TRANSCRIPT OF PROCEEDINGS

[illegible]

[illegible]

[illegible]

Pages 1 thru 319

[illegible]

MILLER REPORTING COMPANY, INC.
507 C Street, N.E.
Washington, D.C. 20002
546-6666

NATIONAL COMMISSION

ON

ACQUIRED IMMUNE DEFICIENCY SYNDROME

Thursday, November 2, 1989

9:00 a.m.

Pan American Health Organization Building

525 Twenty-third Street Northwest

Washington, D.C.

COMMISSIONERS PRESENT:

June Osborn, Chairman

David Rogers, M.D., Vice Chairman

Scott Allen

Diane Ahrens

Eunice Diaz

Donald Goldman

Larry Kessler

Charles Konigsberg

Susan Neeme [Representing Belinda Mason]

STAFF PRESENT:

Maureen Byrnes, Executive Director

Carlton Lee, Chief Liaison Officer

Thomas Brandt, Director of Communications

CONTENTS

PROCEEDINGS

CHAIRMAN OSBORN: Let the ask that people take their seats so that we can proceed, we have a very full agenda.

It is my understanding that Secretary Sullivan, who is planning to be with us, has some complications. I think we are going to get started and hope that he can join us as his schedule permits, but I know Dr. Mann also has a very full schedule, as does the Commission.

It is a great, great pleasure to welcome all of you today, and several of you very especially, to the second substantive meeting of the National Commission on AIDS. We are very grateful to the Pan American Health Organization people for having allowed us to use this wonderful facility, and as we proceed today I want to point out to the people sitting at the table that this is a very wonderful facility. It is one where you can push a button and it says "on" and "off," and if you whisper when it is on, you will probably get picked up. If you forget to turn it on when you want to speak, you probably won't be heard.

So if you would remember to do that, that would be very helpful.

Later on in the morning I will make more extensive comments about the rest of the meeting, but in view of Dr. Mann's very tight schedule and the very great pleasure I feel in welcoming him to our meeting, I would like to go directly to the first part of the agenda in which we will have a chance both to hear from Dr. Mann and then to interact with him about international aspects of the HIV and AIDS epidemic worldwide.

Before I yield the floor to him, I want to take the Chairman's privilege to comment about Dr. Mann. I happen to know from having worked intermittently over at WHO just, I think, over two and a half years ago, that he and I bumped into each other as he was trying to find out where his office might be in WHO. He was not yet fully installed and was trying to figure out how to start with 166 possible countries to deal with and a worldwide pandemic well underway.

I find it a source of total astonishment that in the intervening time with his wonderful leadership the Global Program on AIDS has established very useful and meaningful relationships with, I think, 151 of those countries--maybe it is more now--and in some instances the lifeline of those countries toward organized help of the global community with this growing pandemic. He has done that while trying to staff up and to establish offices and all those kinds of things, and it is really one of the exceptional accomplishments that I am aware of, both in terms of international organization and in terms of personal diplomacy. I have had the privilege of working with him throughout that time, and my admiration only grows.

I will comment just before I introduce John, I am very sad to tell you that two of our commissioners can't be with us for sad reasons today. Harlon Dalton's father died quite precipitously and unexpectedly a couple of days ago and so he is in Colorado in that regard, and so we will miss him. And Belinda Mason, as many of you know, has been quite ill, is somewhat better now, but certainly not well enough to have been able to join us, and I am very glad that Susan Neeme will--Belinda asked that Susan Neeme be an observer for her at our meeting, and we are very happy to have you join us.

I know Congressman Rowland has Floor votes I think rather steadily throughout the day and I am very glad that Kathy is able to be here to represent him and to carry back the messages of our deliberation. I think he hopes to be able to join us tomorrow, although we are at a very "iffy" stage in terms of scheduling House activities, so we are not sure about that. And as I mentioned, I think Secretary Sullivan will be joining us, although as always his schedule is quite difficult to regulate.

Dr. Mann, with those introductory comments, could I ask you to join us and we'll look forward to your comments, and then the commissioners please feel comfortable in asking questions when John has had a chance to speak.

STATEMENT OF JONATHAN M. MANN, M.D., M.P.H.,

WORLD HEALTH ORGANIZATION, GENEVA

DR. MANN: Thank you very much, Madam Chairperson and members of the Commission.

During the 1970s the human immunodeficiency virus spread silently and unnoticed around the world, and therefore at the time that AIDS was first recognized in 1981 HIV infections were already present on four other continents. The discovery of HIV in 1983 and the widespread viability of HIV antibody testing as of early 1985, led rapidly to recognition of the global scope of HIV infection and stimulated a worldwide and unprecedented response to prevent and control AIDS.

I would like to thank you first very much for this opportunity to speak with you, for we are today at a crossroads in the history of AIDS. First, I would like to summarize briefly the central features of the current epidemic, the global response, and then look towards the 1990s. There are three central features of the current pandemic. It is worldwide, it is unequally distributed, and it is dynamic.

As of 1 October of this year, a cumulative total of over 182,000 AIDS cases were reported from 152 countries around the world, but we estimate that the actual cumulative number of AIDS cases worldwide is approximately 600,000, more than three times the officially reported number. WHO also estimates that between 5 million and 10 million people are infected with HIV. This number may more likely be between 6 and 8 million on the basis of further and more recent surveys.

The second feature of the pandemic is its heterogeneous distribution. WHO has identified three, and now four, distinctive epidemiological patterns. These patterns are, of course, all based on the same basic modes of spread, but they reflect differences in the temporal spread of HIV infection, as well as variations in personal and social behavior patterns among different populations.

And finally, the pandemic is dynamic and highly unstable. Examples of populations in which HIV incidence has declined illustrate the potential for behavior change and the associated reduction of transmission, and yet the global picture at the end of the 1980s remains dominated by evidence of increasing infection, increasing incidence, and increasing geographical spread of the pandemic.

HIV I is now reaching new areas, such as Southeast Asia, West Africa and Eastern Europe. Wherever behaviors which permit HIV transmission persist, they create a vulnerability for individual HIV infection and a potential for smoldering or explosive HIV spread. For example, each of the well over 100 million cases of sexually transmitted diseases in the world each year represents, symbolizes, a potential opportunity for the spread of HIV. The spreading global epidemic of drug use threatens to expose new populations to explosive HIV spread.

The United Nations has estimated that there may be as many as five million injecting drug users worldwide. Of these, the majority--in fact, the large majority--remain vulnerable to HIV infection.

And yet the decade of the 1980s has seen much more than the further spread of HIV. Starting in 1985 when the global dimensions and impact of HIV and AIDS was first realized an extraordinary and unprecedented mobilization has occurred in response to the pandemic. During the period 1985 to 1989 the World Health Organization, which was created precisely to direct and coordinate international health work, created a global AIDS strategy, initiated global action, and promoted global solidarity in the face of the pandemic and its common threat.

The global AIDS strategy is the first truly global strategy to prevent and control an infectious disease. It is also the first health strategy ever to have been debated by the United Nations General Assembly, where it was approved. The United Nations then resolved to coordinate all the actions of its many agencies in the worldwide fight against AIDS under the leadership of WHO.

During the period 1986 to 1989 the strategy has been transformed into action. In dramatic contrast with only three years ago, today there are national AIDS activities in every single country in the world, including some of the strongest programs ever seen in those countries in the area of public health. These programs are not just Ministry of Health programs.

They include many sectors of government, from education to women's affairs to information and justice.

Most importantly, in many countries non-governmental organizations and community based organizations have led the way, reaching people with information that they will believe and giving support where governments cannot reach or in ways that governments cannot provide. Worldwide there is a direct relationship between the diversity and commitment to AIDS by non-governmental organizations and the overall quality and strength of the national AIDS program.

National AIDS programs, as you can imagine, differ in many ways as they are adapted to the local social, economic, political and epidemiological situation. But they share a common shape and common purpose. Also, in every society facing AIDS certain complex preexisting issues have been highlighted and some imbalances, deficiencies and inequities in the existing health and social systems have become more evident.

And therefore, in confronting AIDS, societies around the world have been forced to ask if the status quo is good enough, In education of youth, in the care of the sick, in support of the rights and dignity of all people. Through their energy and their resources, through their intersectoral quality and the recognition of the essential role of community action, national AIDS programs are stimulating a critical rethinking about health by the public and by health and social service providers, and national AIDS programs are making broad and as yet often unrecognized contributions to improving health for all by strengthening the health system even beyond control of an epidemic infections disease.

At the international level a coordinated effort has led to sharing of resources between the industrialized and the developing countries. Worldwide the arduous work of AIDS prevention and control has been started, notwithstanding inevitable gaps and delays, in record time.

And finally, in addition to a global strategy and global action, a spirit of global solidarity has arisen in the face of AIDS. This solidarity makes AIDS one of a small number of issues, such as the protection of the environment and the prevention of nuclear war, which are deeply and widely felt to be global concerns.

In the face of such accomplishments, some satisfaction is in order, but complacency is not. In early 1989 WHO carried out a survey, a study, which predicted that unless a cure or vaccine becomes available, two to three times more HIV infections would be expected to occur during the 1990s compared with the 1980s. When this estimate was applied to an AIDS forecasting model, we estimate that approximately nine times more adults may develop AIDS during the 1990s than have developed AIDS during the 1980s. And therefore, in terms of the number of infected people and people with AIDS and the social, economic and political stresses and impact associated with this problem, WHO believes that the decade of the 1990s will be much more difficult than the decade of the 1980s has been.

Overall, despite all our collective efforts, the global epidemic is gaining momentum. Major barriers to effective action still exist, and dangerous complacency about AIDS is spreading. We have arrived at a crossroads in the global fight against AIDS. At great human and financial cost, the foundation for successful action has been built. We now know how to slow the spread of HIV infection, although the work is difficult. New technologies already provide hope for infected people, and work on a vaccine is underway. The lessons of public health are linked with global experience and with compassion in the global AIDS strategy.

And yet, if complacency, indifference or denial lead to relaxation of current efforts, or to a crippling of future initiatives, we will falter and fall further and further behind the pace of the worldwide epidemic. We must act and we must speak out. We must strengthen social and political commitment to AIDS programs that are consistent with the principles of the global AIDS strategy. We must ensure worldwide access to technologies of AIDS prevention and care, therapeutic drugs, diagnostic tests and ultimately a vaccine.

We must build alliances to confront the

difficult social realities--drug use, prostitution, sex education of youth, access to health and social services, inequities, discrimination, and prejudice. For if these problems are not better addressed, national AIDS programs cannot succeed. We must increase the involvement of community organizations in reaching people with information and with support, and we must broaden the participation of the private sector, the international development assistance community, and the United Nations system in the global alliance against AIDS and for health.

What has thus far been accomplished is extraordinary and without precedent in public health. It is a continuing challenge to us that leadership, commitment and vision remain as important today as five years ago. AIDS prevention and control is not yet ready to be on automatic pilot. This is our appeal to the international community. A world with an expanding AIDS epidemic cannot be a safe world. Either we build upon and strengthen what has been accomplished, or the fears of the 1980s may become a tragic global reality.

We appeal to the United States, with its unparalleled capacity to help in times of need. The future of AIDS, and our future, will depend upon leadership, creativity, courage and a global vision of humanity and solidarity.

Thank you, Madam Chairman.

CHAIRMAN OSBORN: Thank you very much, John.

Let me ask commissioners to feel free to ask Dr. Mann for further clarification or for additional comments. Don Des Jarlais?

COMMISSIONER DES JARLAIS: John, you made reference to the spread of AIDS associated with drug use, both in Southeast Asia and more recently in Latin America. Do you have a sense for where that part of the epidemic is going and what the appropriate response of the United States Government should be toward that particular aspect of the epidemic?

DR. MANN: It is, as you know, extremely difficult to get good data on questions of injecting drug use. Also, because it is an evolving situation. We know, for example, as you mentioned, that injecting drug use appears to be becoming more common in areas of the world such as Latin America where previously this was much less common. We know of situations, for example, in Pakistan where the large number of opiate users are apparently beginning to turn to injecting drug use.

We know there are populations, in some cases large populations, of drug years, even in the United States, let alone in other parts of the world, who remain relatively less affected, in some cases almost untouched by the epidemic, and yet they have the behaviors that appear capable of spreading the virus. And we have the evidence of Bangkok, which is so illuminating because it was so predictable, and it occurred and unfolded in front of our very eyes. That is to say, an increase from, as you know, a seroprevalence of about 1 percent in December of 1987 to well over 40 percent today among Bangkok's minimum estimate of 50,000 injecting drug users.

