame the debates, how do we frame the issues, how do we articulate sensible response and humane and effective responses.

But I think that there is a difference between that and what do we look to for federal laws to do. And I'm not sure that there is a consensus, and in fact, our way of handling this kind of hatchet stuff--and I'm going to stop and let Chai finish in a minute--around the types of regressive activities we have seen in the Congress at different times, has been to take a safer harbor in state deliberation where the opportunity to reflect on incidence factors, resource availability and community capability at large frame some of those things somewhat differently.

I think we would be well-helped by model policy discussions. I'm not sure we are well-helped

by--and I think this is certainly true for our NORA coalition and on the Hill and for you--you will see an ongoing debate about the extent to which we are equally well-helped by federal laws.

And I think that one of the things this points out and a challenge that you particularly face, and one that I feel is a result of the interchange in our question and answers, you are faced with a responsibility to be attentive to an issue that is a dynamic. And I would like to tell you that the things we set out today, they are your priorities, you can set up your task forces, focus on them and go from there.

But I'll tell you, around the corner is some resolution on early intervention, short term resolution. You know, you need to speak to that piece too. And then maybe the day after that we are going to find out that no, really the system pieces were not--I mean, I think that your challenge that you are facing is being able to be committed to broad based capital "P" policy issues and having the flexibility to move as the target moves. In that regard, I don't think the target has sufficiently settled on some of those

issues.

You will find in our piece, I think, some very good rationales for why we don't want to see these issues debated during a Floor debate in the Senate on a funding bill. You will not find a rationale in terms of where they should ultimately be resolved, and that debate I do expect you to enter into. So I hope that clarifies that somewhat moreso, and I would like Chai to maybe finish up.

MS. FELDBLUM: I think it is important that there not be confusion on this. As Jean said, what often happens here in the Congress is someone will come forward and say, we think there should be a federal law mandating the states to set up an HIV, for example, reporting system by names and addresses. The response on the Hill to that, the response in the NORA coalition and the others, is to say, let the states decide how they want to deal with this. When this issue came up in the omnibus AIDS bill last year in the House an alternative amendment was put in the bill--that ultimately never became law but did go through the House--that said that states, to get funds, had to set

up some system of HIV infection reporting, enough for statistical and epidemiological purposes, and left the issue of, quote, names reporting up to the states.

Now, separately though, the coalition also has stances and positions on the pluses and minuses of names reporting and, as Jean said, then at the state level would be saying we would recommend that you not require names and addresses because that is going to hurt your efforts to get people in for voluntary testing and you don't need the names and addresses to do partner notification.

And therefore, as Jean said, I think on one hand it would be important to have a clear statement that these things aren't best dealt with on the federal level, but it would be useful to have a blueprint for the state level about the type of reporting that is necessary, the elements that make a partner notification system both something that works as well as something that protects everybody's rights, the person who is HIV infected as well as the person who might be at risk. That type of blueprint could definitely be useful

MS. MCGUIRE: And we, of course, are responding to the fact that there are constraints that we face in the politics of the Congress in terms of what we can actually pass. And those constraints maybe charge us to look at having those issues resolved at other levels, although we know we deal always with the discrepancies of the health care financing issue as it is reflected throughout the states.

So I think my urge to you is help us frame the debate and then, to the extent that you think it is important, to deliberate about where that debate is best resolved. We look forward to doing that cooperatively with you. Thank you.

CHAIRMAN OSBORN: Thank you ever so much for your testimony, both of you, Jean and Chai, and we will now break for lunch and try and get back at 1:30 for continuing our proceedings.

MS. MCGUIRE: And we hope to see you all tonight at the reception. Thank you again.

CHAIRMAN OSBORN: Thank you.

[Whereupon, at 12:15 p.m., the hearing was recessed to reconvene at 1:30 p.m. the same day.]

AFTERNOON SESSION

CHAIRMAN OSBORN: I'll ask the Commission to reconvene at this point. Some of our members are not yet with us, but I think we should try and remain on schedule. In particular, I am very, very grateful to our next witness for making a special effort to meet with us at a time which is absolutely not convenient for him. And so we are particularly honored to have Dr. Robert Newman with us. He is president of Beth Israel Hospital and CEO there, and is also deeply knowledgeable about illicit substance use and its patterns and problems in this country, and one of those very rare people who knows a lot about AIDS and about substance issues at the same time.

I'm particularly grateful to him for making the effort at this meeting, since Dr. Des Jarlais, who would normally be with us up here as a member of the Commission, was unable to make this meeting because of a much earlier scheduled commitment in Europe from which he could not get back in time.

So Bob, double thanks for coming at an inconvenient time for you and to help us out when Don

particularly couldn't be here.

STATEMENT OF ROBERT NEWMAN, M.D.

PRESIDENT AND CEO, BETH ISRAEL MEDICAL CENTER

DR. NEWMAN: Thank you very much. It is a great privilege to be here.

As you indicated, Dr. Osborn, my hospital, Beth Israel Medical Center in New York, indeed treats a huge number of both IV drug users and patients with AIDS. We have, as you know, the largest drug abuse treatment program in the country, and we have one of the highest patient populations with AIDS. So we certainly experience directly the devastating impact of both of these related problems.

About 18 months ago I appeared before President Reagan's Commission on the Human Immunodeficiency Virus and I prefaced my testimony by apologizing for what I felt was a self-evident conclusion, and that is that, number one, there are huge numbers of heroin addicts and addicts using other drugs throughout the United States, that they are engaging daily--actually several times a day--in behavior which is more closely linked to the spread of the AIDS virus than almost any other behavior, that

among the addict population there are tens of thousands--and I personally believe probably hundreds of thousands--of people in this country who not only are willing to accept treatment but desperately motivated to do so to give up the illicit use of drugs and all the dangers and the hazards that are associated with it, both for them and for the general community, but who tragically are thwarted in their efforts to obtain help because treatment programs, treatment programs of all kinds in all cities of our nation, are filled to capacity and then some and simply have to turn them back to the streets to continue using drugs.

Apparently the message was self-evident, but at any rate the report of the Presidential Commission did include as one of its key recommendations the statement that treatment on request absolutely had to be pursued and that that goal had to be achieved if we were going to have an impact on the problem of AIDS as well as the problem of drug abuse.

That's the good news. Unfortunately, the recommendation of the Presidential Commission was simply ignored in the subsequent 18 months. It is not

that people disagreed with it, it is not that people took exception to any of the premises or the conclusion itself, it was simply ignored. None of the federal agencies even commented on the recommendation that there be treatment on request for all addicts. Nobody came up with a plan, nobody even dignified the recommendation by explaining why it was too ambitious a recommendation, it was simply ignored. And not only at the federal level, but to my knowledge that recommendation, so forcefully made by the Commission, and so convincingly made, I believe has also been ignored in the past 18 months by every one of the 50 single state agencies of our nation that are responsible for addressing the problem of drug abuse.

Now, that brings us up to the national strategy that was announced within the past two weeks by President Bush and Mr. Bennett. I should say at the outset that I think it is a major step forward that our country at last has a strategy to deal with the horrendous problem. It is almost inconceivable that we have gone for years and years and years lamenting this terrible problem of drug abuse and that there has not

been any kind of a strategy, good, bad or indifferent. There has been no strategy to deal with it, so I think it is a major step forward and I commend the Administration for having at last developed a strategy.

Unfortunately, as the strategy relates to a treatment of addiction, and specifically treatment on request, it basically continues the pattern of ignoring that key recommendation of the Presidential Commission last year. And it does so despite the fact that it acknowledges first of all that addiction is a chronic illness and that there is no permanent cure known for it. That is an acknowledgement that I must say I was gratified to read in the strategy, because there are still many people, unfortunately and erroneously, who claim that the whole problem of drug addiction can simply be eliminated if people only pulled themselves together and resolved that they were going to stop and that we really don't need treatment, that this is just a matter willpower. Clearly Mr. Bennett and those who assisted in drafting the strategy do not feel that way because they explicitly state that drug addiction indeed is a chronic illness for which no permanent cure

is known.

Secondly, it is gratifying that the strategy does not take the cynical approach of many people in our country in saying that treatment is ineffective, maybe it is an illness, maybe it isn't, but in any event, there is nothing we can do about it, treatment doesn't work. The strategy does not say that. The strategy very clearly acknowledges that treatment is effective and that it is effective for a very substantial proportion of the people who seek it and accept it.

And finally, it was gratifying to see that the strategy does not minimize the numbers of people who are using drugs, who are killing themselves and others with drugs, as well as through the related spread of infection, particularly AIDS. The strategy does not minimize the numbers that could be reached and helped by treatment. As a matter of fact, the strategy uses the figure of two million who fall in the category of those drug addicts who can indeed be helped by treatment.

But having acknowledged all that, it then

fails--totally fails--to even mention, let alone to address, the recommendation, the seemingly self-evident recommendation, that treatment on request absolutely must be made available to every single addict in this country. Not only does it not acknowledge or accept the premise that treatment on request is a goal that must be achieved, it does not even partially address it. It has absolutely no targets whatsoever that it enunciates with regard to the need for treatment expansion.

Contrast that with the strategy's reference to prison expansion. There Mr. Bennett has been very clear and he has come up with a specific number. He has said that the prison expansion in this country should be 85 percent, that we should increase by 85 percent the prison capacity in the United States. One can agree or disagree with that figure, but certainly the target is very, very clearly expressed.

Similarly, in the case of the numbers of casual drug users, there is a very specific target included in the report. I think it is an embarrassingly modest target. It specifically says

that the aim should be to reduce by 5 percent per year the number of casual drug users in this country over the next 10 years. I think it is particularly embarrassingly modest since the report does say that over the past three years without the benefit of the national strategy and the resources that presumably will be allocated to it, casual drug use already has dropped by 37 percent. So that the target is considerably less for the future as we have actually experienced without the strategy over the past three years, but again, one can quarrel, one can quibble with the adequacy of the goal that has been enunciated, the important thing is when it comes to that particular issue, the number of casual drug users in America, the strategy has an explicit goal, 5 percent reduction per year.

And while, as I have emphasized, I feel that that is a very modest goal, I might just say that if the same modest 5 percent per year had been applied by the strategy to treatment expansion, it would mean that in the coming year an additional 40,000 plus addicts would be enrolled in treatment. Two years down the

road 80,000 additional addicts would be enrolled in treatment. So even a modest number would have been encouraging, but in fact absolutely no target whatsoever has been enunciated and there is nothing to suggest in reading that report that anything will be done to significantly narrow this unconscionable gap between the availability of treatment on the one hand and the demand for treatment on the other.

Now, what do I suggest be done? First, and perhaps this is unaccustomed, but I agree totally with President Bush in his statement that the strategy should not be judged by its price tag. The goal of the United States in dealing the addiction problem and the related problem of AIDS should not be measured in terms of how many dollars are allocated or how many dollars are spent. That should not be our national objective.

Our national objective should be to do something about these problems. Personally, I would have been happier if the strategy made no reference whatsoever to dollars. For sure, dollars are important, but they are not the only constraint, and I personally believe they are not even the major

constraint to a significant treatment expansion for addiction in this country.

Instead of focusing on dollars I would have liked to have seen and I still hope to see in the future a clear, unqualified commitment of the federal government to make treatment on request a reality for every single addict in this country who is willing to accept it. I would hope that the federal government having made such a commitment would then demand that every single state and every locality share that commitment and come up with ways to meet that goal.

Finally, I would like to make two analogies to try to explain why I think the focus on dollars and the absence of commitment are something that will hurt us if we don't change it. First, with regard to education, which certainly is Mr. Bennett's field and not mine, but the fact is--and I think most people agree--that the school systems throughout the United States are overburdened in many, many ways and face a great deal of difficulty.

There are a lot physical plants that are woefully antiquated. Teacher shortages are major

problems. The adequacy of funding is a major issue. And schools throughout the United States have had to accommodate these various problems as best they can. There are schools on split shifts, there are schools with terribly overcrowded classrooms and so on.

And yet in addressing all of those problems, nobody would ever suggest that the solution, the way we should go, is basically to do the best we can for some students and then if there isn't enough money left over we should simply have waiting periods for all the other millions of students who could not be accommodated in the way that we all would agree the educational system should accommodate them. Nobody would say wait a year or two years or five years until there is a spot in the school which has the ideal number of teachers, the ideal amount of space, and so on. We accept as a given in this country, fortunately, that every single kid must have access to school. And the resources may be inadequate but that shortage never obviates the requirement that every single student should be accommodated.

In the case of treatment for addiction, we

approach it from the other side. We say first, how much will it cost, where will the money come from, will there be enough money? But there is an absence of a commitment that every single person who wants and needs and can benefit from treatment indeed will be able to get it.

The second analogy has to do with the shelter system in New York City, and I apologize for the parochial nature of that analogy, although it might apply to other cities as well. Several years ago everyone in New York knew that the shelter system for the homeless was simply inadequate, that it simply couldn't accommodate all those who needed shelter. In that particular case a judge simply imposed a commitment on the Mayor of New York, and he acknowledged all of the constraints to massive expansion of the shelter system. And it is interesting, because the constraints are essentially identical to the constraints that affect the expansion of the drug addiction treatment system. Not enough money for sure, but equally important, lack of facilities, the "Not in my backyard" phenomenon, the

fact that to ideally accommodate the homeless would require huge amounts of space, buildings, money, personnel, security and so on.

All of those constraints were acknowledged by the judge, and he said, Your Honor, you deal with the constraints, you figure out how to provide shelter for everybody who wants it, but I'm telling you that you must within a specified period of time be able to accommodate every single person, every single family that comes for shelter. And in fact today, to the credit of the city administration, there are many shortcomings in the shelter system--to say that they are far from ideal is a gross understatement, there are many problems--but the one fact that the city justly is proud of is that nobody is turned away from the system because there is no room.

No person, no family, is told, gee we can't accommodate you tonight, try us again in three weeks. Because the commitment was and remains that every single person will be accommodated when he or she seeks shelter.

I would urge this Commission to do everything

you possibly can to obtain a similar commitment from the federal government and through the federal government from the state governments to ensure that the same commitment applies in connection with availability of treatment for addiction.

Again the biggest hurdles, the biggest obstacles that I as an advocate of treatment expansion have had to face in the past, those hurdles are behind us. We no longer have to argue that addiction is not just a matter of willpower. We no longer have to argue that treatment is effective. We no longer have to argue that there are huge numbers of addicts who desperately want and can benefit from treatment.

But having accepted all those premises now, it is simply inconceivable to me that this country permits a continuation of waiting lists for treatment. I mean, it is just mind-boggling. Somebody who comes into a program in New York City, in San Francisco, and everywhere in between, and says three, four, five times a day, I am sticking dirty needles in my arm, I am sharing needles, I am risking killing myself, killing others, killing my unborn children, and I know the

dangers and I want to stop using drugs and I am hopeful, I am confident that treatment will help me do so.