The challenge we see immediately, in addition to the challenge of drug prevention and control, has to do with the question of evaluating the approaches to reducing the risk of HIV infection in drug users. There have been a number of very creative experiments, as you very well know, in terms of how to reduce the danger of HIV infection while struggling simultaneously to reduce drug use and to help drug users escape drugs. And your work, in fact, has been very helpful to us, and the work in the United States, to demonstrate that drug users are people and that drug users, faced with the danger of HIV, in many instances may wish to escape not only HIV infection but drug use, itself. We have to play our part, we have to play our role.

Now, WHO is in a good position to look at experiments throughout the world that have been carried out with needle exchange, with bleach programs, with programs to try to even change the pattern of drug use away from injecting drug use towards other forms of drug use in an effort to halt the spread of HIV. I am not yet convinced that we know what is effective. We are trying very much to learn that, and by learning that, to then be able to share that information with programs around the world. This is a part of how we see WHO playing a useful role to try to help everyone move forward by taking the experiment from wherever, and through careful evaluation be able to share that experience, and hopefully that increasing effectiveness, to deal with this obviously extremely difficult problem.

CHAIRMAN OSBORN: Dr. Rogers?

COMMISSIONER ROGERS: John, I was pleased with your stressing the sort of multidimensional needs of people with AIDS and your suggestion that health systems, or public health systems, all over the world, were beginning to expand in terms of the kinds of health professionals, the sorts of services that might be offered. I am sure one thing that follows from your suggestion is that we can use this for lots of kinds of illnesses that are plaguing our world if we could get it squared away with AIDS.

My question, I was also pleased to hear that you have got units in place in most of the countries of the world that you are following. How much of those are governmental, how much of those are volunteer in countries other than the U.S.? I would be interested to know what the balance is there.

Are other governments contributing helpfully? Are they denying the problem? Who is doing the work in other nations?

DR. MANN: Thank you very much. First, regarding your comment, it is very, very difficult, as you well know, to challenge the status quo. It is also very important, obviously, to do that. And what we try to do is maintain a position that we are not necessarily saying that people with AIDS should be treated differently from people with other conditions, but we sure have to look at how they should be treated and then perhaps use the additional knowledge, or the perspective we gain on AIDS, and then look at other conditions and say, is it appropriate.

Too much of the reasoning that takes place in public health is the other way. It goes from what has been to say, well that's the way people with AIDS and AIDS should be treated. We think that it is important to challenge that status quo. Sometimes the status quo is as good as we can do, but mostly it represents where we have agreed to stop trying. I guess that's what the status quo represents.

As far as the national AIDS programs, programs around the world are national programs. In other words, in a country in Africa and Latin America or Asia, it is the national government that creates a program, and WHO's role is to support that government every way we can, which means with technical support in developing a national plan. It means in technical support on specific issues of epidemiology or laboratory support, training courses, and then, in many instances, with financial support as well.

So I am pleased to report that the Chairman's number is a little bit low, it is 157 at this stage, countries that we work with, providing either technical and/or financial support to those countries.

Now, within countries the attitude towards non-governmental organizations varies considerably. There are some regimes in the world--and I would prefer not to specify--where non-governmental organizations are not approved of, they represent alternative potential sources or foci for political opposition and they are not allowed to exist. But usually even in those countries religious orders of various kinds are allowed to function, and often they assume an important role in providing care.

Overall the major effort in most countries is national government supported with international resources. In some of the countries there is an extensive non-governmental response as well, and some of the most creative things that are being done, particularly in the area of community based care, are being done by non-governmental organization, which for us, in our jargon, includes everything from the established church all the way through to a private voluntary organization. We call them all non-governmental. It is very variable, but as I said, the strength of a national program is in many instances directly related to how much the non-governmental sector, the community, is responding. Where they respond it is a strong program. Where they don't respond it is too often a national capital declaration based program as opposed to a program that is reaching people with information and support.

CHAIRMAN OSBORN: Dr. Konigsberg?

COMMISSIONER KONIGSBERG: Dr. Mann, what would you recommend to this Commission and to the United States Government as far as what additional role that our government should play, and particularly with respect to international cooperation and leadership? Could you elaborate a little bit beyond the drug abuse issue that you mentioned?

DR. MANN: Thank you very much for the question.

The role of the United States I would hope would be considered, again, not in terms of the status quo, not in terms of what has been, but in terms of what is needed and what might be appropriate. I think that there are tremendous opportunities for the United States in terms of learning from many different countries about approaches that have been used. I am more and more impressed with my opportunity to visit different countries and speak with people involved with AIDS at how similar some of the challenges really are.

I think we really sometimes are blinded a little bit by the resource availability to confuse resource availability with creativity, and a lot of the real heart of AIDS prevention and control is going to be heart. In other words, it is going to be will, it is going to be attitudes in society. And, of course, you need resources, but resources can't buy you AIDS prevention and control. There has to be the social and political commitment.

So when you see, for example, a community based program developing in Zambia or Uganda, I really believe that there are potentially some things to learn, just as they can learn from the so-called San Francisco model, perhaps. There are opportunities that need to be strengthened. I think there is a lot to gain in this regard.

Secondly, I think the question of responsibility--and, or course, here I do speak as a representative of the World Health Organization, although I am a U.S. citizen--that the U.S. is looked to, as I mentioned in my remarks--so much for help and so much for help in times of need, and the generosity of the United States and of the citizen in the street to an appeal to help an earthquake or to help a tidal wave is so overwhelming, resources can be mobilized so quickly and at such a level for an immediate tragedy, particularly when that tragedy has an individual human face. One picture can sometimes catalyze this nation into international action, and yet the challenge here is sustained international action. It is not a tidal wave. It is a wave that is growing, that threatens to be a tidal wave.

And our action in that regard is a little bit more difficult to mobilize, but I would help the U.S. would feel tremendous responsibility to help deal with a problem which in itself is so deeply engaged in dealing with. It is not just helping the others, it is really also helping one's self.

Now, in terms of actual amounts, the U.S. contribution to the Global Program on AIDS in 1989 is $25.5 million, representing just shy of 30 percent of our budget. In 1990 we anticipate that that relative proportion and absolute proportion will decrease. We are anticipating approximately $21 million of resources, which will be about 20 percent of our overall budget.

The support to the Global Program on AIDS is not the only way to support global AIDS. It is one of the key elements, but it is not the only investment. What has to increase at the same time is support to the

Global Program for the work we do, but also bilateral support to the countries directly between the United States and the involved country.

You see, WHO helps the government of Uganda develop its national AIDS plan, and once there is a plan there is something to invest in, there is something that can be monitored, there is something that one can actually see as a national AIDS plan and program. At that point the U.S. Government's generosity is critical, not through WHO, but directly to the country, itself. So in both areas, to WHO and to the governments, themselves, additional resources are going to be needed.

If you ask me how much will it cost, I don't know yet. We are in the process of learning how much the national AIDS programs costs, but I can tell you that we estimate the overall international support for developing countries in fighting AIDS in 1989 is somewhere between $250 million and $300 million total, including all the support to WHO, and that, as you well know, is much less than is spent in individual states in the United States to deal with AIDS in 1989.

I think that we have got to try to close that gap, although I can't yet put a price tag on the total cost. The U.S. has the potential to play an extraordinary leadership role that will bring the United States involvement into the public health vision of the future, or the United States can play a more peripheral role. The choice is really very clear.

CHAIRMAN OSBORN: Mr. Goldman.

COMMISSIONER GOLDMAN: Thank you. Speaking of attitudes of society, I know the World Health Organization and your office has often pointed out that immigration restrictions cannot prevent the spread of HIV disease. I was wondering if you would tell us what the response of the rest of the world has been to that clear understanding and the effect of that on international collaboration?

DR. MANN: We believe, as you say--and what we have seen is in essence there are three groups to consider, there is the immigrant, there is the long-term resident or student, and there is the traveler, the more casual traveler. Thus far we have been very successful on some aspects of the casual traveler. There is only one country in the world still today that requires an AIDS certificate, that is an HIV test certificate, in order to enter that country as a casual traveler, and that's the frequently visited country of Iraq.

Every other country in the world has avoided taking that step. There are now, however, a number of initiatives, some of which involve the United States, that would restrict even the short-term travel, the tourist travel, the business travel potentially of HIV infected people or people with AIDS. Fortunately, this has not yet really become a ground swell. There are a few countries that have done this.

When a country like the United States passes a law it has tremendous international impact, because those people that are friends of the United States, if I may say so, see this as evidence of perhaps a policy they should follow, and those people who are not friends of the United States, use it to document or to claim that the United States discriminates, and then in a strange manner of reasoning, then why shouldn't they.

And so your position, the role that you play, the policy leadership of the United States is really quite important. And here I think we have been only partially successful. I think overall international collaboration has survived what has happened so far in the way of restrictions to travel, but I can tell you that every year we have to fight at the World Health Assembly to prevent measures that would require that on your certificate that currently has yellow fever and cholera, that there would also be an AIDS test requirement. The wastefulness of that, the inefficiency of that, and the illogic of that approach unfortunately is not sufficient for some people to counterbalance what I have to describe as the political expediency and attractiveness. Building walls remains a very attractive idea in most people's minds, even if building a wall creates more danger than it does help.

CHAIRMAN OSBORN: Diane Ahrens.

COMMISSIONER AHRENS: Thank you, Madam Chair.

Dr. Mann, in looking at areas of the world where the United States may be exporting this disease, I am wondering if there are any efforts underway to address the prevention issue for, for instance, workers who come in to work in the United States and then return to their homeland? Particularly I am thinking of areas where the incidence is very high, of Belleglade, perhaps, or some areas in the southwest of this country. And do you have any suggestions for this Commission as to how we might address this issue?

DR. MANN: Well, I can tell you that from the other country's viewpoint, in some instances people who have been to the United States are considered a, quote, "high risk group." We think that is quite unfortunate. We think it is just as unfortunate as the United States considering people coming from other countries to be high risk, given the number of people already infected in this country.

So that does create some problems for certain kinds of migrant workers, not just in the Caribbean region, but also, for example, Filipinos who come to the United States and return to the Philippines. And this is another element of this difficult issue of pointing fingers.

Overall, while the United States probably did play a role in unwittingly contributing to the spread of HIV infection, for example through the export of blood products that were unknown to be infected, nevertheless that's history. And where we are now in these countries, like India, Thailand, where the first cases may well have been linked to the United States, we are far beyond that stage. Now the prostitutes in southeast India who are infected report having sex with Indian men, not with foreign men. And in Thailand the problem long ago escaped from the narrow circle of those people who had just had contact with Europe or the United States where they may have initially acquired infection.

So it is history, it is passed, and what we have to do, I think, is to try to grow out of that early stage where we saw fingers pointing in all directions and intensify our willingness to not only speak of solidarity but to pay the price of solidarity. And that's where the Commission or the U.S. Government can do something. It is one thing to talk about solidarity, it is another thing to consider what does it mean.

I was very pleased that when I was in San

Francisco a few weeks ago, just before the earthquake, actually, speaking at the National AIDS Update, that I said to the people there from San Francisco, and they applauded--I was really pleased, because I wasn't sure how they would react--I said, you can't wait, you have got to share what you have with the rest of the world. You can't wait until all the problems in San Francisco are taken care of before you turn to the problems outside this country. There is a responsibility to give to people who have less, and there are lots of people who have less and are dealing with the same difficult problems.

So I think if you can help lead towards a view of solidarity that isn't just rhetoric but actually involves commitment, then we are really talking about progress in international relations that will overcome a lot of that finger pointing, because over time that kind of solidarity will be much stronger than a newspaper report about someone coming back from the United States and being infected with HIV.

CHAIRMAN OSBORN: Larry Kessler.

COMMISSIONER KESSLER: John, I have first a statement. I want to express, I think, for many, many people around this table and across America our gratitude for your consistent clarity and your strong voice that I think has helped maintain a sane approach to the global epidemic. So your leadership I think really needs to be applauded and it is very deeply appreciated.

I have two questions, and the first one is on that topic of leadership. As you have traveled around the world, what do you see in terms of ministers of health or governments, the local scene, as the most helpful, based on your definition of leadership and models that I guess we could look to as ways to perhaps inspire some of our leaders to take action?

And my second question is the whole issue of restrictions on government funds. As you know, here in the United States some of our AIDS appropriation bills and so on have come with restrictions, particularly around needle exchange and safe sex information.