People who come in with that story throughout the United States are being told every single day by treatment programs staff, "Gee, it is terrific that you are motivated, you are right, you do need help, and hopefully in a few months, if you survive, we will be able to accommodate you."

This is not a question of any specific type of treatment. Waiting lists exist for methadone maintenance treatment, they exist and in fact are even longer for therapeutic communities. All forms of treatment that offer help and hope must be expanded and they must be expanded not only in the interest of the individuals who need the help, but in the interest of every single American. And I very much hope that this Commission will do everything in its power to see that the commitment is made to truly make treatment on request a reality throughout the United States.

I would be very happy to answer any questions I can, Dr. Osborn.

CHAIRMAN OSBORN: Thank you very much. Are there questions from commissioners? Congressman Rowland?

REPRESENTATIVE ROWLAND: Thank you.

Mr. Newman, I'm sorry that I missed the first part of your presentation. When one realizes that the drug abuse problem we have and the increase in HIV is inextricably woven together, the points that you make are well taken that we certainly need to do all that we can to make treatment available. And you did not want to couch this in terms of dollars, you wanted to talk about it as something we really needed to be doing as a country, and I sure agree with that. But we have to look at the cost of the program.

And in that respect, realizing that we have this tremendous federal budget deficit and the constraints that that places on Congress and the Administration, how much do you think that state and local government should be involved in this? How would you go about involving them, and how about the private sector too, how do you get all of these working together?

Because I think it is a problem that every aspect of our society needs to be dealing with, and what advice would you give to us in so far as our activity is concerned in trying to coordinate or getting that to work together?

DR. NEWMAN: Sir, I agree with everything you have said. I think the problem clearly is of such magnitude and of such complexity that clearly it does require the direct involvement, the major involvement of all levels of government as well as the private sector. I think there is a lot that Congress can do though, even given all of the financial constraints that face us.

Number one is to insist that the federal government, the appropriate agency and the appropriate agencies at state government, come up with a plan how they will reduce this gap between availability and demand for treatment. The frustration I have and that I would try to have this Commission share is that nobody has addressed the problem of this gap between availability and demand for treatment.

I think it is unconscionable that the

respective agencies at federal and state and local levels have not even tried to plan how to lessen the gap, let alone to eliminate that gap. I don't know why one wouldn't make the continued flow of support for addiction from the federal government contingent upon the development of some kind of a plan. And maybe the goal that would be derived from individual states would be very modest, maybe even a 5 percent increase in the availability of treatment, or 10 percent. One could argue about the specifics, but I think at the very least Congress should demand that there be some target set and some way to utilize whatever dollars are made available by Congress, how those dollars will be spent to address this aspect of the problem.

There are many aspects of the problem, but with regard to treatment dollars, I think you should know clearly how these dollars will be utilized to deal with this aspect of the problem.

CHAIRMAN OSBORN: Harlon Dalton?

COMMISSIONER DALTON: Yes. Actually my question really follows up on Congressman Rowland's and I may just want to push you for a touch more

specificity. I should say, by the way, that you make a very powerful case and I do share your frustration.

I am also wondering though what this Commission can do specifically. That's not to suggest any doubt that there is work to be done, but I'm just trying to figure out what it is that we should be doing. What is the analog of that order from the judge in New York to the city to provide shelter that this Commission can come up with and connect with that? Is there something that we can do about the NIMBY problem at the local level?

DR. NEWMAN: I'm not sure what the Commission can do in terms of that local problem, to start with the "Not in my back yard" phenomenon first. I think if a commitment existed at the local level and at the state level, there certainly are ways to overcome the NIMBY problem. Hopefully with sensitivity, hopefully not in too capricious, arbitrary a way, but declaring a health emergency and saying we must have facilities for the treatment.

With regard to just an analogy, emergency departments, certainly in New York State, are big money

losers--big money losers--but hospitals don't have the option to get out of the emergency room business, simply because the state in its wisdom and with its power, decided years ago that emergency medical service is a requirement in every community and if a hospital wants to be in the hospital business, it must provide emergency services. And if the neighbors don't like the sirens, that's unfortunate. I am not minimizing the objections of the neighborhood, but somebody has to decide, hey, for the greater good of the entire community we must have these facilities, we will try to place them appropriately, but we can't give veto power to every single block in the city, otherwise there will never be any program expansion at all.

In terms of the dollar problem and how it affected the massive expansion of the shelter system in New York, some additional dollars--I don't know the number--but some additional dollars were allocated for housing the homeless, a woefully inadequate amount, which is the reason that the shelter system in New York is far from ideal. As a matter of fact, some people would say it is almost barbaric in a way. But there

everyone acknowledges that anything must be better than telling people who say, "I got no place to sleep, just the sidewalk," and say, "Well, since we can't accommodate you in the way you really deserve with a little kitchenette and privacy and security and this, that and the other thing, stay out on the sidewalks."

That was not an option. In the case of drug addiction--and I really have to emphasize this--the governing rationale for our system over the past 20 years has been if we cannot offer the absolute ideal form or forms of treatment that we think are appropriate, then those junkies are just going to have to wait in the streets until we can accommodate them. That is the reality.

There are regulations that dictate capacity figures to every methadone clinic in the country. I'm not quarreling with any of regulations. In the best of all worlds I would probably want even tighter, more stringent regulations, but the result of the regulations limiting capacity in methadone programs is to tell thousands of people, we have decided it is better for you--and presumably for the community--that

you stay out on the streets shooting dope because we don't have enough vocational rehab counselors, or we don't have enough paralegal advisors here to help you. It is irrational.

CHAIRMAN OSBORN: Larry Kessler?

COMMISSIONER KESSLER: Doctor, I really appreciate your passion and I hope that you will continue to drive all of us toward a more humane approach to this problem. I'm curious as to what your feelings are about needle exchange programs and changing paraphernalia laws, and whether you feel in your experience there is an impact that can be derived from those who aren't ready to request treatment in light of the whole issue of transmission of AIDS and HIV.

Do you have a perspective? I'm sure you have a perspective. Would you like to share it?

DR. NEWMAN: I try to syay a one-issue person, but I will delve into the needle question. I think, particularly given the fact that the established treatment networks throughout this country are forcing people to stay on the streets even though they want

help, I think that gives a greater sense of urgency to the whole question of needle exchange or needle availability.

But I'm also a pragmatist. I think the logistical problems of needle exchange are horrendous. Where to exchange the needles, how to exchange the needles, what hours and so on. I think the simplest, most straightforward way to make sterile needles available to those who would use them is simply to have the 12 states in our country that currently forbid the over-the-counter sale of needles and syringes to go along and adopt the same philosophy and the same laws as govern 38 other states in this country, and that is to say, hey, if you want a needle and syringe, you go into your neighborhood drug store, you stick 30 cents or 50 cents or 20 cents on the counter and you buy one.

That is the current state of affairs in 38 states in this country. Those are the 38 states that have the least drug problem. It is the easiest, quickest, doesn't cost Congress or anybody else a nickel, and I would just think that that logically would be a course to pursue. In terms of the arguments

pro and con on needle availability and the concerns it will stimulate more addiction or give the wrong message, or condone drug use, all I can say is that every reported study all over the world and within this country where needles and syringes are available indicate that it does nothing to increase addiction, it does nothing to lessen the motivation to get treatment, and it does indeed seem to have an impact on lessening the spread of AIDS. So in terms of the experience, I think it is very difficult to make a case that sterile needles and syringes should not be made available.

But again, the simpler, the easier, the better. And nothing is as easy and nothing is as free of cost than simply saying, hey, you want one, go and buy one.

CHAIRMAN OSBORN: Curiously enough, you have stimulated quite a lot of interest. Diane, and then Jim Allen, and then Dave Rogers all have comments or questions.

COMMISSIONER AHRENS: I wonder if you would comment on the effectiveness, efficacy of cocaine and crack treatment, its status now in the country.

DR. NEWMAN: Clearly the ability to have a major impact therapeutically on somebody who overwhelmingly is involved in crack and other forms of cocaine is not nearly as great as the experience shows the impact can be with the heroin user.

On the other hand, therapeutic communities, as far as I know, pride themselves on being able to treat chemically dependent people, regardless of what that chemical dependency consists of. It may be a little bit more difficult, a little bit less difficult, but I have never heard therapeutic community advocates say, gee, there is nothing we can do with cocaine users. Exactly the opposite. They claim--and I have no reason to disbelieve the claim--that they can indeed help people who come to them, regardless of whether the primary drug, or the major drug that they use is crack or cocaine or heroin or alcohol or barbiturates or others.

With regard to methadone maintenance, also, however, there is a very clear role and I think a very major role, even with respect to cocaine crack and other derivatives of cocaine. We know that, certainly

in New York and I believe the experience is similar elsewhere, cocaine users to a very large extent at some point or other in their pattern of using cocaine begin to use heroin as well, either to get the supposedly better high that comes from what is termed "speed balling," using both cocaine and heroin together, or to use the heroin to counteract some of the unpleasant effects of coming down from a binge of cocaine.

At any rate, more and more people over time use heroin. We are seeing a lot of people who come to our methadone program with a heroin dependency which began after their use of cocaine began. And even though methadone itself as a medication has no pharmacological impact on the use of cocaine, we find--and I am as impressed of this as I am of any aspect of methadone treatment--we find that when patients had their heroin dependency, their heroin addiction successfully taken care of, that a great many of them are able somehow to deal with cocaine use and other forms of drug abuse.

There has not been a pure heroin addict on any significant scale for years and years and years in

this country, long before crack, and yet methadone treatment is effective in helping a great many of them restore themselves to normal life.

So there is treatment available, there is effective treatment available, albeit it is much more difficult, in my estimation, to treat than somebody who is overwhelmingly involved in heroin.

CHAIRMAN OSBORN: Jim Allen, next.

DR. ALLEN: Dr. Newman, thank you for your presentation.

Dr. Koop in his statement before the Commission this morning urged that we not allow HIV and AIDS to remain a separate problem or that it be separated from the mainstream of public health and medical practice.

In actual fact, drug abuse has often been separated from the mainstream of medical care, as well as from the mainstream of public health. In other words, it is rare that you will find that the drug abuse communities and the public health community are perhaps even in the same agency in a state or city.

Would you comment on what--in your

opinion--what the separation of drug abuse from public health has had in terms of our failure to deal adequately with drug abuse and HIV?

DR. NEWMAN: Absolutely. I think it is a very, very perceptive observation and I do believe that the major frustrations that I deal with as somebody who is responsible for a very, very large addiction treatment program, is that it really is not viewed as a medical program. If it were a medical program like other forms of medical programs, medical treatment for diabetes, hypertension, ulcer, cancer, whatever, even AIDS, one would never say, well those sick people are simply going to have to wait on the streets with no treatment until we can accommodate them in the ideal way we would like. It would be inconceivable.

So that unfortunately even though today--and I view it as an enormous step forward--the national strategy clearly, without hedging, acknowledges addiction to be a chronic illness. And that's an amazing breakthrough.

Most physicians, most hospitals, most public health agencies continue to view it as maybe a criminal

problem, a sociological problem, a political problem, an economic problem, but not a medical problem. And I think the fact that it has not been accepted by the medical profession as an illness that requires treatment, I think that is one of the major reasons why we have the problems we do. I think the constraints that the federal government imposes on methadone treatment programs, specifying the number of patients who can be treated, the exact staffing pattern--in the State of New York we even have specific regulations regarding what they call the "stroke width" of the lettering on the exit signs. It has to be a minimum stroke width, whatever that is.

That type of constraint in any other medical program would be unthinkable. I think you are absolutely right and I think Dr. Koop is right, we have to bring both AIDS and addiction totally within the health care system.

CHAIRMAN OSBORN: Dr. Rogers?

COMMISSIONER ROGERS: Dr. Newman, it is always an enormous pleasure to listen to your evangelism. And I simply, in following up on

Congressman Rowland's question, it seemed to me you say you are a single issue candidate, but I thought you had more than more one bullet in your gun.

In terms of costs, I recall hearing you one time rather eloquently indicate the costs of not treating in terms of crime, of the expense of muggings, of the cost of the habit, et cetera. You may not have those figures in your head, but it seems to me if this Commission is--as I hope they will--going to powerfully support treatment on demand, it would be very nice to have some clear cut figures indicating how expensive it is not to have treatment on demand. Maybe you have got the figures in your pointed little head, but I don't know.

DR. NEWMAN: Dr. Rogers, you are absolutely right. I don't have them in my pointed head, but the figures clearly and overwhelmingly demonstrate that this country already is paying a huge price, both for drug addiction and for the related problem of AIDS, and one can justify--I mean justify so overwhelmingly--expenditures, I believe in almost any magnitude for drug addiction treatment on the basis of

the savings, of reducing the cost of addiction, as well as, independently, the savings that result from reducing the spread of AIDS. That's strictly on a financial level, to say nothing of the humanitarian savings that are associated with it.

So overwhelmingly the case is there and I would be happy to try to provide numbers to the Commission.

CHAIRMAN OSBORN: Belinda?

COMMISSIONER MASON: Dr. Rogers pretty well addressed my concerns, Dr. Newman, but I'm wondering if you would spin that out a little bit farther and kind of elaborate for me on addiction. Is it a chronic illness now? I hate to sound so elementary.

So does that mean that we are talking about a lifetime treatment situation in the way that diabetes and that I know many of us hope that HIV will turn out to be? Are we talking about a medical intervention at points in the individual's life that you have spaced out and can identify?

DR. NEWMAN: Not really. Accepting addiction as a chronic illness makes it reasonable and appropriate, when indicated, to continue treatment on a

lifelong basis. One of the criticisms against methadone is that there are people such as myself who are willing to accept lifelong treatment for this, quote, incurable illness.

On the other hand, even though whatever causes addiction is unknown and how to reverse those causes of addiction remains unknown, there are many, many ways that people can overcome the use of drugs. I make the analogy with Alcoholics Anonymous. Alcoholics Anonymous is phenomenally successful, not universally successful, but enormously successful in helping people stop drinking. And yet AA more than any other group adamantly and almost with a religious fervor insists that alcoholism is an incurable illness.

There is no such thing to the AA advocate of a recovered or cured or former alcoholic. But happily, with the help of AA and through other means, there are a lot of alcoholics who have stopped drinking for months or years or decades. Exactly the same situation applies to addiction, where either with medication or with therapeutic communities or with other forms of treatment or with no treatment, some individuals are

able to put behind them the use of drugs. I think it is a very analogous situation.

COMMISSIONER MASON: And it is very clear to you that the cost of recovery is not nearly so great as the cost of--what's the word I'm looking for? It is late in the day.

DR. NEWMAN: The continuation of the habit.

COMMISSIONER MASON: And you have those numbers?

DR. NEWMAN: Absolutely. And as I indicated before, the numbers make the argument very convincingly, but also intuition. I mean, if you think that everybody who is using drugs three, four, or five times a day risks killing himself or herself, risks infected unborn children, sexual partners, others with whom they might share needles, I mean, every injection that isn't taken has to be a boon to society.

COMMISSIONER MASON: Thank you.

CHAIRMAN OSBORN: Eunice Diaz?

COMMISSIONER DIAZ: Dr. Newman, you come from a part of the country that has a very high rate of AIDS within the minority populations, Hispanic and black.

We don't like to talk about that many times because we feel that perhaps as minority individuals our communities might be more stigmatized because of the drug use, AIDS, being a minority, many times coming from a culture of poverty.

But from your experience would you say that these treatment programs ought to be designed in a special way that meets the needs of the ethnic and cultural populations to be treated, or is this not as necessary? I recently heard a person, an expert from the Department of Health in New Jersey who indicated that the needs, for example, of the Hispanic female addict are such that when she enters a treatment program, it is many times impossible to treat the woman unless she has the availability of having her children enter the program with her and actually take them into the facilities.

Have you seen this kind of thing in your experience?

DR. NEWMAN: Yes, absolutely. And I would just say again--and this is really in part a reference to the earlier question about addiction treatment being

part of mainstream medicine. Exactly the same principle that you so clearly enunciated applies to the treatment of any kind of illness. One has to understand the population being treated, special needs, cultural and other, that that population has, and one has to respond to those needs.

I think in the field of addiction, the needs of minorities are somewhat better addressed, just because in the addiction world, regrettably the minorities frequently are the majority and not the minority. My concern is with other types of special population groups, gays and lesbians, I think their special needs are all too often tragically ignored, if not blatantly worked against, so that I think any special population group has to have their needs understood and accepted and responded to by those who purport to help them and to treat them.

CHAIRMAN OSBORN: Let me take one last question from Irwin Pernick.

MR. PERNICK: Dr. Newman, from your experience, do you have any even rough estimates on the percentage of drug abusers who actively seek treatment

voluntarily, and of those who are treated, what percentage remains on the wagon, if you will, or can remain on the wagon?

DR. NEWMAN: I believe the strategy actually gives some pretty impressive figures of 50, 60 percent of people who enter treatment who are able to be helped and to leave behind drug addiction.

In the case of the methadone maintenance programs, specifically the one that I am responsible for at Beth Israel Medical Center, we find that over a three, four year period some 60, 65 percent of the people who enter--and they are all voluntarily enrolled--50, 60 percent are in productive ways of living again, either working, in school, either not using drugs or excessively using alcohol, or using them in a very, very restricted way, which is still a problem but a vast improvement.

So I would think that 50, 60 percent is not an unreasonable figure for most types of treatment. The same figures apply to graduates of therapeutic community treatment programs as well.

In terms of the number that would accept

treatment if it were available, the problem is that we are dealing with a population that is known for a lot of things, but being able to plan in advance, or as the psychiatrists say, delay gratification, those are not usually the attributes which are ascribed to them.

So we are talking about people who are coming forward every day to apply for something they know is not available for many, many months, and even so, we talk about thousands of people in New York City today who are on waiting lists, over a thousand for methadone maintenance, over 2,000 for drug free residential programs. I think it if were available, let alone if there were some encouragement through mass media, notices or what have you, to come forward and accept help that is available, I would think we are talking about many tens of thousands of people just in New York City, and surely hundreds of thousands throughout the country. And there is nothing in the strategy that would argue against that either.

CHAIRMAN OSBORN: Dr. Newman, thank you very much for your eloquent testimony and for taking the special efforts that I know you did make. We would

love to keep you here, but I also know you have a plane you have to catch. Thanks so much.

Let me propose that we revise our schedule slightly as follows. I would like to ask Jim Allen to proceed as we have asked him to do, to talk to us about the National AIDS Program Office and the ongoing efforts of the U.S. Public Health Service and related agencies with respect to present federal levels of effort.

And then I think at that point after Jim has had a chance to make his presentation to us, we might move our break up a little bit and then after the break proceed to the discussion of how the Commission wants to proceed.

If that is satisfactory with everybody, Jim, thank you for playing two or three or four roles for us today.

STATEMENT OF JIM ALLEN, M.D.

NATIONAL AIDS PROGRAM OFFICE [NAPO]

DR. ALLEN: Thank you. As you know from our discussion at lunch time, this is a little bit of a different topic than I had been prepared to discuss, but I think nonetheless that I can give you some useful information and give you some time for some questions.

The National AIDS Program Office in the Office of the Assistant Secretary for Health, Department of Health and Human Services, is a relatively new program office. We have been in existence at this point for approximately a year and a half. It grew out of the function of the AIDS Coordinator position that was established approximately four and a half years ago to provide assistance to the Assistant Secretary for Health.

The current functions of the National AIDS Program Office will be described to you in much greater detail in written information that we'll submit to you. But let me suffice to say that our primary function is one of assisting the Assistant Secretary for Health in developing policies and setting priorities with regard

to HIV infection and AIDS.

We provide staff support to his office and, obviously, indirectly to the Secretary. We get the budget each year from the agencies of the Public Health Service and we pull together in a rather unique function a consolidated budget for HIV infection and AIDS.

Let me say very quickly here that although Congress has chosen not to act on the consolidated budget as such, in that they have chosen instead to continue to give appropriations directly to each of the Public Health Service agencies rather than in a single consolidated budget, it has been a very useful function to us to pull together and be able to take an overview of all of the activities of the Public Health Service through this process.

Finally, my role as the director of the National AIDS Program Office is perhaps one of facilitator. As I have already indicated, I work up through the Assistant Secretary and the Secretary. I work with my staff to provide a variety of support activities, so that I'm functioning in a downward

capacity also. I reach out to Congress to a variety of organizations, to groups such as the Commission, to provide assistance in any way that we can, certainly state and local health departments are included in that broad group.

In addition, within the Public Health Service, the agencies of the Public Health Service, we function as facilitators. Let me give you one example. We have worked with the National Institutes of Health and the Food and Drug Administration to help pull together the process for developing the parallel track to improve or expand the accessibility of new therapeutic agents to people with HIV infection. I think we have been able to provide a facilitating role in this developmental process.

In addition we work as a facilitator with other departments of the government. For example, we worked with the Department of Justice and the White House staff in terms of helping to facilitate the position of the government on the entrance of short term visitors who were HIV infected who wished to come to the United States.

With that as a brief overview of what the National AIDS Program Office does, let me turn quickly to each of the agencies of the Public Health Service and give you an overview of the work that they have been doing in the last several years and how it fits into our overall strategy.

The National Institutes of Health has had a budget this last year for AIDS and HIV infection of something over $601 million. That has gone to support basic science research, development and evaluation of new therapies, development of vaccines, and a variety of epidemiologic studies. I think it is fair to say that we have had unparalleled success in terms of the basic science aspects of the work that has been done. We very quickly after the recognition of the epidemic helped to isolate the virus, characterize it. I think the progress that has been made in terms of the understanding of the virus function, the genetic structure, has not had a parallel in medical history.

I think we have finally had a lot of success in the development of new and promising therapies. Those are for the most part still in the evaluation

stage. They include anti-retroviral drugs as well as drugs that would be useful for the treatment and prophylaxis of opportunistic infections that affect people with HIV infection. I think our real challenge at this point is to continue to move rapidly with the evaluation of these therapies and then to bring them into the mainstream of medical therapy.

The development of vaccines I think has also had some promising work, but has moved much more slowly. We need to be able to respond rapidly, however, when there is a breakthrough, as I'm sure there will be at some point in the future, with a very definite direction that researchers need to follow. And I think we need to build into our response process the capacity to respond adequately when that breakthrough does come.

We perhaps are having a little struggle at the present time in setting priorities. We have made so much progress in terms of basic science research in the last five or six years that there are many, many directions that the new efforts could take, and I think we have to look very carefully at those areas where we

will get the most success for the dollars that we have to expend on biomedical research. Because certainly the need--our ability to conduct the research throughout the country will far outrun the dollars that we will have available.

Let me turn quickly to the Centers for Disease Control, whose primary responsibilities are surveillance for cases of AIDS, seroprevalence studies to understand the frequency of HIV infection in the population, epidemiologic studies of a variety of types, prevention, public education, and capacity enhancement.

In these first areas--surveillance, seroprevalence and epidemiologic studies--I think we have done extremely well. We have one of the best national surveillance systems for any disease in the country. We have a very broad-based participation from health departments on that, but we have had that success in part because we pay health departments to carry out that surveillance. I think it goes without saying that the health departments themselves--and Dr. Konigsberg can perhaps address this later--have

been greatly stressed in terms of personnel, particularly, to carry out the work that needs to be done.

We are doing very well with our seroprevalence surveys at the present time. Sero incidence, however, understanding the frequency of new infections is still in its infancy, and this is an area that we need to give major attention if we really are going to be able to find out on a current and continuing basis how many people are becoming infected at the present time. That obviously will be a measure of success of our prevention programs.

Our epidemiologic studies yielded an extraordinary amount of information early on. At the present time the progress continues, but it is at a slower pace as we refine the studies and develop additional information. It is not quite as exciting as it used to be.

I think an area that continues to need careful evaluation are some of the perinatal studies. We have a relative paucity of patients to enter into the studies. There is a fair amount of money out there

and I think we need to look carefully to make sure that we are getting the best study designs for the very important area of perinatal infection.

In our prevention activities, despite the fact that we have a lot of money going to this area, I would have to say that the results have been mixed. We are primarily talking about giving people education about the way that the virus is transmitted and asking them to change their behavior. This is an area we know relatively little about. It is not--in terms of either drug use behavior or sexual behavior--it is not enough to simply tell people change your behavior and expect them to do that.

We need a lot more effort to really understand what types of programs work, how to make them work, and how to put them into play. And obviously the problem of doing this sometimes with government funding is significant.

Similarly with our public education programs, we are constrained in some ways in terms of providing the most direct information to the populations that need it. It is an area that needs quite a bit of

attention and some innovative and creative work.

Finally, in terms of the CDC's programs, let me mention capacity enhancement, which sounds like a wonderful bureaucratic term. Basically it means trying to work with the health departments around the country, or our medical institutions, to increase their ability to handle this public health and medical problem.

We need to look at ways to quickly get more public health advisors available and assign them to state and local health departments around the country. We need to look at ways now, particularly with the recent announcements, to enhance the capacities of laboratories across the nation to do T cell subsets and to do them reliably. As you well know, that is a complicated medical procedure, or laboratory procedure, and I think one of my fears is that we will have laboratories offering the test without the quality control that is necessary if we are going to assure that the results are reliable and useful.

Let me just go back for one minute. The budget for the CDC for this last fiscal year is $377.6 million approximately.

Next, the Alcohol, Drug Abuse and Mental Health Administration, with a budget of $173 million has a variety of activities in basic science research, outreach and prevention, primarily to substance abusers of different types. I think there has been some exciting progress made in our basic understanding of the problems of substance abuse and ways to approach it. There has been some progress announced recently in terms of the success of outreach programs, but all of these have been done simply as demonstration projects and I think the former speaker eloquently expressed the need that me now have if we are going to take the results of our success in demonstration projects and make them a more widespread and routine part of our need.

Finally, as also mentioned, we need to look at ways to intertwine the prevention efforts and our efforts at reducing the use of drugs by people in our country with the national program to control drug abuse. And I think if we don't have a combined and intertwined program, we are going to have real problems in terms of reaching the people who are substance

abusers.

The Food and Drug Administration has a budget of $68.4 million for AIDS and HIV activities. They, of course, are our primary regulatory agency. They deal not only with licensure and evaluation of the anti-body and antigen tests or other types of diagnostic tests, they deal with medical devices such as condoms and rubber gloves, and certainly with the evaluation of medical therapies, drugs for treatment, and the vaccines when we have prototypes ready for evaluation in humans.

One of the problems with the Food and Drug Administration budget is that much of their budget goes to personnel. It is a very personnel intensive agency and it is a bit difficult to predict today, or to predict at the time that the budgets are formulated, exactly what the need is going to be in terms of the number of well-educated people to carry out efficiently the evaluations and the regulatory aspects of drug approval.

I think that, again, this needs to be looked at very carefully in terms of defining whether or not

we have achieved the appropriate balance. The FDA has moved fairly aggressively to develop some innovative approaches such as the parallel track. I think that within the next six to eight months we will be able to judge whether or not we have been successful in bringing that into play and having it be a successful component of therapy.

The problem, obviously, for FDA is to carry out these innovative approaches and to carry out the regulation that they need to do while trying to adhere to the difficult aspects of being a regulatory agency. It is not an easy balance.

The Health Resources and Services Administration has a budget that is just under $60 million for AIDS and HIV related work, and the Indian Health Service has a budget of about $800,000. These are the two agencies, obviously, that have the responsibility for providing most of the medical care for special and underserved populations. Most of the work that they carry out is through demonstration projects, and I think it goes without saying that there is a real need then to take the work that is done in

the demonstration projects and to find a means of making them permanent programs of some type for those people who continue to have these needs.

Finally, HRSA had the responsibility, when money has been available, to provide reimbursement for medication therapy. At the present time there is neither authorization nor appropriation for fiscal year 1990 to continue those programs unless Congress acts on that in the next weeks ahead.

Within the Office of the Assistant Secretary for Health there are two other program components, the Office of Minority Health and the National Centers for Health Services Research. Both of those groups have some monies that are available to them for AIDS related activities, Office of Minority Health primarily to give small grants to minority community-based organizations, predominantly for a variety of education and prevention activities. The National Centers for Health Services Research has long term studies underway looking at costs and financing.

The real problem that I see here is that we need data now in terms of the costs and financing, and

for some of the contracts that they have got underway we are looking at data coming in two to three years down the line.

In summary, I am very proud of the work that the Public Health Service has done on the AIDS epidemic over the last eight years. I think we have responded reasonably well, and extremely well in some areas, to a difficult problem, one that has continued to move ahead of us in a very rapid pace, often in ways that we were not able to expect or predict. Our progress has been especially significant in terms of biomedical research, epidemiology and surveillance. We have done less well, obviously, with prevention, education and health services delivery.

I look forward to working with the Commission in resolving some of these major dilemmas of the AIDS epidemic. We clearly will need to have a broad-based approach to solving these problems since solving them for AIDS and HIV infection really requires solving the long-standing social problems that are present in our country today.

CHAIRMAN OSBORN: Thank you very much,

Dr. Allen. As Jim suggested, I got him to somewhat artificially split some of his comments because he will later be talking with us about where we stand with respect to some of the Presidential Commission recommendations and so forth, which is one of the challenges to his office to try and keep track of.