Are the dollars that are contributed to WHO or to other AID programs restricted at all, or is there something that we as the Commission can do to make sure that that doesn't occur?

DR. MANN: Thank you very much for your statement. In terms of leadership, there are clearly many different styles of leadership. Coming right to mind are, for example, Uganda where not only the Minister of Health but the President of the country has really made AIDS a national crusade of a kind, and he is right to do so. The level of infection among pregnant women in Kampala, the capital city, was 11 percent in 1985 and was 24 percent in 1988; 24 percent of all the pregnant women infected with HIV.

The level of infection in the rural area of the central highlands of Uganda, a rural district, is 12 percent overall in the population. So this is a national--this must be a national crusade, and they have taken that approach. That approach has involved a good amount of courage. That has required going in front of the international community and saying, we have a tremendous problem with AIDS at a time when the international community is still too ready to talk about sexuality somewhere else in generally stigmatizing terms. One of the things that I have learned from traveling around is that everybody considers other people's sexuality to be rampant with certain features that turn out to be rampant in one's own culture if one is willing to look, whatever the features are. It doesn't matter, and they vary a great deal.

So it took courage, and they have had that courage, and the response of the international community has strengthened their willingness, because millions of dollars have now gone into Uganda to support their program.

Another kind of leadership is in Switzerland. Now, Swiss leadership is more discrete, and Swiss leadership has involved consistent support to the development of programs in collaboration with the non-governmental organizations in Switzerland. And the Swiss have documented now changes in behavior of the general population, not just in the groups that are targeted by the education, but in the general population regarding condom use, for example.

So this is a kind of leadership that is quiet but very effective. That is maybe Swiss, also, very efficient but very quiet. And then there is the example of France where the leadership on human rights has been absolutely unbending and unyielding, where they have refused to yield to some of the virulent and sometimes racist statements by some of their own domestic politicians--the name of LePenn comes to mind--in terms of attacks with threats, implying that those foreigners represent the danger not only to the essence of France but also as far as AIDS, that they may carry AIDS. And they have resisted--the French government has resisted under the leadership of President Mitterand, and he has spoken clearly and articulately in public meetings time and again about the need to protect the rights and dignity of infected people.

Well, these are different styles of leadership, and I think what is common to them all is that in the end the support is provided. That's the bottom line. Either the support is provided to the national AIDS program or it is not. Sometimes that is declamatory and sometimes that's quiet and efficient, but the bottom line is whether the support is coming.

And each country has to, of course, decide what style of leadership it needs.

Personally I am in favor of the more visible kind. There aren't too many Switzerlands in the world and most countries need a capacity to hear from the highest source in the country not only the word "AIDS" but some of the meanings of AIDS, and to call upon all sectors of society to not discriminate, to work together, and to face a common challenge.

Next week or the week after there will be a meeting in the Vatican, and what we hope--we do not expect to be discussing issues of condoms in great detail--but we do expect to be talking about leadership, and we are looking for additional leadership from the religions of the world, if not into prevention, at least into care, because we are going to be facing a tremendous increase in the number of people ill with AIDS and HIV-related diseases worldwide in the next few years, and every religion has at least a vocation in the care of people who are ill. And I must say that some of the statements by the Pope, the Roman Catholic Pontiff, as well as other religious leaders, while perhaps not totally satisfying to our public health spirit of prevention, at least have been absolutely extraordinary statements of human solidarity in the face of established disease, and we need that as we also need prevention.

In terms of restrictions, no, the resources that we receive from the U.S. Government we spend according to a budget and a plan which we present, and this includes the capacity to help a country develop its own national program and the country decides itself what words to use.

CHAIRMAN OSBORN: Dr. Rogers.

COMMISSIONER ROGERS: Dr. Mann, we are enormously in your debt for not only being with us but being the leader you have been. Larry kind of stole my thunder, but I did want to thank you for your consistency, your clarity, the wonderful set of values you have portrayed in terms of championing the rights of those who are infected. And I have learned enormously from you being here. I think all the nations of the world are in your debt and we are lucky that we have your. Thank you so much for being with us.

DR. MANN: Thank you very much.

CHAIRMAN OSBORN: Thank you very much on behalf of all of the commissioners, John.

We are very pleased again--this is a wonderful morning in terms of the honor we are paid--to have Charles J. Carman, President of the World Federation of Hemophilia, Montreal, to join us and make some remarks.

I think his testimony is in the packet that is before you for the commissioners to look to later for reinforcement or to follow it.

STATEMENT OF CHARLES J. CARMAN

WORLD FEDERATION OF HEMOPHILIA, MONTREAL

MR. CARMAN: I would like to thank the National AIDS Commission for asking me to testify before you today. My name is Charles Carman. I am the President of the World Federation of Hemophilia. I have hemophilia.

It would be useful to tell you something about the World Federation of Hemophilia. The WFH was founded in 1963 for the purpose of advocating comprehensive medical care for persons with hemophilia. It is dedicated to influencing providers of health care worldwide so as to bring this care to as many persons with hemophilia as possible, wherever they live. To date 68 countries have national hemophilia associations that are members of the Federation.

The WFH constituency consists of persons with hemophilia, their families, physicians and scientists treating the disorder, and the blood industry, both public and private, that provides the coagulation products that are essential to the care and maintenance of hemophilia.

Our national members represent the global spectrum from the industrial, economically wealthy nations of the world to developing countries in the Third World. The Federation is thus dedicated to improving the quality of care of persons with hemophilia and related bleeding disorders.

Hemophilia is a bleeding disorder in which the affected person is missing active blood coagulation protein. About two decades ago scientific breakthroughs led to the separation of these proteins, known as Factor VIII and Factor IX, from human plasma. The key to a quality of life is an adequate supply of safe Factor VIII and Factor IX coagulation products at affordable prices to persons wherever they live around the world. The ultimate aim is that persons with hemophilia should be productive members of society and not restricted in school, work or life activity because of the bleeding episodes.

The appearance of the human immunodeficiency virus, HIV, has had an enormous impact upon health care delivery for hemophilia patients. The spread of HIV infection among persons with hemophilia through contaminated blood components and blood products has had devastating medical, social and economic effects. The dimensions of these still remain unmeasurable. At least 75 percent of heavily treated persons with classic hemophilia are infected with HIV. Older persons who probably sero-converted before 1983 seem to be at the greatest risk for development of AIDS. The curve of progression to AIDS is open-ended, thus their life is continually faced--even though they may be asymptomatic at this time--with the potential onslaught of this disease into their lives.

Wives and sexual partners of persons with hemophilia have shown an anti-HIV seroprevalence range of 10 to 20 percent. Again, a second tragedy to this among our community then is that the disease is now one in which it is not contained to the person himself who was born with a genetic disorder, but he must be conscious of those he is most intimate with. No transmission to household or casual contacts has been documented. Infected persons with hemophilia thus have two coexisting, chronic illnesses, both demanding comprehensive and continuing care.

As of the end of 1988 when our WFH statistics were put in place, there were 895 persons with hemophilia with AIDS reported in the United States, 308 in Europe, 220 in the Americas, 23 in the Western Pacific, but very small reported numbers from Southeast Asia, Africa and the Eastern Mediterranean, mainly because of record keeping processes and very few patients even reported in those areas for other health care record keeping problems. Fatality figures for persons infected with hemophilia are about 50 percent.

HIV infection is not only a tragedy for the person with hemophilia, but for the family and for the extended family. The HIV antibody positive hemophiliac suffers from terrible psychological trauma which may be intensified by the effects of the HIV infection, itself, upon the nervous system with subtle intellectual and memory changes. The medical problems associated with HIV infection represent a spectrum of complications that increase as time progresses. In terms of the family, the HIV positive hemophiliac is now recognized as having these two life threatening conditions and it is threatening to disrupt the very fiber of the family, itself.

An emotional impact upon the family not only comes from the disease, but from the social stigma which may be attached to the HIV positive person, and from the unwarranted victimization which can occur from that stigmatization. The degree of association of AIDS with hemophilia differs for different cultures in different regions of the world. However, the stigma in many parts of the world has more intense pressures upon it, as it varies from one part of the hemisphere to the other.

One of the consequences is an increased request by a number of female family members requesting carrier detection. The possibility of a hemophiliac child has always been a concern to the women in a family with a history and a presence of hemophilia. Now to this already troublesome burden has been added the association of hemophilia with AIDS, thus carrier detection for the purpose of making decisions is now compounded, the detection is difficult, time consuming, and has significant medico-legal overtones.

Perhaps the most difficult and saddest

experience for the family, however, is to observe their hemophiliac son, brother, husband or father dying from AIDS due to no action on his own part and to see him develop complications that cannot be treated effectively. At that time the patient requires skilled nursing care and continued emotional support as his condition deteriorates. Delivery of health and emotional care to the person with hemophilia and to his family has been enormously affected by HIV illness, and it has been an area that the World Federation of Hemophilia has dedicated much of its resource to trying to counter. Central to this entire issue is the need for skilled, compassionate and sensitive counseling for the entire family network.

In 1983 the WFH took its first stand with regard to hemophilia and HIV and AIDS. The World Hemophilia AIDS Center became operational under the auspices of the World Federation of Hemophilia and in association with the Orthopaedic Hospital of Los Angeles. Also, in 1987 the WFH formed its Committee for Education on AIDS. The goals of the WFH Aids Education Committee were two-fold; one, to assist people with hemophilia and their families in living with HIV and AIDS and to further prevent it's transmission; two, to support health care professionals in assisting people with hemophilia and their families in living with AIDS and HIV and to assist in counseling them in the prevention of further transmission.

In 1989 the WFH and the Global Program for AIDS of the World Health Organization are collaborating in the cosponsoring of an educational workshop that will be given in developing countries on hemophilia and HIV. The project of this collaborative effort has two goals. One is the development of educational materials that will be adapted to different cultures for professionals and people with hemophilia within that culture. Number two, the establishment of international workshops in developing countries for health care professionals and for people with hemophilia. I might add that the strength will be to utilize the experience that has been developed in the developed countries and adapt these to the developing nations. The pilot country for this project is Chile.

New processes to inactivate viruses in blood products have improved the safety of Factors VIII and IX. However, the more purified products have contributed to worldwide shortages of these vital products. The collection of donated blood in the preparation of coagulation factor concentrates, endeavors upon which persons with hemophilia are totally dependent, as we have mentioned, have been affected by the spectrum of HIV. A new era has thus begun with all aspects of transfusion procedures, blood collection, transfusion medicine and the production of coagulation blood components.

For example, in the United States it was estimated that supplies of Factor VIII concentrates were reduced by 60 percent in 1988 as compared with 1987. In the United Kingdom, where 60 percent of the Factor VIII products are imported, major steps have been taken to increase plasma supplies and to develop a new blood products laboratory at Elstree in Hertsfordshire. In Australia, where production was never more than 65 percent of the requirements needed, treatment of plasma products has further reduced the production-to-need ratio.

Now in 1989 the shortage of products seems to be resolved. However, the products are much more expensive as a result of the more complex purification processes which have removed the virus exposure. Health cost reimbursement systems in the U.S., Europe and all countries are now under strain. I urge this Commission to support federal reimbursement initiatives that will provide for reimbursement of these more expensive high technology Factor concentrates that are free from HIV and viruses, and thus free future hemophilia patients from the possibility of AIDS exposure.

I would remind us, however, that about 65 percent of the world's population of hemophilia patients receive minimal or no treatment with Factor concentrates. The global blood safety initiative of the WHO, a part of the Global Program on AIDS, and a committee on which I have had the privilege of serving as a consultant, is defining criteria for blood safety and availability for countries that depend upon national transfusion services to meet their patients' needs. Donor screening and blood testing is essential to reduce the spread of AIDS among patients that are treated with plasma in these developing countries.

Great strides have been made in our quality of life. Factor VIII and Factor IX concentrates have freed patients from hospital beds and emergency rooms. These products are not only lifesaving and preventers of crippling, they have allowed patients to treat themselves at home, in their offices, or wherever the treatment may be required. Health costs have dropped, patient employment has risen, and comprehensive care has become a reality. Both material and non-material benefits are a result of today's therapeutic products.

However, none of us can rest on our accomplishments. Only about one-third of the world's hemophilia population have access to modern fractionated concentrates. The remaining two-thirds live in countries that cannot afford this treatment, or are barred in other ways from access to such lifesaving products. The WFH must serve all its constituencies and is working with many national initiatives around the globe to do that. We are addressing issues that ensure continued access to commercial concentrates for countries that have been using them. We are addressing issues in countries that are solely dependent upon transfusion services. We must be leading health ministries toward actions that will bring modern products to developing and Third World nations.