But for the moment, wearing the present hat as Director of the National AIDS Program Office, I think it has been very helpful to have you give us this brief overview, and I wonder if the commissioners have questions in this context.

COMMISSIONER GOLDMAN: Jim, you indicated that the budget that your office produced with respect to AIDS reflects, I think the language is "our strategy."

Other than the President's Commission report, is there a document which defines and identifies what you are referring to as "our strategy" in the context of the budget?

DR. ALLEN: Yes. There are two types of documents. Last year in June of 1988 the Public Health Service held a series of meetings with invited outside

consultants to help us pull together recommendations and ideas for our strategy, or for a national strategy. This was followed by--actually, the meetings with the outside consultants occurred before June of 1988, and then in June of 1988 there were a large number of people from the Public Health Service, from all of the agencies and the Office of the Assistant Secretary for Health who met in Charlottesville, Virginia for a couple of days to discuss and pull together our plan.

This was published in Public Health Reports--I believe copies have been provided to you, if not we will get them to you--and it sets out a national strategy. Interwoven within those are certainly components that go far beyond what the Public Health Service itself plans to do or is enabled to do. The more direct document I think that you are referring to is the budget that we have proposed, and within that budget, to the extent that the detail is there, there clearly is an outline of the strategy in terms of where the priorities are, where the money is going and, obviously, where the programs will be developed.

Those can be fleshed out, and I'm sure will

be fleshed out, for the Commission in the months ahead as you get additional information from each of the agencies, and we will be glad to work with you on that.

COMMISSIONER GOLDMAN: Thank you.

CHAIRMAN OSBORN: Other commissioners have questions? I think it is rather important to recognize as we go just how very much work is going on and has gone on throughout the long and difficult years of the epidemic. I know I always try to remind myself, I hope successfully, when flailing a bit about the overall lack of leadership, which is a phrase that is often used, it sometimes has seemed as if everybody was lambasting the entire governmental response. And I know in great detail of the truly heroic efforts of many people in the U.S. Public Health Service, so I was particularly eager to have Jim, who is one of those heroic people, tell us about the things that are being done as we begin to evaluate what else can be done and where we can be helpful.

COMMISSIONER KONIGSBERG: Jim, would you elaborate a little on the CDC aspect from a budget standpoint in terms of what percentage the AIDS portion

of the budget constitutes of the total CDC budget, and maybe contrast a little bit the differing rates of either growth, or maybe in some cases, no growth, just to get a feel for the impact that AIDS has had on the nation's Centers for Disease Control?

DR. ALLEN: I don't have the exact figures in front of me, so what I will be giving you are relative numbers. In 1981 when the first cases of AIDS were formally reported--recognized and reported--we obviously didn't have any budget devoted, it was a brand new problem. I believe 1983 was the first time that we had some monies in our budget. It could be 1983. I think it was 1983. Before that time and actually continuing at that time, we diverted resources from--including personnel as well as budget--from our continuing programs in order to fund our surveillance studies, our program, epidemiologic studies and so on, laboratory studies.

At the present time, the HIV/AIDS budget is about, I believe it is actually over 40 percent of the total budget of the Centers for Disease Control. If you look in inflation adjusted dollars at the non-AIDS

budget, you see that it has been absolutely flat, or perhaps has declined over the years, over the decade of the 1980s. And in terms of personnel, there certainly has been a decline in terms of those working on non-AIDS related activities, when you adjust for the change in programs. For example, at the beginning of the decade the National Center for Health Statistics was not a part of CDC. It now is, so you have to adjust for programs that have been added.

CHAIRMAN OSBORN: I think seeing no other hands that perhaps we will break at this point and give Jim a brief break too, and then reconvene in about 20 minutes to continue and begin to get into the hard work of seeing where we stand with our predecessors' recommendations and how this Commission can best help to move society's effort along. We will reconvene in 20 minutes.

[Brief recess.]

CHAIRMAN OSBORN: Let's reconvene so that we can turn to the harder work of the session.

The elegance and configuration of this room has lent wonderfully to starting off with a good deal

of esprit, but now we do need to get into an interactive mode with each other and start talking about how the Commission wants to go about its work, picking among the very many opportunities of trying to help with efforts in the epidemic and using our time and energies wisely. To do that we decided that we would try and make it a bit more of a circle for purposes of interaction.

Tomorrow we will be having our afternoon session in the GSA building, which Maureen will tell you about in a minute, and then we will be back in a square configuration where it will be much easier still to carry on an interactive discussion. But for present purposes and to use the microphones and so forth, I think this is a good compromise.

May I ask all of the commissioners, I think now, to turn on your microphones so that you don't have to keep remembering it, because it might make it much easier for the recorder. And if by any chance you are still having trouble, let us know, because this is going to be, I hope, an important set of interchanges as we start working together.

In order to lead the discussion, I am delighted that Dave Rogers is willing to try and lead the next stage of things in looking at how we can best array our strengths to deal with the issues. And before he starts, I would like to introduce publicly Maureen Byrnes, who is Executive Director of the Commission, known to a great many people in the room for her diligent work over the past many years here on Capitol Hill, and at the moment carrying two of the fullest time jobs you can imagine, but soon to be fully involved in the activities of the Commission.

And Maureen, would you take a few moments to introduce the rest of the staff? We haven't completed that process yet, but we have been fortunate, through Maureen's efforts, to take on a number of excellent staff people and I'd like to have them recognized publicly.

MS. BYRNES: Thank you, Dr. Osborn. I know that I have expressed individually to each one of you how grateful I am for the opportunity to work with the Commission and how excited I am to work with a group of people who are so well recognized in a variety of areas

related to HIV and AIDS and who seem very dedicated and enthusiastic about taking on those issues that so many people talked about this morning that for whatever reasons have not yet had a leader or have not yet had a group of people come together to show us where to go in the directions of financing and others that I know we are going to discuss this afternoon. They are issues that are near and dear to my heart and I really welcome the opportunity to use whatever gifts I have to offer to do what seems to me to be a very needy and important and essential role that this Commission has chosen to take on.

In that regard, I'd like to introduce the members of the Commission staff who have agreed to join you and to join me in putting some of these issues and activities together. I've said again to each of you that it is very easy for me to interview candidates to work on the National Commission. I just tell them why I'm going, and it is a way that people light up, they seem excited about what the Commission is doing, and so many people have expressed interest in coming to work for the Commission that I have been interviewing people

on Saturdays, Sundays, seven, eight o'clock in the morning, and it doesn't seem to be an imposition at all to people who are very excited about coming to work for the Commission.

One of the people who did accept my invitation and I am thrilled about is Jane Silver. Jane Silver is a woman who is recognized in the field of public health. She has a Master's in Public Health from Yale University, and she is certainly someone that anyone who is in the business of providing services and treatment and trying to identify needs that need to be responded to in the District of Columbia, people know who Jane Silver is. She is essentially Reed Tuckson's right-hand person and she runs the District of Columbia program for AIDS activities, and I truly am thrilled that she has accepted the offer to come work with the Commission. Jane, would you like to just stand up so that everyone knows what you look like as well as what your credentials are.

Karen Porter also recently accepted an offer to join the Commission staff. Karen is behind all of you on the dais there. Karen is a graduate

of--undergraduate, Yale University as well as Yale Law School, and has had some very interesting experiences both in the employment area and summer internship, worked within the prisons and has some experience with some of the sensitivities and some of the concerns I know the Commission is interested in working on in terms of the prison systems and HIV.

I also am very hopeful that Karen will be interested in working very closely with the Commission at large as well as any other working groups that will be developed to address the specific ethical legal issues that we may be exploring related to HIV and AIDS, and that's Karen back there.

Carlton Lee I think most of you have met. He essentially was able to join us fairly quickly after I accepted the offer to be the Executive Director. Carlton will be the Chief Liaison Officer for the National Commission. In fact, he is the Chief Liaison Officer for the National Commission on AIDS. Carlton before this was with the Human Rights Campaign Fund and has been very active in Washington in helping explore the different legislative alternatives and options that

the House and the Senate have looked at over the last three to four years, and again, is recognized as someone who knows not only Capitol Hill but the issues that need to be addressed related to HIV and AIDS, and I'm hopeful that he will be able to develop a very close working relationship, both with you individually as well as your offices.

I think it is important that Carlton be a liaison not only between the Commission and the federal government but that he get to know many of the state and local health officers and players in this arena, as well as provide you a mechanism, in addition to myself and any other Commission members, as a listener, as a connection, as a facilitator while you are outside of Washington and we are trying to work together closely as a group. So he will be serving as the Chief Liaison Officer.

Tom Brandt many of you met over the telephone and I hope have had the opportunity to meet in person, was the communications director for the Presidential Commission on the HIV epidemic and has graciously accepted the offer to be the Director of Communications

for the National Commission on AIDS. He truly, as they say in Washington, has hit the ground running, and I am very excited about Tom also coming to work with us to share with the Congress, the public, and I often say whoever will listen, the message and the information and the strategies that the National Commission has to share. That's Tom over there.

Lu Verne Hall is not here because she is answering our telephones. Lu Verne Hall is a woman who I met about three weeks ago, has had extensive experience administratively in establishing commissions, and I kiddingly said earlier, was someone who really understood about price per square feet and leases and personnel forms and those of administrative requirements that are so important that they be done well but also can boggle the mind of someone who might be overwhelmed at the moment of looking at all of those administrative needs. So she is assisting us in identifying office space, which we have done.

It will 1730 K Street. We are not there yet. They are as we are speaking and meeting painting the walls, replacing the carpeting and hopefully putting

our name on the front door. I assure you that we are anxious to move in there as quickly and possible. I also assure you I am doing everything within my power that that happens as quickly at possible. So we can still be reached at the old telephone number that most people have. We are still operating in temporary quarters with the General Services Administration, but definitely by the next meeting and well before then we will be at 1730 K Street.

Lee Marovich was here earlier and may be joining us in a little while. She will be the person who has agreed to come on initially as a receptionist and general assistant to all the Commission staff and to you. She was a summer intern on Capitol Hill, is currently working in a Subcommittee on the Judiciary on the Senate side and she'll be leaving and is very excited about coming to work for the Commission staff.

There are two other people that I would like to mention at this point in time, both of whom you may have met. Patty Delaney and Jason Heffner have been extremely helpful in putting this meeting together, travel arrangements, logistics for getting some of

those other details that Lu Verne Hall and I just didn't seem to be able to have happen in order for this meeting to take place and also to go smoothly. They are both here, they have been very helpful to the Commission. I know that both of them are interested in pursuing a position with the Commission, but I would like to acknowledge them because they have been extremely helpful to date in really putting this meeting together.

That just about brings us up to date in terms of staffing. I am still actively interviewing. If you hear from people who have sent resumes or placed telephone calls, I have them. I'll be returning them. I'll be getting back to people. I'll be following up. All the staff positions have not yet been filled and I look forward to exploring the opportunities and recommendations that many of you still have to make, and I understand that. The staff positions have not been completed, so I would encourage you to continue to forward them, as you have, and I, obviously, should express my appreciation for that assistance on the part of many of the Commission members.

One last detail, tomorrow afternoon after the tour of the Whitman Walker Clinic we will have a bus provided in order to take the group of Commission members to the Whitman Walker Clinic. It will then return us to the meeting site for tomorrow, which is not here. It is at 18th and F, as in Frank, Street, and that is the General Services Administration Auditorium.

It is in the books, it is on the schedule. I just did want to remind everyone that we would not be returning to the same place. The morning meeting essentially consists of a site visit to the Clinic. We will go back to the site for the afternoon meeting. People are essentially on their own and we'll make recommendations for some convenient places for lunch, and the meeting will resume--I think the book says either 1:30 or 2:00 o'clock at the GSA auditorium at 18th and F.

Thank you.

CHAIRMAN OSBORN: Thank you very much, Maureen. Now I would like to more or less turn the microphone over to Dr. Rogers to lead us in the next

stage of our discussions, and I've asked Dr. Allen to play the role that he has already played for many of us and will continue to as the liaison person with the National AIDS Program Office, but from the vantage point of the director of that office as we discuss ways to focus our energies and learn from him where things stand from their vantage point.

So Dave, why don't you take over at this time.

COMMISSIONER ROGERS: June, thank you.

First, I simply must comment that it is more intimidating to sit down here than it is up there, but I thought this way I could see all of you and we could participate in a general discussion.

Well, we've had a very powerful day and a very powerful and important series of people talking to us. And one of our hopes was that we could put together, or at least begin to put together, what would be the initial focus, what would be the areas of concentration for the Commission, keeping in mind what a number of people told us today, which is put your nickels, put your efforts, put your time in areas that

have not been fully covered by other groups.

You may recall in a non-meeting that we had on the phone we did ask the staff to start trying to put together from the Presidential Commission some of the areas that they felt might be most important for us to look at. And Maureen and her crew have done so, and you have before you a series of proposed issues for consideration in terms of where might we first put some of our time and energy.

Now, I'm going to modify that some, on the basis of what I heard this morning, and make, just as a straw man, put before you several suggestions.

First, I think--and some of you know my sentiments here--we would be wise, at least at the outset, to pick two or three or four areas to focus down on--not 50, not 60--three or four that we feel we really could make some impact on, and June and I have talked about this at some length and I think both of us feel that might be an appropriate way to get started.

Secondly, I felt, from what I heard this morning, I will be commenting from what Maureen has put before you, but I'm going to give you another order of

importance. First, it seems to me that this group ought to look carefully at the whole area--I will simply--it is under the last bullet on page two that Maureen put together, and you notice she hasn't put them in any order of importance. But I would simply put it under the shorthand of discrimination, confidentiality.

I think from Mathilde Krim, from Belinda and her group of people with AIDS, from Surgeon General Koop, we heard that one of the really crippling defects has been the continuing problems of discrimination, stigmatization, inabilities to grieve, inabilities to talk about the disease. I thought that thread went through virtually everything that we heard. I thought I would simply use as an illustration our last testifier, Bob Newman, who pointed out to us that we have a group of people in this country, for example, who have a fatal disease. They are IV drug users, yet we don't permit them into treatment.

And he pointed out that if you had diabetes or heart disease--well, let me put it another way, I know of no other fatal disease where you would say,

come back and see me in six months. That is discriminatory, that is a value judgment issue, and it is one of the things that is making for more suffering than I have ever seen in my 40 years of professional experience, for people with AIDS.

I mentioned discrimination, or areas surrounding that, as one of the first areas of potential focus for this group because it seems to me unless we deal with that in some constructive ways, virtually everything else that we do makes less difference. That's number one on my list.

Number two, I have the financing of care. It seems to me many of the new findings, many of the new potentials for people who are HIV positive, add urgency to this. And we heard about that in a number of ways today.