There is a final issue regarding AIDS and hemophilia that I would like to bring to the attention the commissioners. Every two years the World Federation of Hemophilia holds an international congress. These congresses are intended to be a forum by which eminent physicians review the latest care processes and techniques, stimulate the leadership among the lay leaders from around the world, and thus carry back to the far corners of the world the most appropriate avenues by which to explore and expand comprehensive care.

For example, the past three international congresses have been in Madrid, Milan, and Rio de Janeiro. Washington, D.C. has been selected as the site for the XIXth International Congress, scheduled for August, 1990. A cloud of gloom hangs over this occasion. In August 1987 the United States Congress passed a rule amending the medical examination of aliens regulations, 42CFR Part 34. This rule requires visitors to declare their HIV status and even possibly submit to serological testing before a Visitor's Visa will be granted. This action puts the United States in the company of such countries as Iraq and Cuba, which also have some restrictions upon visitor travel. No other country with the leadership stature of the United States has barred visitors from its shores based upon status of HIV exposure.

At this time the national hemophilia societies of the United Kingdom, Canada, Ireland and Greece have already stated they will not attend this international congress as long as the law and the regulation exist. The World Health Organization adopted the following resolution on May 13, 1988. It urged its member states, quote, "Particularly in devising and carrying out national programs for the prevention and control of HIV infection and AIDS to protect the human rights and dignity of HIV infected people and people with AIDS and of members of population groups, and to avoid discriminatory action against and stigmatization of them in the provision of services, employment and travel."

As we have already heard this morning, the WHO's Global Program on AIDS has stated on March 2, 1987 that, quote, "No screening program of international travelers can prevent the introduction and spread of HIV infection."

The WFH International Congress has served as the means to disseminate the latest and the best in comprehensive care. We may be forced to move this important tool used in directing global health care. It would be tragic if the land of liberty has policies which infringe upon the personal dignity, privacy and freedom of innocent victims of HIV infection.

I ask on behalf of all persons with hemophilia, and all persons who are victims of HIV infection, to use your influence upon the United States lawmakers to revise their action of August 1987. As Dr. Mann has stated, the U.S. is looked to by the rest of the world as a model. Infringement of the human dignities and the human rights that are facing us with this international body could in fact spread to policies around the world, and it would not be but shame that we would have that leadership role.

I thank you for your time today.

CHAIRMAN OSBORN: Thank you so much for bringing that important issue forward so clearly. I think your comments are most helpful.

Are there questions briefly from the commissioners? Mr. Goldman.

COMMISSIONER GOLDMAN: Mr. Carman, could you amplify a bit on--you mentioned the issues of social stigmatization--and would you amplify on that a little bit in terms of some of the different kinds of cultural and national responses and how that stigmatization manifests itself?

MR. CARMAN: The pattern of which I would answer that is extremely complex. There are some nations which in fact have considered and even used quarantines simply based upon the fact that the person has hemophilia and therefore hemophilia is associated with HIV virus and therefore families then are refraining from seeking medical care to provide for the care of hemophilia simply because to be designated as one with hemophilia would mean their son or father may in fact be put in detention areas or sanatoriums simply because of the statement of hemophilia.

In other parts of the world it revolves somewhat around the explaining of what AIDS consists of, and there is such an association with the disease that there is an attack emotionally upon the male image, the male ego, the male dignity in the eyes of that culture, particularly among some of the Latin American countries, and as a result there is a denial of hemophilia, an avoidance of care, because of the fear that that person is going to be stigmatized by having AIDS if he has hemophilia, and he does not wish to have that known among his peers.

In some parts of the world, there is immediate employment dismissal if one in any way may have hemophilia, not because of the hemophilia but because of the association with HIV. So the result is there is no one answer I can give you, but it really varies by language, by culture, and even by attitudes that are ill-founded and based upon ignorance or fear.

CHAIRMAN OSBORN: Are there any other

questions?

Thank you very much, Mr. Carman.

Excuse me. Don Des Jarlais.

COMMISSIONER DES JARLAIS: Mr. Carman, what is your sense of trends in the stigmatization? Is the situation getting worse, getting better, or perhaps people not caring as much any more?

MR. CARMAN: No, I think they are caring perhaps even more. This is one of the reasons that, as we look towards this international congress coming up next year, that there is a growing ground swell to boycott the conference, because there is such a ground swell that on an international level it is the era of stigmatization must stop, and that there must be a direct confrontation, that there is no risk of spreading of HIV because one has hemophilia, and not only that, there is no risk of spreading HIV regardless of whether one has hemophilia or is from the other risk groups because of casual contact. And so the hemophilia community is becoming, I'll use the phrase braver, around the world, becoming more socially responsible, is trying to carry its share to change the national norms, and as a result, is becoming far more public in its role to educate the public and at the same time to carry the responsibility to change the public opinion.

I think it is the right thing to do and I feel that among the WFH we feel very strongly that one must recognize that this disease is no respecter of groups and that all must stand together to educate the public to eradicate it, and it is with this type of an attitude that I see spreading among the hemophiliac community.

CHAIRMAN OSBORN: Susan Neeme.

MS. NEEME: What do you suggest that the government do to help expand safe treatment to hemophiliacs in the countries that currently are not able to provide the level of treatment that we have in the United States or in European countries?

MR. CARMAN: The first essential is that the access to blood component therapy not be denied, but that the materials which are used in that therapy must not be compromised in terms of the standards for donor screening, for testing, and therefore ultimate use by the patient.

Now even, of course, the collection process, whether it is from the volunteer sector, which is what is usually the case in developing countries, require a lot of attention towards donor selection, donor screening, and even testing that is a financial burden on many of these countries. So I would say what we depend on very heavily is direction and guidance from such organizations as the World Health Organization, the League of Red Cross, the national transfusion services and, to work in a very partnership fashion so as to encourage the governments in these less economically advantaged countries to not compromise the care based upon the minimal testing and the minimal screening. That can never be compromised in this era of the HIV virus.

CHAIRMAN OSBORN: Thank you very much. I hope that we can find a way to amplify the message that you present, and we certainly appreciate your efforts in joining us today.

Those of you who have served as government advisors before will know that we have great difficulty in the United States providing coffee to our consultants and committee members, and once again we have great difficulty doing that, so that as we take our break I will point out to you that there is a small cafeteria on the fifth floor. One must pay for one's coffee. The commissioners, the staff will try and help so that we are able to proceed promptly with a 10 minute break, but we'll take that break right now and then get to our next witness.

[Brief recess.]

CHAIRMAN OSBORN: Let's proceed. I know some people are still getting back, and the constraint on the coffee supply makes that understandable, but we need to move on.

We are changing gears sharply at this point. Although I think that the morning's testimony is wonderful food for thought as we turn to look at where we stand in the area of health care in the AIDS/HIV epidemic. I think we don't stand as well as we want to and I think this Commission is likely to need to devote a great deal of its energy and attention over a long series of meetings to the issues that will be introduced today. So that I hope no one has the uneasy feeling that maybe we are going to do health care today and move to something else later.

What the staff has done is to try and bring together a group of people who can frame for us an overview of very complicated problems and problems that are pervasive and by no means restricted to issues of AIDS. I have often commented that if we were very clever in what we did--using the pressure that this epidemic places on us--but if we were clever and not narrow in our thinking, we stand to be able to move the whole country's health agenda forward, or to help in that regard, and I think that that will become a very clear part of our considerations as we proceed today.

Normally I wouldn't do this to you, but I have recently written the latest version of a sort of general AIDS in the 1990s talk which I get asked to do a lot, and some of the people who had heard me give the introduction suggested it might be as good as any way to introduce this topic to you. So I will take your indulgence for just a few minutes to introduce it that way.

Reflection on disaster and human tragedy has become almost a national pastime in recent months. Indeed, it almost literally replaced the national pastime there for awhile. There have been hurricanes and floods, landslides, and a massive earthquake that we are told ominously is not yet the big one. In fact, we have absorbed a wearying litany of devastation and loss of property, dispossession and sudden homelessness.

The associated deaths have been tragic in their randomness, although it is worth noting that the loss of human life in the disasters has been significantly mitigated by advanced planning and often by early warnings. There have been occasional ghoulish vignettes of looting in the midst of chaos, but far more commonly there have been unforgettable displays of altruism and compassion, and there have been palpable pulses of national awareness that we are indeed one human family bound together by our frailty against the elements but empowered by a collective determination to survive in order to create anew.

As earthquake news from the Bay Area has come in, I have been uneasily aware of a depressing counterpoint as well. After all, this is San Francisco's second massive disaster, and the first one has been met with chilly silence. The unfolding of the AIDS epidemic tragedy has been far greater in scope and has been going on there for a decade now. Brave rescuers have been shouting for help, but in strange contrast to the scenes from Route 880, the cries of overwhelmed health care workers and trapped people living with AIDS have gone almost unheeded.

In response to the earthquake the national leadership declared their intention to do whatever it takes, but in response to the threatened collapse of the health care system in San Francisco, and for that matter in New York and Los Angeles and at least half a dozen major cities whose public hospitals are being flooded with sick young adults, we hear only about Gramm-Rudman.

This national paralysis in the face of the AIDS disaster is very puzzling to me. Is it because the awful numbers have climbed so tediously? Surely not, for their increment is no longer slow. More new diagnoses of AIDS are made each month in San Francisco than there were deaths in the entire region due to the earthquake. Is it because only lives, not property, are at stake? What a perverse idea. I hope not.

Is it because of who those AIDS people are? How could that be when we held our collective breath in empathy not knowing whether the waving arm and signs of life in a flattened car might belong to a philanthropist or a felon or, as it happened, a longshoreman.

Is it perhaps because we have failed to connect with what is happening? I think so, and to borrow from the language of the nursery, the eerie silence of our leadership has helped to foster a national game of pretend. To explain what I mean, let me remind those of you sufficiently grizzled to recall that many years ago during a particular mean-spirited political campaign one candidate proposed the image that one might saw off one or the other coasts of the United States and let it slide into the ocean, thereby dispensing with distasteful regional variation.

His fantasy seems almost to have taken hold belatedly. "It can't happen here, not in my back yard, it is happening only on the coasts," and people exempt themselves even from the duty to pay attention.

As the AIDS silence has grown ever more deafening I am reminded over and over of comments made by David Schoenbern in his autobiography as he reminisced about entering a freshly liberated concentration camp with General Patton at the close of World War II. He wondered at how people in the surrounding area could possibly have tolerated such bestiality in their midst, and concluded that it could only have happened because they dismissed it as happening to others. He then mused that only when men and women comprehend to the depths of their souls that there are no others will humanity be saved from its own extinction.

Those reflections are intended to be an introduction, but to finish them off, I want to point out to you that there are some uncertainties about earthquake forecasting that we don't have to deal with. We want to talk today and in the future about what we should be doing to brace ourselves for the full impact of the big one in health care that is sure to come in the 1990s.

With that, let me introduce first Dennis Andrulis, the National Association of Public Hospitals, National Public Health and Hospital Institute, and a very articulate and widely written expert on what is happening to our public hospitals.

Dennis, thank you so much for being with us.

STATEMENT OF DENNIS P. ANDRULIS, M.P.H., PH.D.

NATIONAL ASSOCIATION OF PUBLIC HOSPITALS

NATIONAL PUBLIC HEALTH AND HOSPITAL INSTITUTE

DR. ANDRULIS: Dr. Osborn, members of the Commission, thank you very much for the opportunity to speak before you today.

My name is Dennis Andrulis and I represent the National Public Health and Hospital Institute, for which I serve as president. The Institute is a relatively new research and education organization dedicated to the needs of the medically disenfranchised and the providers who treat and care for them.

Established in 1988 as the research and education arm of the National Association of Public Hospitals, the Institute has since undertaken projects involving both public and nonprofit institutions concerned with the safety net mission; that is, those hospitals located primarily in our major cities that treat large numbers of low income patients.

The primary work to date of the Institute has focused on AIDS provision and financing of care, hospital care in particular. The work has been supported by the Centers for Disease Control, the Robert Wood Johnson Foundation, and the National Center for Health Services Research. Details of the research itself are attached to the testimony and appeared in the Journal of the American Medical Association.

Today my remarks are intended to highlight the pressing problems faced by our health care system, and especially safety net hospitals which are attempting to meet the needs of those persons with HIV related diseases. Drawing on the results of our national study and individual hospitals' experiences, I will address three basic questions. First, who treats persons with AIDS? Second, how much does this care cost? And thirdly, who pays for that treatment? And finally I will offer some recommendations for change at the state, local and federal levels.