Three, and this is really the area of diagnosis and care, I have called it community-based care. All of the issues of diagnosis, of treatment, of testing, of counseling, the problems of special groups, the poor, the black, the Hispanic, those in prisons. I think developing some kind of coherent, comprehensive,

sensible, compassionate system of care that will deal with the AIDS patient ought to be of critical interest to this Commission.

And four, the issues of prevention and education. Those would be my four. I would also say whatever we do, whatever we try to evolve during the course of this afternoon, I think we should feel this isn't in concrete. We are dealing with a very rapidly changing situation. I think if we selected several areas to suggest that staff begin to focus on these, they might readily change over time, but thanks to June and thanks to Maureen, this Commission has hit the ground running and it seems to me we might identify several areas that we would start out and practice on and learn how to kick the fenders and slam the doors and see if we are doing right with an issue before moving on.

One further suggestion, Madam Chairman. You and I have talked, and we have all talked, about setting up task force groups. I'm currently of the feeling--and I offer this simply as a suggestion--that if we were able to decide two or three or three or four

areas to focus on initially, that we try it without the task force approach, that we in essence have got an extraordinarily talented staff who can also call on experts anywhere in the country, that we ask that they develop information for us in a particular area, that we encourage commissioners who have a particular interest in one area or another to work with them, but that until we get better acquainted, until we begin to get our act together, that we avoid with this very small but really very cohesive group, breaking into small groups, because I think we would have to do our work twice.

I have the feeling that if Don Goldman is the expert in financing of health care, when he comes back to the Commission he is going to have to educate me and he is going to have to go through it all over again, and perhaps we could move more speedily if we asked for good staff work, those of us who wish to work with that group, but that we continued to serve as a Commission of the whole.

So those are my suggestions about areas of particular focus, but now you can tear it apart in any

way that you so desire.

CHAIRMAN OSBORN: Thanks very much, Dave.

In the context of the last suggestion, let me make the comment for those who haven't been involved in earlier discussions, that the Commission has indicated its intent to meet at least six times a year. Indeed, I think Maureen has the dates. We have mentioned the two next meetings, and if you could repeat that for general purposes, but then three additional sets of dates that fit with everybody's calendars, that will at least give us a sense of the times of meetings as we discus Dave's last discussion about whether to have task forces or not, as well as informing people in general.

MS. BYRNES: The dates would be November 2nd and 3rd here in Washington D.C.; January 25th and 26th 1990 in Los Angeles; March 15th and 16th, May 7th and 8th, July 18th and 19th. At least one of those three would be outside of Washington, D.C. That certainly is open for discussion.

CHAIRMAN OSBORN: Now, those are the six times a year meeting dates at roughly two-month

intervals that we had agreed on. There was in addition discussion of some visits and so forth and that has not yet been worked through, but I wanted those to be in mind as sort of a minimum commitment that the Commission has already decided on though the first of a two-year span. So have that in the background of your thinking.

I think just before we turn to discussing the structure that David has put forward for discussion, Congressman Rowland I think had an announcement.

REPRESENTATIVE ROWLAND: I have a real pleasant announcement to make here on our inaugural day, that I have just received information that the Burroughs-Wellcome Company today announced a 20 percent reduction in the price of AZT effective immediately.

Now, I know we had a lot to do with that. That's not enough, but that's a big help, and so I just wanted to let folks here on the Commission know about that.

COMMISSIONER ROGERS: Very good. Don't you think we could claim credit for that?

REPRESENTATIVE ROWLAND: I think we ought to.

COMMISSIONER ROGERS: Well, I'm now in a position where I can see all of you, so please go ahead. Dr. Konigsberg.

COMMISSIONER KONIGSBERG: A couple of things, Dr. Rogers.

I am at this point not sure whether the work group concept is best or not. I can see some pros and cons on it. I guess I would think that the Commission members would want to stay personally involved with the issues. Obviously, we all have our areas of expertise, but it strikes me that this group, that everybody has some particular expertise, and I guess it is sort of a plea that we not act so much as a board of directors but in a partnership with the staff. We can't do it without them. That means we are going to have to work hard, not just come to meetings. There may be, I would think, hearings or work that we would do or research that we would do ourselves.

I would tend to agree that if we try to duplicate the whole laundry list of issues that we may get lost, and I don't know how much agreement or disagreement there would be in this group. I'm going

to make a couple of points, just speaking for myself.

The President's report had a very short chapter entitled "The Public Health System." In fact, it was about the sketchiest chapter in there. And yet it pointed up the importance of it, and if you recall the questions that I directed at Dr. Koop this morning, there is another distinguished report out from the Institute of Medicine on the future of public health that calls into some real question, at the state and local level at least, what the nation's public health system's capacity is to handle the three basic components of what we do, which is assessment, policy development and assurance; theoretically in that order but not necessarily.

There is a lot of disagreement with that report. Dr. Koop, himself, I think feels that it was overly pessimistic. Whether it is or it isn't, if we depend that much on the public health system in response to the kind of epidemic we have with HIV, somewhere, whether it is a separate kind of issue with a bullet or weaved in there, I feel--and obviously I have my biases because I work in that system--but I

feel that we need to look at that.

The second point I would like to make has to do with the aspect of prevention. The discussion of measures such as reporting partner notification or, for that matter, needle exchanges are controversial and in my way of thinking need to be discussed, even though the way our public health system in this country is constituted that is a state responsibility, there is no question about it. But states and localities have a lot of other responsibilities, including the care and treatment. I'm not sure that the public health measures are necessarily that unique in terms of the states's responsibilities. And what I'm suggesting is that those at least be included in the prevention section. I don't see them really as a separate bullet. I don't think that would be appropriate for a number of reasons. Thank you.

COMMISSIONER ROGERS: Thank you. Yes, Eunice.

COMMISSIONER DIAZ: Dr. Rogers, I think that the eyes of the public are upon this Commission for a comprehensive and very thorough follow-up of the

Presidential Commission report. And this is not to be really against any of the focus that you are requesting that we look at perhaps three or four areas we can really do well and make an impact. But I would like to say that as one Commissioner I would feel that it is our responsibility to have staff and the National AIDS Program Office really go through those recommendations as they are listed there and give us a status report, albeit it as brief as can be. It still would provide us a contextual framework within which to make a decision, that I think should be a joint decision of commissioners, of saying these are the four or five areas that we would like to focus on.

In addition to that, I think that because our meetings will be every other month, we then focus a meeting priority on one of those subjects and really then concentrate our efforts so that we have something that is really highlighted as the work of this Commission and an impactful conversation or discussion for each meeting.

The meeting we had today was introductory and wonderful in nature, but we have jumped around a number

of areas. I'm saying I think with this process if staff and the National AIDS Program Office could weed through those recommendations and say, some of these have been done--the report is a year or a year and a half old--a lot of these things are being taken care of, and these are the things that haven't been touched, I could make a much more informed and intelligent decision as to what might be the four or five focus areas for the work of this Commission. Then I would submit that we've got to focus our future meetings so that they stay within how are we going to impact that particular area.

COMMISSIONER ROGERS: Eunice, I don't think we are really that far apart. Of course, one of the things that the staff did do in putting before us the three or four was to go through part of that process of looking at where do we stand. They reviewed the document, did do through in terms of trying to decide what are the areas that work is already well along or what are the areas that have been underserved, and one of the things we have asked of Jim Allen, which we can return to and as a matter of fact might want to have

before the next meeting, is where do we stand on each of those recommendations.

But my point being that the piece that you have before you from Maureen went through part of that exercise. I just want to assure you that this document has in no way been ignored.

COMMISSIONER DIAZ: It just doesn't tell me where specific recommendations--we get recommendations under each section. Many of them say such and such an institute ought to do this. I don't know whether that has taken place, and therefore, I could not make an informed decision as to what ought to be the four main focuses of this, based on what I have heard this morning. And I am just saying that something a little more methodical that says, of these five recommendations that were given under the ethical group, three of them are already being taken care of, two have not been taken care of. Under care and delivery, this is what is happening.

I don't think that the two pages you have given represents that.

DR. ALLEN: One of the problems of dealing

with recommendations that come from an oversight group, if you will, is that often there is nobody to receive and then act on the recommendations. In other words, they may not be directed at a target audience, or even if they are directed at a target audience, that target audience may choose not to accept them, or it may be so diffuse that nobody really picks up the responsibility.

Very clearly, I will say I'm delighted. It is going to take some work for my office, but it is one of our responsibilities to pull together a detailed response for the Commission in terms of the agenda items, the recommendations from the Presidential Commission that we feel the Public Health Service has either some or total responsibility for, and we will give you recommendations to that.

But it seems to me that one of the things that might be addressed also by this Commission are those recommendations that fall outside of the Public Health Service's sphere of responsibility, either in part or in total. And to look at those to see which ones have not been adequately acted upon by the system and if they are still important, to perhaps refine them

or refocus them and direct them to a very specific target audience and see if you can get some accountability for them so that they are carried out.

COMMISSIONER DALTON: That is exactly what I was going to ask for, Jim. I can't believe you are begging for all this work. But it really would be helpful for us to know which of those recommendations have not been pursued because they fall between the stools or between the cracks. And so I would hope you wouldn't limit yourself to your Public Health Service hat. Maybe you can work together with Maureen so we can fudge the accountability issue here in terms of where, but it would really be enormously useful to know why it is the recommendations haven't been followed up on.

MS. BYRNES: That might be the second piece to what the National Commission staff can do, because I would assure you that we could give you what you are asking for very quickly. We did go through the report and the recommendations and essentially came up with very broad topics that we assumed some of the recommendations that had not yet been met would still

be addressed. Within the four topics that we presented to you, the nurses shortage is still here. We have a serious problem with the nursing shortage. We have the Americans with Disabilities act, but we still need to look at discrimination, but perhaps we need to look at discrimination and protections against discrimination in a context that now includes the fact that ADA has passed the Senate and needs to be passed by the House.

But we could certainly go through the report, I think in a fairly fast turn around, indicating for you what the assessment of the Commission's staff would be as to which has been addressed and which has not, and clearly work with the National AIDS Activities Program to talk about perhaps why not, were there reasons why there was not clear enough direction about how to pick up those recommendations, or whose responsibility the follow-up was. But I think to some degree many of us have looked at the report and identified some issues that have been addressed, and many which have not.

COMMISSIONER ROGERS: Congressman Rowland.

REPRESENTATIVE ROWLAND: Well, near the

bottom of the page here, three items are mentioned that much of the debate in the Congress revolves around, and that's confidentiality, who should know who is infected and how should you deal with people that are infected insofar as protecting that confidentiality is concerned, and testing--of course, they are interrelated--and discrimination. As already mentioned, the Americans with Disabilities Act is to a large extent, or to some extent, addressing the discrimination part of it.

But it seems to me that in setting a national policy that we need to be advising the Congress that we are going to address this on a national level of whether or not it should be left to states or local communities, but it seems to me that we ought to be making some kind of decisions about what recommendations we ought to be making to the Congress with reference to discrimination and testing.

You know, people went off in different directions with the testing business, and I believe Illinois has just repealed their premarital testing. And you know, I have just read that there is another test that is

very inexpensive that may detect the antibodies that was developed in Georgia, in fact, and maybe you know something about that, Jim.

I'm not sure, but it seems like there are a lot of advances in technology that are being made and I think that we are going to be responsible, having assumed this mantle, to try to advise Congress. And I just want to point out those particular areas where we really need to give a lot of thought and to making recommendations about where these things ought to be addressed.

COMMISSIONER ROGERS: Very good.

Mr. Goldman?

COMMISSIONER GOLDMAN: Thank you. On the question of working groups or not workings groups. The major advantage, it seems to me, to putting together a working group of some kind--or whatever you call them, it doesn't really make a whole lot of difference--is that I would hope that the work of the Commission is not going to be two days every other month. And clearly, we can't really develop some policies, we can't--none of us have enough time if all of us are

going to hear what is necessary to be heard on all of the issues that are involved in this document or whatever other agenda we establish for ourselves.

There is no way that all of us can be here unless we decide to turn the Commission into our full time job and avoid very other responsibility we have, and we may be getting to that point already, but we would have to literally go to that point. And it seems to me that working groups are some way of being able to at least allow some people to focus. I certainly wouldn't suggest that, you know, if somebody were on working group A that they couldn't attend the meetings of working group B. But it just seems to me that it is going to be impossible to function unless we have whole Commission hearings three or four days every single month to deal with one specific issue of one sort or another.

The other point that I would like to make is that it seems to me that it is important that we distinguish between two different types of issues. One of them are some of the issues that we have discussed here in which I think that there aren't clear answers.

And the Commission itself still has to arrive at a consensus. Among those issues, for example, are issues involving the provision of care, comments of Dr. Koop in terms of separating out AIDS versus including it, the issues I think that some of our experiences have been in terms of the advantages of providing comprehensive health care services limited to a specific categorical disease and the advantages of being able to put together the expertise under one roof, and the advantages to care that derive from that kind of system, and how you balance the two, how you maintain expertise in a large enough setting but still allow community-based facilities and services to be rendered near where patients are in a compassionate way, and how we deal with those kinds of issues.

I'm not sure that there are any easy answers, but I think one of the things we may be interested in doing is trying to develop at least some models of how things should be done and then at the same time provide suggested mechanisms for financing those systems.

In other areas however, I think that there is a general agreement as to a consensus. I mean, we have

already voted to urge the adoption of the ADA. I don't think there is a member of this Commission, and I don't think, frankly, that there is a member of this Administration, and I doubt whether there many people even in Congress who suggests that discrimination against people with AIDS or HIV infection is a good idea.

The issue is how do we deal with it and how do we avoid it, and those end up being tactical political issues. I don't know, frankly, what--beyond the resolution that we passed--what we can do as an official body. Maybe instead of having a working group and a meeting on a discrimination working group, maybe the thing we ought to be doing is instead of meeting here, walking around the halls of this particular building and speaking to the members of the House before whom the ADA is pending to urge their immediate passage.

Maybe the thing to do would be to try to meet with representatives of the President's staff to deal with how the Administration could get more effectively involved, not only in terms of the legal issues

supporting fighting discrimination but as well as in providing the moral leadership that is necessary to set an example. And I think some of those issues require some careful consideration entirely separate from the underlying policy issues. There ought to be a mechanism for dealing with that as well.

COMMISSIONER ROGERS: Thank you, Don. It may be a little bit more reassuring in putting forth three or four, I wasn't, one, suggesting that we necessarily limit to that. I was suggesting here might be some areas to get our teeth into to see how we function, and it wasn't to suggest that other areas should be excluded, and I sensed, Eunice, from your comments that you felt maybe we are moving too fast. I just want to reassure you that I was simply saying from what I heard this morning there were some big, obvious ones, and that if we want to hit the ground running it might be wise to begin to get some information on these to begin to see how we would work with it to begin to see if we did have something constructive that would result in change in behavior and/or financing or function, not simply a recommendation.