The first question, who treats AIDS patients? As the epidemic has unfolded there are basically two--roughly two--scenarios that could have occurred. One is you could have seen a scenario situation where hospitals throughout the nation, in our nation's cities, began to take on more and more of the load in a diffused way. In other words, throughout the health care system you could have seen more and more hospitals take on more and more patients. Therefore when you would look at the pattern of care you would see that diffusion. On the other hand, one of the other alternative scenarios is that you would actually see an increasing concentration of patients in a relatively few hospitals.

It has become clear as we end the first decade in which we have been coping with AIDS that the latter scenario has occurred. As a matter of fact, what we have found is that as few as 5 percent of the nation's institutions are treating as many as 50 percent of those suffering from AIDS. Areas such as New York City estimate that on any given day AIDS patients require 1,800 beds, enough to fill three large hospitals.

The consequences of this situation are very ominous for those providers, as well as our nation's health care system. Many of these institutions are major providers of emergency care, trauma care and specialty services. They are also grappling with the problems associated with care to low income populations as the epidemics of violence and drug abuse are affecting our cities. I think in one poignant example there is one hospital in New York City, Queens Hospital, that actually had an AIDS patient who a few years ago was free-basing on the unit and caught fire and proceeded to not only inflame himself, but also some other people, or hurt some other people on the unit.

Those kinds of problems weren't with us 10 or 15 years ago. It is now part of the system, and it is related not only to AIDS. That is a tragically bizarre example of AIDS and drug abuse crossing, and I think we are likely to see this criss-cross more frequently as time goes on.

The consequences in particular for the allocation of hospital beds, staff and equipment will obviously affect AIDS patients and non-AIDS patients alike, rich and poor. This has no social or financial barriers, this situation.

What does it cost to treat AIDS patients? Very simply put, AIDS treatment costs more than payor sources reimburse. On average hospitals incur about $700 a day for treating an AIDS patient, and about $18,000 per year. Revenues met on average about 80 percent of the costs. Our conservative estimate is that total inpatient costs for care approached about half a billion dollars, but this included only inpatient hospital care. No other costs outside that setting were included.

In the provision of AIDS care on average everyone loses. Hospitals' revenues are not meeting costs of treating AIDS patients. As a relative comparison, the average inpatient hospital loss per day for an AIDS patient was five times greater than the loss for non-AIDS inpatients.

Public hospital losses were slightly more than $200 per AIDS patient, and private hospitals were about half that amount. A closer analysis, however, reveals distinct regional variations. You have a situation where in the Northeast and the West private institutions lost more than their private hospital counterparts in the Midwest and South. In the Midwest and South you had public hospitals losing more than their counterparts in the Northeast and West.

Why? It appears directly related to the influence of state Medicaid programs. In the Northeast and West where Medicaid coverage tends to be more expansive, private institutions treated a greater proportion of low income patients, patients with AIDS, than private hospitals in other regions. In the Midwest and South where Medicaid coverage tends to be more restrictive, these low income people with AIDS were treated in public institutions, increasing the public's per patient per day losses.

But the per day losses tell only part of the story. When we examine losses by institutions and by volume of care, we find that due to the sheer numbers of patients seen in Northeast public institutions, for example, a volume of care that is dominated by children with AIDS, by drug using AIDS patients, the average public hospital lost over $600,000 per year. Private hospitals in that region did not escape either. They also lost on average about $200,000 per year.

In the South, where the public hospitals had the greatest proportion of non-Medicaid eligible low income patients, public hospitals also lost about $600,000 per institution. Their private hospital counterparts lost about $3,000.

In other words, when it comes to treating the medically disenfranchised AIDS population, there appear to be no economies of scale, the larger the proportion of low income patients, the greater losses for the institution.

Who pays for AIDS care? Differences in these hospital losses, as I mentioned, appear clearly related to Medicaid and who pays for care. Medicaid is the predominant payor, we found, and the evidence suggests that if a state has a supportive Medicaid program private hospitals appear more willing to treat large numbers of low income people with AIDS, absorbing their corresponding losses. For public hospitals, at least on a per day basis, a more expansive Medicaid program provides better coverage and lower per day losses than a restrictive program excluding individuals.

What I believe also exists in this country, there is a fantasy about Medicaid, and I think this comes through very strongly in the work that we have been conducting, the fantasy being that Medicaid covers most of the poor. Payments for services rendered to AIDS patients not covered by Medicaid--and as I pointed out here there are quite a large proportion--must be absorbed by the hospital paid through county and state charity.

Less than 20 percent of the persons with AIDS treated in southern hospitals were covered by Medicaid, compared with 55 percent in the Northeast and about 44 percent nationwide. Still, inpatient Medicaid coverage is not enough to prevent substantial losses for hospitals. In areas with expansive inpatient coverage under Medicaid, the lack of non-inpatient coverage, or the lack of inpatient alternatives, has created great financial strain on these facilities.

I would like to turn to Medicare for just a minute. The relative youth of those infected with HIV and current eligibility requirements prevent many people with AIDS from qualifying for another major provider of medical assistance, Medicare. The issue of Medicare, you may or may not have heard of the proposals to consider waiving the eligibility requirement regarding Medicare, but there is another side of the coin, and it is hospital sources of revenue related to Medicare.

You might consider the revenues from a hospital as a big pie, and when you consider the overall revenues of a hospital, on average let's say a teaching hospital, which many of these hospitals are, you find that there is a sizable chunk of that pie, a slice of that pie, that is related to Medicare. It is about 25 percent, as a matter of fact. When the question comes up for AIDS, AIDS patients, that slice of that pie is not there for Medicare. Okay. Well then, what is that slice of the pie? Is it more privately insured? Is it more Medicaid? Is it more some other group?

Well, evidence to date we have indicates that it is clearly not privately insured. It is clearly not privately insured for the public hospitals, and in general, it is not privately insured for the private hospitals as well. It is primarily Medicaid and indigent patients, and that is creating, again then, additional stress on the system.

For private payors, private insurance obviously plays a vital key role in support for AIDS care. Overall, about 30 percent of all patients have some private insurance, and in private hospitals nearly 50 percent of all AIDS patients have private coverage.

However, the prevailing thought is that you are not going to see increases in the privately insured, you are going to see more draw down on the public sector as you see a change in the population needing care that will include more IV drug users and children with AIDS, and the poor.

Finally, I can't ignore outpatient financing. While our information is more tenuous in this area, it appears that the situation for such care makes essentially inpatient coverage look like a road paved with gold. Outpatient per visit losses are much higher, especially for public institutions. As a result, there is little financial incentive to encourage expansion of outpatient services while non-hospital based service alternatives also remain severely limited.

I would like to turn now to my

recommendations and suggest that they fall into basically three categories--improving Medicaid eligibility and financing, encouraging community public and private sector participation, and targeting assistance.

For the first set of recommendations under Medicaid, the first one I would like to turn my attention to is the financing incentives encouraging providers to treat AIDS patients. I believe states with the most restrictive Medicaid programs should be at least encouraged if not moved toward requiring standards that would include populations deemed eligible by other states. It becomes just a clear situation when you look at what's happening with the states that do not have those more expansive Medicaid programs, and what that means for the greater number of indigents and the distribution of patients, themselves.

Specific changes might include allowing otherwise qualified individuals to apply their disability payments to their medical care costs so that they can qualify for Medicaid, the so-called spend down provision. Public and other safety net hospitals would benefit from such changes by providing greater financial incentives for other providers to accept low income people with AIDS by providing a critical source of financial support.

The general gist of what I got when I was looking at this information, and I have talked with other providers, is that hospitals, especially private hospitals, seem to be willing to take patients if they can get some reimbursement, will take more of the low income patients, but they are much more cautious to watch their bottom line if they are saying, well, these patients, they have no source of income, they are just total writeoffs for the most part, and so we hesitate very much to take many of these patients.

Another recommendation, keeping payment in step with costs. Medicaid reimbursement to providers must keep pace with the cost of care. There are several situations that are emerging now where although eligibility may remain broad, the actual reimbursement is becoming a mile wide and an inch deep, a major concern that the level of reimbursement be kept up.

Increasing Medicaid support for other health services is also critical. With regard to Medicaid, additional support should be granted for outpatient care. That's extremely important. And HCFA in particular, Health Care Financing Administration, might consider adjusting Medicaid payments for outpatient care to approximate more nearly the treatment costs. At the very least, this critical program should provide additional reimbursement to hospitals serving disproportionate numbers of low income AIDS patients in their outpatient departments.

With regard to alternative services and models, the federal and state governments must take a more active role in identifying and encouraging communities to adopt non-hospital focused services. However, before we even take that step it may be worthwhile to conduct a national assessment of outpatient service needs relative to the AIDS population since that is becoming a focal point, whether it be in the clinic or in the hospitals, especially as drug related care takes on increasing importance.

The issue of home and community based

waivers. I won't go into detail here on that, but that is a program that is an option available to states that could very well have a positive effect in moving patients or allowing patients to be served in the community, and there are barriers to that related to not spending more on outpatient or community based services under the waiver program than would be spent on their inpatient care, and then there are paperwork requirements. I believe it is worthwhile for the government to revisit those requirements and maybe relax them as we look at the alternatives that might be available.

The second recommendation is encouraging community public and private sector participation. AIDS has clearly become more than a bi-coastal phenomenon, affecting areas throughout the nation. As its effect expands, business citizens, government and other sectors of each affected community must participate in determining how the burden of care should be distributed more fairly and equitably, how to support needed services, how to encourage innovative alternatives, and how to encourage volunteer support programs.

Where necessary, communities must be willing to place pressure on providers reluctant to carry their fair share of the burden. There is an example in one city where some physicians in the community who treat AIDS patients, when it came time to admit their patients to the hospital where they had admitting privileges, the hospital said, no, I don't want these patients. And the physicians, in this case, said, wait a minute, if you don't take my AIDS patients, then you don't take any of my patients, I'll take my admitting privileges elsewhere. That's the kind of action that can actually serve in a very positive way to continue that distribution and then maybe destigmatize as well.

Dissemination of information about promising community based models remains crucial to these local level efforts. In this context, I would recommend expanding the existing federal role in providing such information. I would also support a required community level planning and monitoring role when local entities apply for assistance in developing model or demonstration programs.

Private insurers must also recognize their essential role and responsibility. Without their participation no approach relying solely on public support can succeed. To that extent, private payors should cooperate with state governments and vice versa to develop or modify continuation conversion insurance and high risk pool alternatives. For example, there have been some pilot programs and suggestions that the continuation conversion premiums of people with AIDS who have lost their jobs might be picked up by state or some state/private cooperative effort. To cap losses for private insurance we might also visit the issue of reinsurance.

My third recommendation is targeting assistance. In the short term targeted assistance to the most severely stressed providers may be essential if we are to avoid a breakdown in services. I am afraid what we may very well see is if you don't address the problems related to the hospitals most immediately affected, you may very well see a domino effect where it affects those hospitals, but other hospitals in other parts of the system will not escape the effect as well. Granting direct federal aid to hospitals treating the largest numbers of low income AIDS patients and incurring the greatest losses may be feasible for a limited number of these facilities.

Finally, I would also like to stress the ever changing nature of this epidemic and a situation that I believe calls for continued monitoring of access to services and coverage for drug treatment and other services. It requires continual reassessment of the situation, and I believe monitoring of these courses should include support for AIDS services and financing research. It should also promote the collaborative use of national studies and state and local research to assess the impact more accurately and to assist in the design of new models of care.

In closing, I believe it is time to recognize that AIDS is a mainstream issue. Efforts to inform and educate the public about the epidemic by distinguishing AIDS from other health care needs and issues were necessary to draw attention, public and otherwise, and actions to the lack of treatment and care for persons with AIDS. However, as the epidemic evolves and we search for ways to improve care it becomes more difficult to isolate people suffering from AIDS from other medically disenfranchised in the country. We must relate reforms made necessary by the advent of AIDS and HIV disease directly to the overall health care system and not to the disease, itself.

Thank you.

CHAIRMAN OSBORN: Thank you very much, Dennis, for a remarkably clear and succinct presentation of a complex problem.

Dr. Konigsberg?

COMMISSIONER KONIGSBERG: Yes, I have two or three questions, Dr. Andrulis. The first one would be, what is your definition, at least from your organization's perspective, of a public hospital? I have a reason for asking, obviously.

DR. ANDRULIS: Okay. We don't have a Webster's version dictionary of--

COMMISSIONER KONIGSBERG: A working definition will do, sir.

DR. ANDRULIS: It is a hospital that has a public mission, is publicly owned or operated, and most likely has public subsidies to support indigent care.

COMMISSIONER KONIGSBERG: Okay. As kind of a follow-up to that, I think we have seen--at least in the area that I used to be in in south Florida--a wide range of leadership and activities coming from hospitals that fit the broad definition of public. There are some very fine examples around the nation of leadership coming from public hospitals.

I was particularly interested in your recommendation that community based and outpatient service should be encouraged, and I guess I am pleased to hear that, because at least in my experience that has been a difficulty with some hospitals in not wanting to be, first of all, identified with the AIDS issue, and I would be curious as to what your reaction is there. And I recognize that there is a financial and business aspect that cannot be ignored here.

But is your organization now really in some very active ways encouraging public hospitals to work creatively and supportively with other entities in the community, be those community health centers, be those local health departments, that are taking leadership in developing networks of care with community based organizations? Because I think this is terribly important and has implications for really the entire public health care system, and particularly at the local level.

So I would be interested in your reaction to some of those comments.

DR. ANDRULIS: They don't need much encouragement from us. They are doing it on their own. As I have felt, and actually said before, necessity is the mother of invention. In this case, desperation is the mother of invention, they have to find alternatives. You have a very fine example in Florida of a collaborative effort to move toward a system approach. Jackson Memorial Hospital in Miami has established relations with non-hospital based providers in the community and is participating in the South Florida AIDS Network.

COMMISSIONER KONIGSBERG: Yes, I am very familiar with that, but that is not necessarily seen as the behavior of all public hospitals. I think that's probably one of the finest examples of what can be done. Are people beginning to pick up on that and look to that as a model?

It is not just a question of services provided, but a question of attitude and a question of leadership, and I think it is terribly important that public hospitals recognize that they have a problem out there and that in order to deal with that they have got to reach out to the community and interact in ways that they may not have had to in the past.

DR. ANDRULIS: Two comments on that. When you think of leading hospitals that have led the way, San Francisco General is a really good example of that. Many of our hospitals, many of the public hospitals, are participating in the Health Resources and Services Administration demonstration projects. They are very, very much interested and participating actively. They have to and they are getting out. Dallas' Parkland Hospital is very active.

And also, I just wanted to comment, these are issues that are related to more than just the public hospitals. These relate to the private hospitals that may find themselves in very similar situations. This is a broader issue that relates to those safety net institutions and the need for what I believe is for the other hospitals to persuade, if not place pressure on the other institutions that are less willing to participate.

We have examples of hospitals where they have accepted AIDS patients in their communities and tried to work with the community programs and then hospitals in surrounding areas who didn't want to treat the patients suddenly started sending the patients to them, what I have called de facto AIDS hospitals, they have become, said they didn't want these patients, but suddenly they have become the focus of attention.

They are under a lot of stress in that sense and they had to reach out and they are reaching out to find those alternatives.

COMMISSIONER DIAZ: I have a few questions related to the organization of care and also ways in which we could reduce costs. About the organization, I would look to ask you if you saw any appreciable differences in hospitals that were moving in the direction or already had established and dedicated AIDS units in contrast to those hospitals that do not?

Also, I did not hear you mention the focus or really the benefit of linking that hospital care to a community case management system of working individuals that have AIDS and their families throughout the whole range of services. And the other word I did not hear is a special emphasis or focus on the obligation or responsibility I feel that public hospitals have in serving the needs of racial and ethnic minorities, being that for many racial and ethnic minority groups the public hospital becomes the only choice.

And lastly, I did not hear you mention the work of the public hospital sector in terms of encouraging initiatives that deal with alternatives to hospitalization. In the part of the country that I come from that has been something that the community groups as well as most of us interested in health care delivery have tried, to push the public hospitals into a dialogue and partnership in the development of alternatives to hospitalization as a way of reducing costs.

DR. ANDRULIS: Well, you may have just

sketched the outline. If I come back to talk about services specifically, these are all good points that I would love to spend some additional time on. I can address them in order.

The AIDS unit issue. I have found that hospitals would be best to adapt to their own, allow themselves to adapt to their own situation rather than to say AIDS units are the way to go. I have not found any conclusive evidence so far as to say AIDS units are better than non-AIDS units. In some ways I believe they hold a value and promise in that they concentrate people who are interested, concerned, and focus the expertise. On the other hand, in many of these hospitals, and I think as the epidemic grows, you are just not going to have a unit that is big enough to include all the people with AIDS that are afflicted and are needing inpatient care.

Therefore, your units are much smaller than the actual census for any particular time in many of these institutions, and it is a situation I think is likely to grow. So I think the jury is still out. I think it may just be related to the specific situation so far. It is something--we collect information on AIDS units--and it is something that I would like to look at when I can carve that out a little bit more in detail.

Case management is again something we look at. We have actually asked in our study whether hospitals have case management programs, and if they do, what are they? Since most people, when they refer to case management, everybody says, well, okay, case management. Then they say, well, what is your case management?

Case management, I believe the concept, at least the way it related to organization of care and making sure that the individual is connected up with the elements of the health care system that they need to be connected up with, is an essential part. There is no question about the role of case management as being key, both in the hospital and outside the hospital. So that that is a key component of any program that would attempt to coordinate along a continuum of care the needs of AIDS patients.

With regard to public hospitals' racial and ethnic minorities, the population of AIDS patients in public hospitals in many ways mirrors the population of patients they serve in general. There are a large number of racial and ethnic minority patients that they serve. Their efforts to try to be sensitive to that population are almost in some ways for the public hospital, and I believe for many of the safety net institutions, almost a natural part of the programs that they would try to set up. That it is not to say you wouldn't have a wrinkle here and there, but it has become so inbred and a natural course of events that there is a natural sensitivity.

Many of these hospitals actually have language and translator services that are related specifically to these sub-parts of sub-populations, and it is something that they will continue to be sensitive to just by the nature of trying to fulfill the needs of populations that are predominantly racial and ethnic minorities in many cases.

Public hospital sector alternatives to hospitalization, as I mentioned, the public hospitals and the other hospitals we have talked with are desperately seeking these alternatives, participation, as I mentioned, in the Health Resources Services Administration, the Robert Wood Johnson demonstration programs, many of the public hospitals are participating in that. Some are using the San Francisco model. Others are in the process of trying to develop what are called community oriented primary care programs.

We are looking to try to tie into community health programs ourselves to try to see where we might link up in some way at the national level. The need, I believe, is so crucial to find those links. As I mentioned, by their nature, public and other safety net institutions are reaching out through models and through other mechanisms and through state cooperation where possible, and then, as I said, we are trying to do it as well at the national level.

CHAIRMAN OSBORN: Dr. Rogers.

COMMISSIONER ROGERS: Dr. Andrulis, you have eloquently described the plight of the public hospital. I think both Dr. Konigsberg, Ms. Diaz and I are each pushing you a bit on one part of this, and that is moving to the ambulatory sector. I think my concerns are that many of your initial recommendations are pay us more, we are starving to death, and with that I have complete sympathy. We have just studied this with some care in New York City and you are overcrowded, overstressed, understaffed, underpaid.

But it seems to me, one of the real contributions the public hospital sector could make is to say, look, we are not going at this the right way, we are an overbedded nation, we simply must, and with using this disease perhaps as a model, 90 percent of the care ought to be outside the hospital. We ought to have less beds, but we ought to have--and the funds should follow the patients, not simply preserve our hospital sector as such.

I know this a tricky tightrope to walk, but it seems to me in part the public hospitals would do a real service by saying, we are an overbedded nation and we need, in terms of the kinds of care needed by these patients, to develop a system that is out of hospital. You know the statistics. In New York City we are screaming for acute care beds, but one reason is we have an absolute scandalous lack of any kinds of long term care facilities, home facilities, residential units, any kind of care for these patients outside the hospital. So we persist in putting them in these enormously expensive units, screaming for more money to go to the public hospitals, which they desperately need, where I think it is the wrong system.

DR. ANDRULIS: Well, first of all, I don't mean to leave you with the impression that it is just simply give us more money. As a matter of fact, what I've tried to impress in here is that in areas like the Northeast the issue isn't necessarily a lot more money on the inpatient side for public hospitals or for other safety net institutions. I don't mean to focus specifically and solely on public hospitals with regard to this.

The issue in the Northeast I think dramatically states the problem of trying to find alternative places to put these people in a setting and in a system, to place these people in a setting and in a system that will allow them to receive the services. It is just simply not there. And even when it is there, there are priorities that other settings have. Many of these settings don't want to take AIDS patients. They are reluctant. They are afraid of what it means for the other patients they are going to be treating. They are afraid of the stigma. They are afraid of the service drain it is going to cost them.

So these hospitals are very, very willing to reach out to get the pressure. In fact, if you talk to some of these CEOs at some of these hospitals, they will say, we are very interested in participating in any system, but for God's sake don't make us the point, don't make us the pivot. We are an essential player, but get the pressure away from us, bring it out to the community. We'll be happy to participate, we are participating in many ways as it is. And it seems that what I am hearing from three members of the Commission is that they would like to know in what ways specifically they are participating, and I'll be happy to provide that information for you in detail.

CHAIRMAN OSBORN: Indeed, I think that we'll be wanting to get into very much greater detail about these issues. And as I mentioned at the beginning, today we wanted to introduce them and to give a rather broad view of how serious a set of problems we have. And I want to thank you, Dennis, for really having helped with that introduction to a very complex topic. I have a feeling we will pick on you again.

But in the interest of schedule, I think we had better move on now. And I think, with the forbearance of the commissioners, that we may skip the break that was scheduled for 11:30. I think those who need to can wander around a bit and come back, but in the meantime I think we want to take full advantage of the people who have been willing to come and meet with us.

The next pair of witnesses are Peter Brandon Bayer and Craig Kessler. I think they will introduce themselves as they address us, talking about treatment issues quite directly now. Thank you both very much for joining us.

STATEMENT OF PETER BRANDON BAYER, J.D., LL.M., M.A.
HEMOPHILIAC WITH HIV INFECTION, BALTIMORE, MARYLAND

MR. BAYER: Members of the Commission, I am very grateful and honored to have been asked to testify about AIDS and its effects. My testimony comes from personal experience as a hemophiliac who has tested positive for HIV, the virus which causes AIDS. I hope that my narrative of my experiences as an HIV infected individual will help the Commission understand more fully why the appropriate responses to AIDS are research to combat this affliction, adequate and fully available care for all affected persons, compassion for those suffering from AIDS and its related conditions, and steadfastness to protect AIDS sufferers from irrational and unfounded fears and prejudice.

What I want to do is tell you a little bit about what it was like growing up as a hemophiliac, what early treatment was like, how that all changed with the advent of the discovery of the anti-hemophiliac concentrate, the clotting factor, and what happened to my life and people in my position when that anti-hemophiliac factor became contaminated with the HIV virus.

Now, I am a 36 year old severe hemophiliac. I am lacking Factor VIII, which is a component of the blood which helps the blood to clot. I am called a severe hemophiliac because I have less than 1 percent of Factor VIII in my blood. The popular conception of hemophilia is that hemophiliacs suffer primarily from bleeding cuts and bruises, and of course they do, but for hemophiliacs like me, the most difficult problem has been internal hemorrhaging in the joints, organs and muscles.

I can recall vividly many times each month when I was young that I used to hemorrhage in my knees and ankles and elbows. Sometimes it came from a fall or a jolt, or sometimes from seemingly nothing at all. I missed a lot of school, and understandably I was extremely limited in what I could do physically. I couldn't attend gym classes, I never went to summer camp, and I was restricted in the way I could run and play with the other children. You can imagine as well, the hemophilia use very difficult for my parents and for my sister.

My parents had to make a very difficult choice about me, how to raise a hemophiliac son. I am happy to say that they cared for me with love and with courage. They taught me that I had to accept the limitations on my physical activity, but they never allowed me to become maudlin or cowardly. They even encouraged me to take a few chances, run the risk of a couple of hemorrhages now and then rather than have me grow up afraid and incapable of living an active life.

Now, when I was say around grade school age, treatment for hemophiliac's hemorrhaging was cumbersome and time consuming, There were many nights that my father would take me to the emergency room. For some reasons these bleeds seem to flare up at 3:00 in the morning when you are eight or nine years old.