Other comments. Larry?

COMMISSIONER KESSLER: Well, I think because we are all so busy we are really going to really need to depend in great part on the staff's expertise and their networking ability here in the District to fill in those gaps and to get us up to speed and to keep us up to speed.

I believe that working groups would work well and can be an asset to the staff, but the schedule, as mentioned by Don and others, doesn't give us the chance to make our mark or to influence people without those working groups.

Conference calls are not my favorite form of interaction and I would rather discourage those and would rather take the time to be participatory in working groups and in the general sessions like we have today, as well as in site visits, all of which would converge, I hope, in policy development and recommendations around policy.

COMMISSIONER ROGERS: Thank you. Diane, any comment?

COMMISSIONER AHRENS: Well, I guess I agree

with most of what has been said here. It seems to me by our next meeting we ought to be able to have a document in our hands that says, yes, these things were done, no, these things were not done, and this is why, in terms of the Presidential Commission report. I don't think that that would be too much.

And I think that the points that have been made in the two-page document in front of us that staff prepared are clear and concise and relevant and seem to, as I understand what wasn't done, or at least addressed, left hanging out there, certainly need to be attended to.

My concern is more how we do it at this point, because I think that we are all going to come to some pretty good consensus on what we should do. And I have a real concern that we get out and about and see what is happening in the communities in this country, some of which I think we will be very proud of and will give us a kind of affirmation to move ahead in some of these areas, some of which will be so appalling that we will want to jump in and say that somehow this has got to be rectified and got to be fixed.

And I think it also enables us to hear from the community of people with AIDS. We heard from much of the leadership this morning, but we also need to hear from what's happening to those folks who don't get a hearing, are never invited, are at the grassroots level and living each day as best they can. But I think that is very important and we can do that as I think we go about the country. And as we move in substance with the issues, I think we have to move in concert with the actuality of how this epidemic is being lived across these United States. That's what I'd like to say.

COMMISSIONER ROGERS: Belinda, I see you shaking your head. Do you want to comment?

COMMISSIONER MASON: I hate to do this, but I was in the ladies room lounge. Is there a question that I need to answer, or can I just pontificate?

COMMISSIONER ROGERS: You can pontificate if you would like.

COMMISSIONER MASON: Okay. I'm serious, Harlon. Harlon thinks I'm just doing this for the effect. I'm serious about this.

COMMISSIONER ROGERS: Belinda, I had suggested three or four areas we start--

COMMISSIONER MASON: That is this, right?

COMMISSIONER ROGERS: Yes. I sort of changed the order, which helped confuse people, but it was here are some areas that we might ask the staff to begin to explore, and added to it now has been the suggestion of Eunice and Diane that we have before us a score card in terms of where do we stand on each of the recommendations from the President's Commission.

COMMISSIONER MASON: That is a great idea. I like all of these areas.

Now, what is the question about--is there still a question about whether or not to have working groups?

COMMISSIONER ROGERS: That's one of the questions I have raised.

COMMISSIONER MASON: That is one of the questions. Okay. Well, I kind of think we really ought to go ahead and try to have some working groups, because there is no need for all of us to beat our brains out on all the different things, you know. We

can just pick the things that we are good at, or the things that we feel like we can bring special expertise to and bring it back to everybody and kind of trust each other on these things.

One thing that I was enlightened about when I spent some time last week with Dr. Konigsberg and Don and Scott in Sante Fe is that we'll be able to create the kind of environment where commissioners can bring forth ideas that might not be entirely politically correct and realize that they will have a full opportunity to air those concerns. You know, I'm sure that the two different constituencies--or I'm not sure, Don Goldman is always telling me not to make judgments--but I think it is probably safe to say that the public health community and the PWA community often diverge on issues like testing and contact tracing, but still in all, I support Charles' need and desire to bring these public health questions to bear on the issue.

And I don't think we ought to be afraid of hearing things that are new for us and stuff. So I think really this working group model, if we could do

that, I would like that a lot better. I have limited energy, you know, and also in a very real sense limited time, as all of you all do, although maybe you are not as aware of it.

But I would rather spend my energy at the pressure points where I could provide the most impact and not just--you know, I don't really need to be brought up to speed on a lot of things so I could do everything about the AIDS Commission well, just a few things. And if I could just do a couple of things well, that would be enough.

COMMISSIONER ROGERS: Belinda, thank you. Harlon, you wanted do say something?

COMMISSIONER DALTON: Yes. I hadn't quite figured out where I stood on the workings groups versus no working groups, but I think you have just convinced me. But what I really wanted, when I put my hand up I just wanted to second what Diane had said about getting out and about.

At our last meeting in August, in-person meeting, the suggestion was made that one way to sort of maximize or optimize our efforts was to conduct

hearings in those places and at those times when there were other preexisting conferences that some of us would be going to would seem to sort of make sense except as I think about it now, I think we might be better served by figuring out where we go, where we want to go, what we want to see, what we want to spotlight, what we want to learn. And if we can then match that up with places where we are going to be, fine. But I'm a little concerned that we may sort of have the something wagging the something.

And I love the way that you sort of put that in terms of trying to get to all those people who can't otherwise get to us and learn from them. So that seems to me also then points in the direction of sort of working groups, because I'm really asking for us to take on another task, I mean one that we have already sort of talked about, but that is in addition to our six meetings, Getting out and about. Maybe for some of us that means going to fewer conferences than we might otherwise have planned to go to, which, frankly, Wouldn't bother me one bit. But that then suggests--I too have limited energy, and I like the way you put

that, that some of us may not be aware of it, haven't been driven to appreciate it in the way that you have. But we should accept our own mortality and limitations, but within those limits press ourselves.

COMMISSIONER ROGERS: Thank you, Harlon.

Scott?

COMMISSIONER SCOTT ALLEN: Yes. One of the things that I need help on is a legislative analysis. If we are going to advise Congress we need to know what Congress is up to and what they are doing and what are the issues they are dealing with. Some of these issues may not be important to us, we have already dealt with them sometime in the past, but we need to know, for instance, about the prison system, what is happening in Congress concerning prisons. So that kind of analysis would be very helpful to help tailor our issues along that line.

Also what I'm concerned about is the expansiveness of these four issues. You are saying that you see us as concentrating on four issues. Well, how expansive is that list within that framework? That is a concern that I have.

Another concern--and I just wanted to bring up Larry's comment at the first meeting on the education and prevention. I don't want to get too specific, but we are talking about, especially, effectiveness for the populations targeted, the high-risk behavior populations. Also the concern of mass media and how we can use mass media in dealing with this is very crucial.

Then ethical and legal issues. One of my concerns is the depletion of resources coming up in the '90s and how are we going to deal with that and how are we going to deal with the turfism and how are we going to deal with the priorities and bioethics. So that is a concern that I have.

And then finally, you say that some of the these have been dealt with, Maureen, but I would like some information--not at this point--but about the international response and the need for the United States to deal with this on an international basis and how well we are doing and what needs to be done, especially in coordination of research--well, coordination all the way up and down the line, just for

one individual, the continuum of care, which you have mentioned, but there is also coordination of care, but also internationally, that is a big issue. So those are some of my concerns.

MS. BYRNES: We can certainly follow-up in terms of the international recommendations as part of an overall review, if that's what I hear the Commission asking for the Commission staff to provide, what has been done, what's not been done, particularly at your request in terms of the international efforts. I would also point out that we have scheduled some time for tomorrow afternoon to do a legislative update, and I would agree with you that that's important and probably something we will want to do on a continual basis, interim, between meetings, as well as at each meeting. I think it is a great idea.

COMMISSIONER ROGERS: June?

CHAIRMAN OSBORN: I'm pleased to interject just one solution to all these problems, and that is that I was delighted to discover that our next meeting dates coincide with one of Dr. Jonathan Mann's visits to the United States and so he will, I think, probably

be our opening speaker at the next meeting, but also will spend some time with the Commission informally if we can arrange that, perhaps with a dinner and so forth. So that we will be very wonderfully introduced to those issues by Dr. Mann, and in addition can stay abreast to the extent that--

COMMISSIONER ROGERS: You might tell the group who Dr. Mann is. Most will know.

CHAIRMAN OSBORN: He is the director of the Global Program on AIDS of the World Health Organization. In addition, I think it will be useful to get some sense from you of how closely you want to follow the international situation. As I think you know, I am one of the four American members of the Global Commission on AIDS and would be eager to tell you as much as you think is appropriate as time goes on with that. So that will be a place where we will be eager to get some guidance about how much time. But I took the liberty of inviting Dr. Mann when I learned of the coincidence in our meeting times, so that's one thing you can plan on.

COMMISSIONER ROGERS: Larry, and then David.

COMMISSIONER KESSLER: One of the things that seems to be missing here, although I'm sure it is in Maureen's head, is the issue of numbers, the epidemiology here. We, obviously, are going to be pressed by the media, by members of Congress and so on, to define what it is we are talking about in terms of numbers, just as we will subsequently press them for numbers and commitments.

In all of these cases I think that piece is going to loom as very, very important, and so we need to develop that in a way that makes sense with the best minds working on those numbers for us, whether it be not only nationally but internationally because of the immigration issues and so on that immediately get murky. And that may be the kind of thing we can find some experts within CDC and other areas to help us without inflating our own need for staff or additional resources.

MS. BYRNES: For this meeting we did rely on the CDC and included the HIV surveillance report that they put out monthly, but if what you are also suggesting is that we look at how we are collecting the

data, how accurate that is, and also providing additional information outside of the United States, as well as the accuracy of the numbers inside, I think that is something that we can do on a very continual basis.

COMMISSIONER KESSLER: And also on a long range basis. Although I know how difficult that can be, we may be able to develop a grid that covers a sort of "what if" situation or scenario, best and worst and medium-case scenarios based on treatment availability and progress around vaccines and so on to somehow give us a framework in terms of that health care financing piece, the medical delivery piece, and so on. That is probably a problem too that the local cities, counties and states are not very good at, but there may be a device that we can come up with, or a set of tools that works at that level as well.

COMMISSIONER ROGERS: Jim?

DR. ALLEN: The National AIDS Program Office will certainly be working with the Commission staff and with, primarily, the Centers for Disease Control to assure that you have the information that you need.

The CDC at our request has scheduled a series of meetings that will be the end of October and the first day or so of November, a couple of days in there, that will look at updating the projections on the numbers, They will be looking at estimates that they can develop in terms of the seroprevalence throughout the country, that sort of thing, and we'll be assuring that you get access to that as soon as those numbers become available, and we'll work with Maureen and the others to assure that you've got the information you need.

COMMISSIONER ROGERS: David?

MR. NEWHALL: I can't disagree with anyone's points in the last half hour, but I'm left troubled by this morning's session. Many of you spend more of your time on the front lines than I do, but we heard about death, imminent death, and I find myself--having spent maybe 18 years up here on the Hill and the last six down town--wondering what it is we want as a body to accomplish and how soon we want to accomplish something, and I'm left feeling that we are talking about a long, long production before we get any piece done, and I don't have an answer to suggest.

But to the extent that we could focus on one or two things without excluding the cataloging of what Admiral Watkins' Commission has or has not, what has been done, to the extent that we could begin to focus on some short term accomplishments at the same time that we work toward the life cycle of this Commission, I think I might feel better.

Scott made a comment as we chatted earlier that those of you who are out there, these are life and death questions every day, and perhaps I'm overly optimistic in thinking that maybe we could make a contribution, some small contribution, as just a part of the Commission's charter early on.

I don't know how we organize ourselves to do that, Dr. Rogers. I think maybe something like the staff has put together, saying if we could agree on just one thing that we all felt we should get on with and perhaps complete within two to three months as we work on a whole bunch of other things, that might be good. It might cause the public to pay some attention to this Commission, and I think that that perhaps, as I heard some of the talk this morning, we have to be

influential, that's what people are looking, I think, for, and we are not going to start being influential until we start having some work product.

COMMISSIONER ROGERS: David, Thank you. You have said it much more elegantly. That was my reason for saying let's pick a few right now. We don't need to be restricted to these, but let's pick some that those we were listening to feel intensely, and let's try and make a difference there. That's a way of getting acquainted, that's a way of getting expertise, that's a way of beginning to move as a body. So that was my reason for suggesting a few, not the entire universe to start with.

Irwin, do you want to comment?

MR. PERNICK: I have a couple of concerns in that if we are talking about working groups, how do we intend to address the question of working groups? That is, are they going to be meeting every other month that the Commission doesn't meet, or will they be looking entirely at a single issue without reference to all the other issues? And if we do not do working groups, will all the commissioners really have time to look at all,

even if they are the four issues that you enunciated before? I'm not sure. And there is the question of time, people having other things to do, but anxious to get the work done here.

COMMISSIONER ROGERS: Well, we all are, and I share your concern. I think my reason for at least trying the straw man of giving staff some specific assignments to move briskly in areas, to invite commissioners to be involved, is that my own experience with working groups has been a working group gets informed, brings it back, but it takes twice as much time and that then they have to educate the entire rest of the Commission about it, though I liked Belinda's comment, let's have some trust in one another, and I would share that.

But my feeling was that perhaps in an effort to move with dispatch and decisiveness, I really do think most of us, if we were separately polled, could put on the back of an old envelope three or four things we thought could be done right now that might make a difference, and I was encouraging us to try and get off and get on with those.

MR. PERNICK: I personally like the four you selected.

COMMISSIONER ROGERS: Thank you. Don?

COMMISSIONER GOLDMAN: I think there is one other thing that we have not discussed, and that is the importance of the Commission as a listening body, not only within the communities out there in terms of the persons affected by HIV directly, but as well as the general public and the policymakers out there.

We have to devise a vehicle that state legislators, county officers, state health officers, members of Congress, members of the public or members of various political points of view, perhaps, that many of us might disagree with in some case or another, and advocates of different points of view, have to be made. If we are to establish and do our role as establishing a consensus, then we are going to have to make sure that our wings are broad enough under which all people from different points of view can feel comfortable, and that takes a lot of time to do.

You can't have that kind of broad thing in having a two day Commission meeting every other month

and allow that kind of access and that kind of communication.

COMMISSIONER ROGERS: Agreed.

MR. PERNICK: Dr. Koop this morning made reference to a feeling of mean spiritedness in the society. It may be that we need to--or some of us need to talk to representatives of the mean-spirited groups, If they can be identified. I don't mean Nazi cooks or your extremists who come out of the woodwork, but people who at least are trying to argue the issue with some intellectuality. That will take time, but nonetheless maybe in that case maybe we are talking about some subgroups occasionally for certain issues.

COMMISSIONER ROGERS: Eunice, and then Larry, and then Charles.