After a brief examination by the doctor to confirm that I was hemorrhaging, the doctor would order what was then the accepted treatment, which was a pint of blood plasma for me. Now, blood plasma has to be kept frozen, so that means it had to be thawed, brought down to the emergency room. That usually took about an hour, no matter how fast the doctors and nurses tried to get the treatment going. Then after the transfusion apparatus was set up and the needle injected into me, I had to lie very still for a half hour, three quarters of an hour, while the plasma was administered drop by drop.

About 20 years ago this all changed. Science isolated the anti-hemophiliac factor, or what they call the clotting factor, from the blood. It changed everything. Hemophiliacs could suddenly lead a nearly normal life. Bleeds could be treated quickly. The risk of permanent damage was much reduced. Many hemophiliacs my age have some permanent joint damage from the scores of hemorrhages they have suffered over the years, but for younger hemophiliacs who have grown up being treated solely by the clotting factor, they are not walking with limps, many of them are able to fully extend their arms. Hemophiliacs, thanks to the clotting factor, have been able to lead the kind of lives and perform the kind of activities that they could only dream about when plasma was the treatment.

Certainly no one could have foreseen at that time that years later HIV would find its way into part of the blood supply, including the clotting factor which hemophiliacs rely on. But as I am sure you know, as I just mentioned, the clotting factor is pooled from blood from hundreds of donors. And it did become contaminated with HIV. Before it was isolated and expunged from the clotting factor, in December 1986 I, along with over 60 percent of other severe hemophiliacs, was diagnosed as a carrier of HIV.

Now, not surprisingly, this has had a difficult personal effect on my life, and it has been a great strain as well on my family and my friends. But I am much luckier than many others. Although I am HIV positive, I have not shown any AIDS symptoms or symptoms of other conditions related with AIDS. In fact, my latest T-4 test has been good and I have other indices of a fairly healthy immune system.

It is my hope and expectation that with proper medical supervision and a strong resolve I am not going to get sick. To the contrary, I am going to live to see this disease beaten. But HIV has transformed my life. Although I am optimistic about my health, as I am sure you can understand, I can't help wondering and worrying will I contract AIDS?

At 36 I have anticipated a full life ahead of me. I am an attorney and I have taught and written extensively about law and social issues. I have made many loyal and close friends. I have a loving family. I hope to marry and raise children someday. There are many things I would like to do and experience. There is a lot of good I feel I can gain from life. I hope as well that there is much good I can give in return.

I don't want to become sick, withering away slowly and finally dying. Of course, I share these sentiments with I guess most people. You don't have to be HIV positive to love life and living. But my contact with HIV presents a new reality where the possibility of death and illness is perhaps more acute and impending than it is for other people.

I mentioned I would like to marry and have a family. Now, these dreams are not impossible, but I have to face the stark reality that it is highly unlikely at this time that I can find a woman who is willing to run the considerable health risk of marrying somebody who is carrying HIV. And even if marriage is the possible, at present conceiving children also runs significant health risks.

Since I learned of my HIV infection, I have dated several women, women who I consider intelligent and good hearted. In each instance when the question of physical intimacy arose, it was, of course, my responsibility to tell them about my medical condition. I would do so even if--not to get too personal--even if I was contemplating a case. Now, I think kisses are probably almost certainly safe, but it can't be said absolutely without risk, and I don't feel that I have the right to make the decision that is so clearly risk free that the person I want to kiss shouldn't be informed.

In each instance, there were long discussions but the relationships ended. I can't accuse these women of insensitivity, callousness or ignorance. They took a lot of time to read the literature on AIDS. They went to their doctors. They talked about it, but they determined that the health risks were too great to become romantically involved.

I miss relationships and intimacy. I miss the prospect of marriage and children. Now, let me just clarify for the record, I am not saying that my social life was perfect before HIV. It wasn't. I shattered plenty of relationships, but I did it through my own actions, even if I chose to do wrong things. I would much rather return to the days when I ruined romances on my own terms.

It is no secret to this Commission that there are many other devastating effects because of AIDS and HIV. Now, again, I have been extremely fortunate. I haven't felt the economic burdens and social disruption that many people in my position have felt. While my prospects for marriage right now are limited, I have not lost the love and loyalty of my family an friends. To the contrary, every one of them without exception has rallied around me. But there are many people with AIDS who have been abandoned and shunned. I know HIV infected individuals who have kept their infections a secret for fear that parents and friends will abandon them. And I know of persons infected with AIDS who are afraid not for themselves but for their spouses and their children who might bear the brunt of unthinking discrimination.

Now, I have been fortunate as well that my HIV infection has not affected by work. I published an article in April in New York Times Magazine recounting my experiences growing up with hemophilia and as an HIV infected individual. My coworkers have read it, and I am lucky, again without exception they have shown support. They have come and asked me what they can do to help.

But we know that there are too many people who are not that lucky. Too many people have been fired because of AIDS or HIV infection, have been evicted from their apartments, have been otherwise victimized by senseless discrimination. Although they pose no danger to others, these AIDS patients suffer from the ignorant and unreasoning fear that still is too often associated with this disease.

In my New York Times Magazine piece I described AIDS as more than a disease. I said it was a sociological event. By this I mean that AIDS challenges not only our abilities as scientists and researchers, as important as those skills are. In addition, the advent of AIDS demands that our society draws from its full measure of compassion to overcome the ignorance and prejudice I have mentioned that I know you have all studied and are aware of.

I hope that this Commission will recommend that we as a society continue with heightened vitality to attack every facet of this disease. Specifically, I hope that the Commission will propose and support the following steps. Of course, to fund the necessary scientific research to find a vaccine, to prolong life, and eventually to cure this disease.

Second, to assure full medical treatment is available to every person who needs it. Third, to fortify and augment civil rights codes and other similar regulations and schemes to ensure that no victim of AIDS suffers from arbitrary discrimination.

And fourth, to promote educational programs so that facts about AIDS continues--as I think it is now--continues to replace ignorance.

Of course, I would have rather not have contracted HIV, and it would have been better if AIDS had never appeared at all to cause such misery. But we have no choice in that regard, AIDS is here and we are struck with it. We do, however, have every choice about how we will respond. My own experiences have compelled me to tolerate if not learn to appreciate the diversity of expression and attitudes in society which fashion and shape each of us as individuals. We have a singular opportunity to advance not only the cause of science, but the cause of humanity by responding to the AIDS crisis without fear or enmity. In this way when AIDS is only a memory we will be able to say that we did not simply survive, but prospered through our enhanced scientific knowledge and our growth as a compassionate society.

Thank you very much.

CHAIRMAN OSBORN: Thank you very much.

Dr. Kessler?

STATEMENT OF CRAIG KESSLER, M.D.

GEORGE WASHINGTON UNIVERSITY HOSPITAL, WASHINGTON, D.C.

NATIONAL HEMOPHILIA FOUNDATION, NEW YORK

DR. CRAIG KESSLER: Distinguished members of this Commission, I want to thank you very much for giving me the opportunity today to describe to you some perhaps different aspects of AIDS care. I certainly believe that I can't be any more eloquent than Mr. Bayer has been on describing the emotional and the physical plight of individuals who have contracted or who have been exposed to the HIV virus.

But today what I would like to do is to speak from my experience as the director of a hemophilia treatment center here in Washington, D.C. at George Washington Medical Center, as well as an associate medical director of the National Hemophilia Foundation, and also having the distinct honor of being Mr. Bayer's physician, to discuss with you some different medical aspects of how AIDS has affected the medical community as well as the patient community.

Mr. Bayer alluded to the fact that 60 to 70 percent of severe hemophilia patients are HIV sero positive. In the United States we have a population of between 15,000 to 20,000 hemophilia patients. It is very interesting that out of this 60 to 70 percent of severe hemophilia patients, that only 1,300 have gone on to develop frank clinical AIDS.

Now, I can't tell you today why that is. On one hand it is very encouraging, because perhaps the hemophilia patient handles the virus in a different way from other high risk populations. On the other hand, perhaps we are only seeing the pessimistic tip of the iceberg at this point and perhaps years down the road in time we are going to see a much greater proportion of our patients develop clinical AIDS.

With this context, I would like to remind you that the patients who have been exposed to the HIV virus by virtue of their hemophilia were obligate recipients of this virus. Essentially, their quality as well as their quantity of life depended on the fact that there was a blood product available for them to treat their bleeding episodes. And yet these medications that we as physicians prescribed for our patients with so much optimism that their quality and quantity of lives would be improved, turned out to be the actual transmitter of a deathly virus.

Now, there is some silver lining in this cloud, because as a direct response of our Factor VIII deficiency, Factor IX deficiency, and some von Willibrand Factor patients developing HIV sero positivity, higher purity and more viral free products have become available. And these products became available because of a direct result of industry's response to the plight of our patients.

I would like to believe that both the patients and their treaters pushed industry much faster than they would have normally been pushed into developing safer products. Nevertheless, I would like the report to you today that it is my belief that any patient born today with a Factor VIII or Factor IX deficiency problem, and perhaps even with von Willebrand's disease, should no longer run the risk of becoming HIV sero positive. And in fact, I would like to report that the incidence of hepatitis related to the transfusion of these products has been greatly diminished.

Nevertheless, we have a large number of adult hemophilia patients, as well as younger hemophilia patients, and very disturbingly, the sexual partners of hemophilia patients, who are now HIV sero positive and who do run the risk of future health problems.

Now, we have paid a financial price in the improvement of these clotting factors. Several years ago a hemophilia patient would receive clotting factor that would cost on the average approximately 10 cents a unit and use approximately 50,000 units of clotting factor a year. Now the cost of clotting factor has increased between six to eight fold, so that the $5,000 expense of a year's treatment for a hemophilia patient has now increased to at least $30,000. And this burden of cost is being born by third party reimbursers or by the patient, himself, and this is a very critical issue to our patients. Because now they have the capacity to prevent further exposure to these viruses, and yet it is quite clear from these prices that I have just presented to you that the cost of taking care of a hemophiliac over his lifetime is quite a lot greater than the cost of taking care of his HIV infection once he develops frank clinical HIV disease. This is a very major issue now and I believe that we need to begin to address very innovative ways of financing the cost of these medications for our patients.

Now, as a treater of hemophilia I would like to describe to you the way that hemophiliacs in this country receive their treatment. And that is through a system of Comprehensive Hemophilia Care Centers. We have been very fortunate in this regard because the Office of Maternal and Child Health over the past 14 years has provided funding for 10 federal regions, 25 grantees, and over a hundred other centers in the country to receive some degree of federal funding to provide nurse coordinator activities within these centers to provide specialized care to patients with hemophilia.

Unfortunately, we are now reaching only 50 percent, approximately, of the hemophilia population in the United States. This is critical. This concept is critical, because the comprehensive hemophilia care center provides an environment for teaching, both for patients and for other physicians and nurses. It provides an environment for state-of-the-art treatment. It provides an environment for psychosocial treatment. It provides an educational center to teach patients how to provide home therapy. Essentially, it allows the hemophilia patient to have their HIV disease as well as their hemophilia treated within the mainstream of medical care in this country.

We all know, as we have seen with AIDS care, that if AIDS patients, or if hemophilia patients with HIV infection, are warehoused, so to speak, that their medical care can only turn out to be poor. Comprehensive care can serve as a model for the rest of the high risk populations within the country. We have been very fortunate to develop this program, and I would like to just relate to you that on a recent survey of the data from Comprehensive Hemophilia Care Centers that comparing patients before 1975 prior to comprehensive care, and then comparing the patients in 1985, 10 years after the Comprehensive Care Centers had been functioning, that on the average there was a 390 percent increase in the number of patients receiving self-infusions on a home-care basis.

In addition, there was a 73 percent decrease in the average number of days per year lost from school or from work. In addition, there was an 88 percent decrease in the average hospital stay and admission days per year. There was an 83 percent decrease in the average number of days per year spent by each patient as an inpatient in a hospital. And, fortunately, there was a 77 percent decrease in out of pocket expenses per patient per year for their care. Essentially then, the overall cost of care per patient per year decreased by 74 percent over this 10 year period.

We have been very fortunate in hemophilia. We have a large number of problems, but I hope that this model may be extended to other high risk populations.

Now, just briefly completing this, I would like to indicate to you that Comprehensive Centers also take care of the sexual partners of the hemophilia patients, as well as their families. We provide a large amount of psychosocial care for our patients. I believe, again, that our model, although not perfect, can certainly be applied to the rest of the country.