COMMISSIONER DIAZ: In regard to item three, I would like to see added to that that these issues also must be examined from the perspective of community-based response. That's very important. I think that whether that response comes through community-based organizations or coalitions or regional networks, that is outside of federal, State and local

government per se, and I like that clearly defined there. But I think that we need to look at these issues of diagnosis and care, financing, and education and prevention, the whole array of issues within the community-based response system.

And I think that would be very important, because we are going to find regional and geographical differences that are going to very helpful to us in terms of mapping out a national consensus.

COMMISSIONER ROGERS: Thank you, Eunice.

COMMISSIONER KESSLER: David, I had a sense that you maybe were looking for some specific suggestions to move us to the next stage of this discussion, and I was going to suggest that there are two areas in which we have the opportunity to move and to establish our credibility and to be the voice of leadership and reason, and the first is the ADA. While we have already spoken for it, what we need to be careful about are amendments that would water it down to make it ineffective. And there will be people, I think, who will try to do that in the future, in the near future. And we need to be firm and clear and

present around the process.

And the other is, in light of all the discussion and the continued debate of whether the drug policy is good or bad, the piece that I think we probably agree on but we are not sure of is the treatment upon request. We certainly can agree that we feel badly, I think, about the absence of that as part of the plan. But from our perspective in terms of AIDS prevention, it is one that we need to work on quickly and become part of the public debate as to whether the Bennett/Bush plan or Bush/Bennett plan, whatever, is a good one or thorough enough and comprehensive enough, and what does this Commission believe needs to be inserted in that debate and in the plan as far as AIDS goes.

COMMISSIONER ROGERS: Are you suggesting that as an immediate step?

COMMISSIONER KESSLER: I think it is immediate because it is timely. It is the kind of thing that we can jump on, whether you want to pose it as a bandwagon or not, I think it is an issue that Americans are now paying attention to again, but we

have had these wars on drugs before that sometimes last eight weeks. And we have the momentum now to say there is also an epidemic called AIDS, it is on a parallel track, there is an intersection in which we see what happens when they intersect, and that confluence is something that we can address that wasn't addressed in the report.

And it is not addressed adequately in terms of things like treatment. Prisons, you know, are not the alternatives, it is not the issue in terms of AIDS. And even when we talk about expanding prisons by 85 percent, there is no mention of infirmaries in the prisons who are going to care for all the people who are infected entering and who are infected now who already are incarcerated. Those are the pieces that are missing, and it is our obligation, in a sense, To address that and say, excuse us, there is something wrong, there is something missing.

COMMISSIONER ROGERS: I don't want to put words in your mouth here, but I thought I heard you suggesting that this Commission might go on record as saying treatment for drug users should be available on

demand.

COMMISSIONER KESSLER: That's right, that's what I'm saying. But there are other issues adjacent to that. But I certainly think that is a good one to begin with, that if we are going to work on the dual epidemics and we see the connections--I mean, everybody at this table I think has had the experience of seeing the deadly connection, and unfortunately that wasn't highlighted in the Presidential address and it wasn't highlighted in the report. So therefore this is an opportunity for us to begin to say there is a Commission on AIDS and they notice a glaring absence of AIDS in that plan, and yet it can't be overlooked, because it has ramifications all across the board and all the other things, as listed on this document.

COMMISSIONER ROGERS: Charles, and then Harlon.

COMMISSIONER KONIGSBERG: I'd like to get back to a point that Don Goldman made a few minutes ago about state and local health officials and government officials, and I'd like to pick up on that a minute.

A large part of the burden with respect to

the response to the HIV epidemic, in fact, does fall on state and local government. I think we have a tendency to come to Washington and focus on the federal government this and the federal government that. And those of us--and I'm sure Diane would agree, and I have worked at both the state and local level--know that it also hits home at that level.

Now, how grassroots that is, we can debate, but it is certainly closer to the grassroots than Washington. Well, there is a lot of money spent at the state and local level, there is a lot of policymaking that goes on, and that policymaking sometimes is all over the waterfront, as I think that I have tried to indicate.

Bear in mind--and I think I need to make this clear--that state and local government gets involved in the entire range of issues with respect to HIV. They get involved, for example, or they don't get involved, with leadership or community organization. Where they don't we ought to worry about that. Where they do we ought to recognize it.

The coordination issue comes up time and time

again. What you see at the federal level also works at the state level, and in larger urban communities at the local level. Who is going to do that? Again, many times that is looked to state and local officials, the elected officials get involved.

Prevention goes on, the whole range of prevention, from education to other things. Then there is the care and treatment issue. Care and treatment by and large, with the exception of perhaps the military and the VA, is not carried on by the federal government, it is carried out by the private sector or it is carried out by, very often what is the place of last resort for many medically underserved individuals, and that's hospitals and outpatient clinics run by state and local governments. And the demonstration projects, I think, have been shown to be successful, but if we are going to look for expansion, again, I guess what I'm saying is there are state and local health officials out there that want to be heard. They have got some viewpoints out there, I would assume that there are county commissioners, Diane, and perhaps even governors who would like to come and express themselves

to this group.

They will say things you agree with, they will say things you don't agree with, which is true for anything, and I just really would like to emphasize the point that we not put certain issues aside, that we not see this as strictly a federal problem, and that we make sure that we listen to all of those who have a concern, and more than that a responsibility and an obligation.

COMMISSIONER ROGERS: Thank you.

COMMISSIONER DALTON: Apropos of that, I notice that on the two-page document prepared by the staff, point number three says, "All the issues must be examined from the perspective of federal, state and local governments," and I take it that as we go through issue by issue we--

COMMISSIONER ROGERS: Eunice has also added community groups, et cetera.

COMMISSIONER DALTON: So I think we should always be attentive, not simply having state and local government day, as it were, two days, but always sort of look from that perspective as well as from the

national.

Bear with me. Now I want to sort of respond to several things that have been said. First of all, in terms of setting three or four priorities, or four or five, I now understand that the suggestion really has to deal with trying to figure out how we can make an impact sooner than two years from now. And I absolutely agree that it does make sense to focus down to those things that we can sort of deal with early as well as long term. I think that the four issues that you identified are essentially the same as the four identified by the staff, but you gave them some priorities. And I like the priorities that you gave, in part because treatment issues gain priority over prevention--not that I'm against prevention, but certainly lots of people for some time now have been talking about prevention. We have really had too little air time and concern and intelligent thought given to a whole host of treatment issues, and that's one of the many reasons why I very much like the priorities that you have suggested.

This David, when he spoke, really

crystallized a lot for me, both in terms of asking what kind of impact do we want to have, how are we going to respond to what we heard this morning, rather than talk about a report two years from now, what can we do in three months rather than in two years.

I think one of the kinds of impacts that we can have is that for all those state and local government officials that are looking for some support for what they want to do anyway, our articulation of what we think is sensible policy may just be a lifesaver, or at least buoy people along, give them something to sort of hang their hat on who are already doing the work anyway. So I think we shouldn't throw away the benefits of just clearly articulating what policy ought to be in particular areas, but I do agree--you are absolutely right--that we need to think about what we can do in three months or indeed in two days.

I think Larry is right that we ought--let me express my hope that by the time we go home tomorrow we can speak to this issue of drug treatment on demand. I am prepared to do it now, but we should give it

somewhat more collective deliberation.

But I think we ought to walk away with something, not simply for public relation purposes but for our own sake. And we talk about hitting the ground running, but let's in fact hit the ground running.

As for a three month issue, I also think that is actually quite a good idea. It occurs to me that there are some issues that we can pull together and give serious consideration to collectively together in a three month period, issues that we have all been thinking about for three years or more, in the case of some folks who have been in this for some time.

The whole set of issues around mandatory screening, for example, I suspect that we could reach some consensus on. Issues of confidentiality, I think we could reach some consensus on. Importance of counseling and sort of helping separate out for the public counseling from testing, that is, for a lot of people testing is simply a way to get people into this thing, counseling or focused education.

I think we can really articulate a position for this Commission on those kinds of issues in

relatively short order, and in this respect, Belinda, I think in fact the PWA coalition and most public health officials and the people sitting up here and there are probably in a fair amount of agreement and we ought to say that and say it powerfully and well and sooner rather than later.

COMMISSIONER ROGERS: Thank you, Harlon, a very powerful statement.

Jim, you had something you wanted to say.

DR. ALLEN: I'm reacting in a way. I stuck my hand up right after Larry Kessler spoke, and then Charles Konigsberg did, and then Harlon Dalton, so I'm going to sort of pick up on a theme that the three of you, intentionally or not, began to express. And perhaps in doing so I'm going to challenge you to increase by an order of magnitude the difficulty of your task.

Let's pick up the one issue of drug abuse, treatment on demand. You go with Harlon's suggestion to pick that as an issue that needs--that you can coalesce around, that you can respond to very quickly. Let's look at some of the longer range impacts, rather

than simply make the recommendation that there should be drug abuse treatment on demand for people who are substance abusers. We need to look at the issue of personnel to staff the facilities. We have to recruit, in many instance, the personnel. We have to train them and we have to make sure that there is adequate pay for them, because I believe substance abuse workers often are underpaid.

We have to look at the physical facilities necessary for the increased services that will be there. We have to look at development of outreach programs, because in many instances people who are substance abusers do not want to come in. Some do. Many can be convinced to come in, but one of the things that I think the National Institute on Drug Abuse has been able to demonstrate in the last couple of years is the marked success of intensive outreach programs to people who otherwise are difficult to reach.

I think we need to look at the issue of coordinating medical services for substance abusers, and if you are talking about a woman who maybe has children, we have got a really complex problem. And

Eunice, you can attest to some of the stories that we heard a couple of weeks ago in Los Angeles at the pediatric AIDS conference.

It is a tremendously difficult effort to provide the care that is needed. We have to look at the impact on families. For many of these people, some of them will already be educated--or, I'm sorry, will already be in jobs, and it is getting them off the substance that will facilitate their keeping their jobs.

For others we are talking about trying to have them get some education, trying to get jobs for them so that they can truly break the whole pattern of lifestyle. We are talking, in other words, in some instances with sorts of rehabilitation programs.

For people who are already HIV infected, we are talking about the need to develop effective sexual transmission prevention methods for them. It is very difficult. Whereas there are many substance abusers who know about trying to prevent HIV infection and are willing to take steps to prevent that type of transmission, they are less willing to take steps to

prevent sexual transmission. And finally underlying it all, obviously, is financing. So we need to have the Commission also address perhaps ways to implement some of the recommendations.

COMMISSIONER ROGERS: Jim, I'm going to disagree with you profoundly. I think those are precisely the issues that this Commission should not address. I think this Commission is to set a tone, it is to keep on the public agenda how do we take better care of people with AIDS. If this group as a body decided that one thing that made sense was to have treatment on request for every drug user, I think we should simply say it. How to do it, how to figure it out--and I thought Bob Newman said that very eloquently--I think the Commission could tie itself in knots.

One of my observations has been, I think, that people who come from very different points of view can often agree on an outcome goal, and this I would call an outcome goal, that we ought to take decent care of people who are drug users. When you begin to get involved in process or how you are going to get there,

that is where people shred each other up and they spend months on it.

My hope would be that this Commission comes out with clarion kinds of statements about what is necessary in a humane, decent, responsible society to do better than we are doing with people with AIDS, and then say, you got to figure out how we do it.

Larry?

COMMISSIONER KESSLER: I agree, David. I think that, you know, in the '50s when this nation decided that it needed an interstate program for the country to really develop and thrive, we knew it was going to cost billions of dollars, and it wasn't going to cost billions of dollars for one or two years, it was going to go on and on, and we are still paying for those highways, but we value them, they have worked, they need to be better, but they are there.

We now have another sort of interstate bridge all over the place, and it is the bridge from the two epidemics going back and forth, AIDS and addiction. And what we need to do is figure out how to put some toll booths up, or do something to interrupt that flow.

It is going to cost a lot of money. The states are going to be handed the bill in one way or the other, because the states are mainly responsible for treatment.

But unless someone says, you have got to do it, the states and then the cities are going to suffer in ways that they never thought possible. You know, it is a cost effective measure that needs to be done now. Even though it will be extremely expensive, it is not nearly as expensive as the care, the disruption, the tearing of the fabric that will occur 5, 10, 15 years from now when, because we didn't do the right thing on this other sort of series of bridges that are built and rapidly expanding in the same ways as--they are major interstates here, we are not talking about foot bridges, we are talking about major bridges that need looking at and need to be addressed.

We can't as a Commission figure it all out, and you can't in the AIDS office figure it all out either. But every governor, every mayor, every selectman, councilperson, congressperson, parent, pastor, needs to join the fray and join the battle if

the war on drugs and the war on AIDS are really going to be successful. And that, in my mind, also means treatment on demand.

COMMISSIONER ROGERS: Let me try just for a moment to bring you back to the charge our Chairman gave me, which was can you try and put before the group, or can we evolve as a group, three or four areas for our immediate focus that the staff might begin to work on so that we had some red meat to really chew on at our next session.

As a straw man I put out four which in essence are really quite similar to this. You have made a number of suggestions. My query to you, how would you like to proceed in terms of, really, the assignment for moving us from where we are in terms of some areas for initial exploration. June?

CHAIRMAN OSBORN: Let me make one set of comments that I seem always to come back to when I try to think about how to get this initial bit of momentum. I think that some of our choices will be driven by events, as several speakers have indicated. And in addition, some of our opportunities will be driven by

events, so that I am not quite as concerned as I might otherwise be about waiting two years and then writing a report. We, in fact, have already gone on record at a cruicial time in the context of the Senate deliberations about ADA. I think we are prepared to keep on going and to visit and call those people that we need to to sustain that commitment on the part of the Commission.

And it sounds to me as if we can probably achieve a similar goal with respect to the drug treatment on demand issue, which, by the way, I want to point out was the other of the two driving recommendations of the previous Commission. Along with efforts to interrupt discriminatory practices, even before that the need for drug treatment on demand had been identified in their interim report as the highest kind of priority. So it is a double shame that we are still arguing at this late date.

I think that some of the points that Jim has brought up are elaborations that we can point out as issues that need urgent attention by appropriately trained people, and I think Bob Newman when he spoke,

because he was talking to a group of people who have been worrying about this for awhile, did not embroider, as he sometimes does, on the cost of not doing things, but I think that embroidery is well worth doing as we gear up and try to take an almost instant position. Because sometimes, in my experience in the epidemic, the obvious has been the last thing that gets to be said and it is oftentimes the first thing that needs to be said.

Getting back to my first comment, however, I think in terms of circumstances driving issues, there is simply no question that the circumstances since our appointment have driven to a sense of urgency the problem of how to deliver available and developing health care to all people in as equitable a way as possible.

It has been made instantly ten-fold more intense by the recent recommendation, or at least finding, that persons who are asymptomatically infected should find that out in order to consider some helpful chemoprophylactic therapies. And the fact that there has been this announcement of today that there is some

cost reduction in the one available therapy, while welcome, does not in any way impact on the kind of problem that we are facing in terms are trying to both finance and deliver care in as equitable a way as possible.

I see that as so urgent that that was always the thing that struck me as a working group focus, taking advantage of the talents of the Commission, of the staff, and of consultants, because I think two months from now--actually it is going to be six weeks from now that our next meeting is scheduled, approximately--that debate will be just as hot as can be as the impact of those recent findings of earlier therapy, asymptomatic therapy, begin to soak in and the great inequity of present access begins to soak in to potential recipients of such advice.

The drug treatment on demand issue folds right into that because I think most people who have been trying to access the drug users in order to offer specific AIDS related care keep tumbling across the fact that they don't have primary care, and so it isn't a matter of doing an occasional T-4 cell count and

deciding when to cut in with a therapy if we could figure out how to fund it. There are, in fact, fundamental issues there in somewhat the same way that Jim Allen was pointing out other kinds of very complex problems.

But just looking realistically at the dynamics of this point in 1989, if we didn't position ourselves to have an intelligent discussion about health care delivery and financing, both short run emergency and longer term planning for some creative solutions to a societal problem, I think it would overwhelm us within the next six weeks.

COMMISSIONER ROGERS: Good. Would the group buy that as one area in terms of putting staff to work on that? Are there others?

I had suggested as a first, because of what I had heard this morning and because I think we could take a very different focus on it, the continuing issue of discrimination, stigmatization, because I think a lot of what will go on in financing or treatment or what have you necessarily follows. But that was my reason for moving that one up as a priority issue.

COMMISSIONER GOLDMAN: I agree that the discrimination issue is important and I would hope that the ADA passes by the time me meet, however, for the next meeting. So that one of the things that I would certainly hope the staff would continue to do is to focus on ways between now and the next meeting in which the Commission might be useful and helpful in that process, either on an individual or in a group basis, and that is something that ought to be done as the highest priority on a continuing basis, and hopefully we'll be able to come to the next Commission meeting and find the bill not only has been passed but has been signed and everything else.

So I think that's fine. And so therefore I'm not sure it is a topic for the next meeting though, hopefully it won't be.

In terms of the issues of things to focus on, one of the things I think that we can do is to try to establish the issue of models of care and what care be rendered, and I think it is something that we have to begin to be focused on.

COMMISSIONER ROGERS: I think that fits right

in with June's--

COMMISSIONER GOLDMAN: And I think it fits right into what June says. It is very disturbing to me, and I think, as you have pointed out, putting together care and the organization of it, the financing of it, are really twin sides of a coin and have to be dealt with. And I'm not sure how you separate the two out.

It was disturbing to me to look at the President's Commission report and note that it established I think the goal that no one could probably disagree with, that there is the goal of treatment on demand, and then to look at the complete absence of that from the President's report here. And also the issue, which again is tied in the same way--and I don't mean this in a hostile way--but whereas the President's Commission on hIV strongly recommended that outpatient care be covered under Medicaid and Title 19, The President's Commission report said, and I'm quoting, "The Administration will conduct a study to determine if amendments to Title 19 of the Social Security Act should be proposed in order to broaden Medicaid

coverage for drug treatment."

I'm just curious as to whether you know who is conducting the study and when it is going to be conducted and when the results are going to be in and what the position is. Do you have any idea?

DR. ALLEN: I don't have a lot of details. The Health Care Financing Administration has contracted for the study. It is a broad-based study, it does not focus just on AIDS and HIV infection, but on financing of health care more generally. I believe that the report is due sometime in the months ahead, but I'll get some more specific information and let you know.

COMMISSIONER GOLDMAN: But I think those are issues that we ought to be focusing on.

COMMISSIONER ROGERS: Thank you. Diane?

COMMISSIONER AHRENS: I want to respond to what June was just saying. It seems to me that with respect to the whole financing issue which, when we get into it, is very deep and very complex if we look at the total system, we are going to be faced, and are now, with this issue of the cost of AZT and the numbers of persons that will be needing it as soon as they get

in and get diagnosed.

And the information that the company has just dropped the price 20 percent, which I guess would mean that instead of costing 8,000 a year it would cost something like 6,500 a year. I think it would be perhaps helpful if between now and November staff took a look at what information we have with respect to that issue and make some recommendations to us as to what we could suggest in terms of alternative funding mechanisms with respect to the AZT issue are available, which might include involving the drug company directly, and might not.

But we could them select, if we wished, from among those alternatives to make some recommendation to the appropriate authorities. That carves off a piece of finance that is a real big piece and speaks to, I think, the equity issue to a large extent, if we could address it and address it appropriately.

COMMISSIONER ROGERS: And certainly couples in to June's suggestion about immediate problems of treatment equity access, too.

COMMISSIONER AHRENS: I don't know whether

that is what you are were trying to say, or was a part of what you were trying to say.

CHAIRMAN OSBORN: It certainly would be a useful part of it, Diane, but I also had in mind something considerably less ornate, and that is looking at the access to care at all. I think that the last two sets of recommendations, those for earlier symptomatic therapy and those for asymptomatic therapy, have both landed in sort of the middle of the thinking of those people who are very sophisticated about the epidemic and outside the awareness of people who either are not medically trained or have not been very much involved in the epidemic, or both. So that, for instance, it sounds superficially reasonable to talk about having HIV testing and then following with T-4 cell counts until a certain threshold level and then cutting in with AZT.

But if you have never had a physical exam, you don't start with a T-4 cell count and go from there with T-4 cell counts. And what I was trying to get at as a basis even for AZT discussions, or for the kind of creative use of clincally based research that

Dr. Krim has talked about, and so forth, is that an increasing fraction of the people that we are officially concerned about, as well as actually lack access to primary care of any sort, and as such some of these recommendations that are now coming and being sort of suspended in mid-air have no realistic meaning for the majority of people who are the recipients of the recommendation.

This has been a regular event when people have come in with very simple maneuvers such as teaching about bleach usage, for instance, in drug using communities, that the response has been an almost overeager interpretation, "Oh, that means that I have an access to medical care of any sort."

And so starting at the AZT T-4 cell monitoring, prophylactic pentamidine level, is one way of taking off a piece. It is also what has been going on and it completely ignores what I for shorthand call the rich man/poor man aspect of this epidemic as it has already developed and is intensifying very rapidly. Those people who have access to private physicians or are in states where there is a very good funding of

access to public care and relatively little pressure from the epidemic are in one world, and those recommendations have some meaning.

But I don't think they do for what is getting to be a majority of the people for whom they are intended, and as we talk about health care financing, we have got much more to talk about than AZT.

So I am very eager to see that we start far enough back along the continuum that we don't get caught in the same snare as there has been in public discourse lately, that if we could only get Burroughs-Wellcome to do something even a little bit more or a little bit differnt, maybe it would be better, because it won't be. It will still be a rich man/poor man discussion until we look at some of the access to care issues that underlie any such maneuver.

COMMISSIONER ROGERS: June, let me make a suggestion here. I sense we differ in emphasis on where we might start, but I'm surprised at the unanimity of feelings, and I would summarize them thusly, that one, we want to make a difference and we want to be doing some things as promptly as we can.

And as you have said, events may dictate some of that.

But we are clearly concerned about the development of a community-based--call it what you will--primary care system which will take care of the enormous problems of people with HIV infection, and we couple to that all of these other things we have been discussing.

The discrimination issue doesn't sound--I think Don feels this may be past us. It may. I think there are some things that might be added to that, but I sense that one is less on the line.

Clearly, the problems of financing, we need to begin to get educated about as we do the prevention, education end of things. It seems to me we do have a potential agenda for staff here. I suggest the hour is late, that we let people think about this, and sometime tomorrow you again ass what are the three or four things you would like us to focus on first. I think we are pretty close to those, and then I think we also reexplore Larry's issue of do we react on the treatment on demand.

Scott?

COMMISSIONER SCOTT ALLEN: Just a couple of comments. One thing, discrimination is more than just a legal issue. So even though ADA hopefully will pass, we still have to deal with it. But what I would see as helpful is the legislative analysis of where Congress is, what--

COMMISSIONER ROGERS: We are going to have that.

COMMISSIONER SCOTT ALLEN: And then to look at a more detailed outline of the four areas that you are suggesting. I think we are all in agreement and, as you say, a different emphasis, but if we have a consensus of exactly what we are looking at in these areas it would be helpful.

COMMISSIONER ROGERS: We are going to have a little bit of chicken and egg problem here, Scott. I mean, I think what we have is a group to say develop some data for us in these areas that we are worried about. I don't think we can have a very precise definition right now. We have got to point the staff either toward Chicago or Detroit or New Orleans and say, here are some things we would like to know about

first and then we'll move from there.

And that perhaps, June, tomorrow we could poll again, as I say. People have had a long day and I'm not sure we want to push it to conclusion now.

Charles?

COMMISSIONER KONIGSBERG: Yes. I would really like to pick up on June's point about not focusing in on the cost of the AZT. It is far more complex than that.

We had long discussions out in Portland, Don Des Jarlais and I were out at the workshop that the National Center for Health Services Research put on and we really talked about the chronic disease model. And I would also kind of mention the fact that as part of that is kind of the concept of secondary prevention, which is preventing symptoms or complications, and nobody knows exactly where that is headed, but at least there is some good news.

You know, I think that as I am sitting here, I think that is also a late-breaking issue and one that we ought to go on and tackle. I would urge that we not take a monolithic viewpoint and say, well, the

demonstration projects ought to be duplicated in Hayes, Kansas, or some place. It may take a different model, but the access to care is not only the rich man/poor man, but it is also going to be getting the medical profession and other health care providers up to speed on what is going on.

Believe me, that is a real problem, and I think we need to be realistic, and while we are making these broad brush comments, I guess I'm a little bit like Jim Allen, I'm out there on the firing line at one level and sometimes we got to get a little bit practical about what we have got to do. But I think that would be a good issue.

COMMISSIONER ROGERS: Thank you. June, I will turn it back to you.

CHAIRMAN OSBORN: Well, Just before you do, so that I don't abuse the chair, let me make the other comment I wanted to in Congressman Rowland's absense. I think he pointed to a rather specific request of Congress that was rather well summarized in what Harlon Dalton suggested as a fairly immediate, or at least very short term goal that we could set for ourselves.

and that would be to try and use the consensus building power of this Commission to carry on an informed discussion and help to lead a national consensus.

We won't convince everybody ever, but nonetheless, we can try and lay the groundwork--some of which is tiresomely familiar to those of us who have been involved in this over the years--about issues that underlie a lot of difficulties being encountered in an otherwise orderly response to an epidemic crisis.

And so I think that the three-month agenda that Harlon detailed earlier is one to be woven into some of these other discussions. If you think for just a minute how much easier it would be to carry on our deliberations if we didn't have always to be braced for somebody to say, "Oh, That's such a good idea, let's force it down the throats of the people it is intended for," if we could in fact bring people's understanding along to the idea that if we push like that we will have people in hiding, if we offer we will have people, especially in the new context of asymptomatic therapy and so on, coming forward to take advantage of the other things we are talking about.

I'd like to make sure that we respond to the Congressional request, which was really quite specific, about confidentiality and screening strategies and so forth. If we work that in, then I think that we will have also accomplished something pretty major, if we were able to develop among this broadly constituted group a rather resounding consensus.

It won't seem so exciting, informed people will have heard the debate already, but I think it is something that we perhaps owe our creators alongside these other challenging things that we are talking about.

COMMISSIONER ROGERS: Very good. June, let me add one other thing on the discrimination issue, and I think it bears on this point. It seems to me also if this group can, in all ways possible to it, both support and encourage those in positions of important responsibility to say there is only one acceptable way that we as a nation should deal with people who have AIDS or HIV infection, I am profoundly persuaded that that is going to make a big difference in financing, in care structure and what have you.

I'll just take the time to tell this story. In my own hospital young surgeons were beginning to be reluctant to do the procedures I thought--many of us thought--necessary on people with HIV infection. In going to the president of the hospital, a surgeon, and saying, you must come out with an unequivocal, powerful statement, you are the leader here, saying there is only one acceptable way that we will have people treated here, it made a profound difference.

And it made me realize--so I'm not talking, Don, in Alice in Wonderland terms about changing people's attitudes, but I discovered immediately this changed the atmosphere within that place, that the young surgeon could still, if he wished, say, "I don't very much like gays," but the boss says, "This is the way we treat everyone in this hospital."

That makes a big difference, and if the President of the United States, or governors, or Commissioners of Health, or what have you, say this, that does begin to change behavior, even if it doesn't change attitudes. That was my reason for putting the discriminatory issue up in front, irrespective of legal

or other issues.

CHAIRMAN OSBORN: Thank you. That's a marvelous thought to finish with. I have one thought to finish with that I will add because it came to mind much earlier in the day as we were hearing from people living with AIDS. There are some uplifting things that happen in this epidemic along with the sadness that has come along. And one of the them has had very little attention and I think is one that we can embrace as a Commission.

David Kerp's book, "Learning by Heart," tells both dreadful and wonderful stories about the different ways in which school children have or have not been accepted into the appropriate school room. The most wonderful of those stories, In my view, reminded me that small children can still point the way for us to behave as members of the human family, and it was of the circumstances in, I think, Wilmette, Illinois, in which all of care had been made to try and maintain the anonymity of the HIV infected child to inform and educate all of the surrounding parents of other children, as well as school officials and so forth.

It was a very well done and concerted effort to have a youngster come into the first grade setting comfortably, and they did, in fact, such a good job that the child felt totally comfortable and confided on the first day to a couple of classmates, six year olds, that he was the child with HIV and AIDS, which of course threatened the whole thing, because his anonymity had been a part of what was being designed.

And the teacher, very brightly and brilliantly, I guess, recognized the hazard of that, sat the children down and said, "Now, of course, this is like family, we are all members of the family and there are some things we just talk about within the family"

And remarkably enough, the secret was never let out at the time of the media crisis. And later on some people asked some of the other kids in the class what they would have done had a person from the involved media come up and asked them who was the child with AIDS. And their response was instant, "Oh, well, We would have said that we were."

And those six year olds reinvented for us an

attitude that I would love to see begin to catch across the country, that we are all people in a family that has an AIDS problem, and whether it happens to be me or a member of my family, in a sense we all are living with it. It is a remarkable re-creation by children in our midst of a World War II strategy that I always thought was quite awesome.

I think that is probably a good way to end the day's discussion and we will get together again tomorrow in the GSA building at 18th and F.

Thank you very much.

[Whereupon, At 4:55 p.m., The hearing was adjourned to reconvene the following day at 1:30 p.m.]