The future of AIDS. We know that as the lifespan of HIV sero positive patients increases by virtue of medication and by virtue of close medical attention, that the cost is going to increase. We also know that this is a high prevalence disease and requires chronic care of their infectious problems as well as their psychosocial needs. I do again believe that the comprehensive care network can be useful in alleviating some of the problems that this society is going to be facing in the near future.

I want to bring up one personal note, too, and that is how HIV infection and the care of hemophilia patients has affected the physician and the nurses who take care of these patients. Now, I started out in hemophilia care now about 10 years ago, and I can tell you that I enthusiastically endorsed the use of clotting factors to improve the quality of life of my patients.

I have an extreme amount of guilt that the enthusiasm that I imparted to my patients may have created the tendency for some of my patients to become exposed to the HIV infection. Now, I can't dwell on this guilt, but I can tell you that every time I see my patients, it certainly does affect the way I approach their care, and I can tell you--and I know that you have heard this from other people who have testified before you--that there is a real risk of burnout on the part of the physicians and their nursing staffs. We see a very high turnover in our nursing staffs. We are beginning to see a very high turnover in the physician staffs taking care of hemophilia patients?

After all, this is a vital group of individuals in our society. They are all eloquent, articulate, productive members of society, and here everything that we have encouraged them to do to become successful is now backfiring. We have a major problem as treaters on how to take care of our own psyches as well as to maintain the psyches of our patients and their families.

In addition to that, new physicians are not going into AIDS treatment. They are avoiding hemophiliac care. They are avoiding anything that has to do with AIDS care. And I think that we as a nation need to begin to address these major issues.

And lastly, I would like to compliment the National Institutes of Allergy and Infectious Disease on their innovation in allowing the Hemophilia Comprehensive Care Centers to deliver innovative, modern, state of the art care of AIDS infections to the hemophilia population through the Comprehensive Hemophilia Care Network.

It is by this mechanism that we will eventually be able to allow our patients to receive the same high level of care and therapy that all other high risk populations are now able to receive. And also we will be able to extend this care to pediatric hemophilia patients as well as to spouses of our patients.

I think I will stop there and Mr. Bayer and I will be very happy to accept any questions.

CHAIRMAN OSBORN: If there are one or two questions I would be glad to entertain them. We are pressing our schedule a bit, but I am very grateful to both of you for your eloquent presentations and in adding some additional important dimensions to our discussion.

Dr. Des Jarlais?

COMMISSIONER DES JARLAIS: This is, I guess, to either of you. The problem of heterosexual transmission of HIV has been certainly acute in the hemophilia population. That may serve as a sort of test laboratory for what may need to be done for heterosexuals through the country, and particularly heterosexuals in areas of the country where HIV infection exists already in substantial numbers of heterosexuals.

Do you have a sense of what was learned from the experience among the hemophilia population in terms of moving rapidly toward preventing heterosexual transmission, either through safe sex or managing the relationship so that it does not have to lead to a complete disruption of relationships?

MR. BAYER: I'm not sure what you mean by What was learned. You mean just what hemophiliacs might be able to share with others?

I think that because of education we have been receiving about the nature of transmission of HIV and safer sex practices--I wish I could say it was safe sex, but safer sex practices--coupled with groups--groups of us sit and meet and discuss not only those aspects but the broader questions of what I mentioned earlier; what are our responsibilities as people who are carrying HIV to inform others, how can we talk with others with about this.

I think what was learned is the need for responsible and thoughtful sexual conduct. It is a little different for me being single than for a lot of my fellow hemophiliacs who are married and who have worked out with their spouses what to do. But for me at least it was recognizing the responsibility to tell people with whom I want to get involved, talking with them about the safer sex techniques and about AIDS and recognizing that this is a difficult situation.

I am afraid that's about the best I can tell you.

DR. CRAIG KESSLER: This is a very important question, because you are absolutely right, that the hemophilia heterosexual relationship has become a model for heterosexual spread of the disease.

I don't believe that in spite of all of the psychosocial efforts that we have attempted that we have been perfect in eliminating the sexual spread of the HIV disease to sexual partners. The reason I say that is the following. I think we have to look at this problem in two contexts. One is with the adolescent patient, and the other is with adult. I believe that we have really fallen short of getting through to the adolescent population. And even though we attempt to try to educate and we try to teach social responsibility, the adolescent has his own agenda, and I believe that we are going to have to formulate new and more innovative techniques to try to capture that segment of our population to make them understand how important sexual responsibility is.

As far as the adult population, there is some evidence now that we have been successful in decreasing the rate of HIV sero positivity to the sexual partners of our hemophilia patients. Unfortunately though, on the other hand, if you take a look at the fecundity rate of the hemophilia population over the last several years, it is actually higher than it has ever been. So that indicates to me that even though we are teaching our patients, or attempting to teach our patients, that there are a lot of other psychological denial mechanisms which we still have left to overcome, and I believe we are going to see the same situation with other heterosexual populations dealing with the spread into those populations.

CHAIRMAN OSBORN: Thank you very much. That is an important discussion that we'll have to pursue some more, but we really do appreciate your input.

Thanks so much for taking the time to join us.

We will move straight to the next panel. As I mentioned before, I think we will take advantage of the fact that there was a break on the schedule to skip it and move on directly to a panel including Dr. Mark Smith, Ralph Hernandez, Dr. Deborah Cotton and James Welch. I believe they will give you their introductions as they speak, and please join us.

I think in order to be quite sure that we get a chance to take advantage of each of the witness' special input, I will ask each of them in turn to present and then have questions at the end. I know that's a bit of inhibiting of free discussion, but I think it gives us the best chance to hear from everybody fully, and then what time remains we'll have questions, if that is all right with the commissioners.

Dr. Rogers?

COMMISSIONER ROGERS: June, let me make a suggestion here also. We are most privileged to have all of you here. I note we also have written testimony. I hope you will speak from your hearts, and fairly briefly. Obviously, we are going to read with some care your testimony. I would suggest where you feel comfortable doing so, don't read your testimony, we will read it, but tell us what you want us to hear.

CHAIRMAN OSBORN: Dr. Smith, I think on the order of listing here you go first, and thank you so much for being here.

STATEMENT OF MARK SMITH, M.D. - AIDS SERVICES
JOHNS HOPKINS UNIVERSITY SCHOOL OF MEDICINE
BALTIMORE, MARYLAND

DR. SMITH: Thank you very much. I will take advantage of Dr. Rogers' suggestion and depart, as they say, from my written testimony.

My name is Mark Smith. I'm a physician. I'm the Associate Director of the AIDS Service at Johns Hopkins Hospital. It is a pleasure to be here and an honor to be asked to talk to you.

What I would like to do is to talk about delivery of care, medical care to people who are underserved in this country. It is not by any means the only issue that is important in AIDS. It is not the only issue that you have to deal with. I won't even necessarily argue that it is the post important, but it is the one that I feel comfortable talking about, and you'll hear from lots of other people on others. So that's what I want to talk about.

In doing so, I would argue that there are four key areas that I would like to you to pay attention to as you examine this subject. And they are, first, provision of adequate trained medical personnel; two, better public awareness of the importance of treatment; three, expanded opportunities to participate in research; and four, a clear delineation of the roles of different levels of government.

Let me first tell you a little bit about me. In June-July of 1983 I was both blessed and cursed to be a member of a very special group, medical interns at San Francisco General Hospital, and I spent much of the next three years in the daytime and the nighttime taking care of people with AIDS on the inpatient service, in the outpatient clinics of that institution and other institutions affiliated with the University of California at San Francisco. I then moved to the University of Pennsylvania where among other things I took care of people at the hospital of the University of Pennsylvania, and I am now at Johns Hopkins.

In addition to my clinical activities, I have played a number of other roles. I was the Executive Director of the Philadelphia Commission on AIDS for a year and a half, and I now have responsibility for helping to staff, finance, organize and run a system of care at Johns Hopkins that includes an inpatient unit with 21 beds, an outpatient unit, nursing home capacity, et cetera, that takes care of over half the people with clinical AIDS in the Baltimore area.

Aside from those kind of doctor roles, I am a citizen And I am a friend and I've watched a lot of acquaintances and close friends, as well as patients, die of this disease. So that's where I speak from.

What I want to talk about is mainly from the vantage point of my responsibilities at Hopkins. If you will turn to the back of the testimony, there are four charts that pretty much tell you the story that I want to tell you about what we do.

The first one talks about inpatient admissions at Johns Hopkins. For fiscal years 1987, 1988 and 1989 you will see that there were 333, 454 and 648 inpatient admissions to the Johns Hopkins Hospital for AIDS. This is not admissions of people who are HIV positive, these are people who were admitted for HIV related illnesses.

The second page talks about the average

length of stay of those patients in the hospital, dropping from almost 15 days in 1987 to a little more than 11 days if fiscal year 1989, and that trend is also continuing. When you multiply those two together and add in a couple of other things you get the third chart, which is the average daily inpatient census at Johns Hopkins, which was in 1987 was 14 patients and at 1989 is 20 patients, and again, about at that rate.

Now, the increase in volume is something that you undoubtedly have seen and will continue to see in lots of institutions in the country. It reflects the growth of the epidemic. The decline in the length of stay in the hospital is we think significant because it says something about both the efficiency and, if you will, the aggressiveness of our outpatient services.

The last of the charts, the fourth one, shows you the number of outpatient visits that the Moore Clinic, the HIV clinic at Johns Hopkins has had. Going from a little over 2,000 in 1987 to almost 6,000 in fiscal year 1989, and we are estimating a little over 8,000 in calendar year 1989, or a little over 8,500 perhaps in fiscal year 1990.

In addition to the numbers of patients, we are now doing things that would have been unthinkable 10 years ago in an outpatient setting. We give transfusions, we do infusions of antibiotics, We do intravenous hydration. We do work up and therapy of pneumocystis carinii pneumonia. So there is a lot more going on in the outpatient setting, and the numbers do not really reflect the acuity, because we now have in our outpatient setting, as do most institutions that take care of large numbers of HIV infected patients, people who range all the way from being asymptomatic to people who are very, very ill, people who are there in wheelchairs. That's just the nature of the beast these days in outpatient HIV care.

And I think the institution is justifiably well known and well regarded for its expertise, but I have to tell you that our expertise has a down side. And the down side is that everybody looks to us to do it, and we can't do it all. I want to tell you about a patient I saw last week. This was a gentleman from the Eastern Shore of Maryland. He has an AIDS diagnosis, he has a history of some drug use, has a slightly unstable personality, can be a difficult fellow to get along with sometimes. He lives with his family, which has about had it in terms of trying to manage him, in a house that has no running water.

He was delivered to Hopkins for a medical problem which can and should be managed in his local community. He lives two and a half hours drive from Johns Hopkins. Now, Hopkins has become the de facto primary care provider for this man because of two gaps, a gap in medical services and a gap in social services.

That is not the fault of his caseworker. She is the one who drove him those two and a half hours. She works real hard. She does the best she can. It is not the fault of other individuals in the Maryland State AIDS Administration who have tried very hard and often creatively to solve these problems. It is the fault of a system that was not well prepared to meet this gentleman's needs before there was an AIDS epidemic, and certainly isn't prepared to meet them now.

So the State of Maryland has funded what we think is a very important new and innovative program.

It is called the diagnostic evaluation unit. It provides a medical and psychosocial assessment for people who are known to be HIV positive, and they are referred from all over the state. The vast majority are from Baltimore, because that is where most HIV positive folks are.

One of my responsibilities is to run the adult DEU which is located at Johns Hopkins. This program has been in effect for 10 months. In those 10 months we have seen 336 new patients, so we get about 34 new patients through the door each and every month. Of these new patients, 65 percent are black; 31 percent are white. Three of those patients, or less than 1 percent, are Hispanic, and seven on other or unknown. Twenty-seven percent of the new patients presenting to the DEU are women, 27 percent. And of those that we have T-4 counts on, that I am able to drag the data out of on fairly short notice, over 40 percent have T-4 counts less than 400.

So these are people who need medical intervention. So the picture I am trying to paint for you is of those who are newly presenting sero positive.

They are largely black, a much higher percentage women than I think is generally understood to be the case. A fair proportion of them have relatively advanced disease as measured by their T-4 counts, and their insurance status is about what you would expect, which is to say lousy. That is who we are seeing, that is who our new patients are.

In addition, a number of epidemiologic studies, such as the ALIVE study which David Vlahov at Johns Hopkins runs, are following hundreds of people who are known to be HIV positive with relatively low T-4 counts. We are now struggling with a way to try to these people into our medical care system, but frankly, we are overwhelmed, and it is going to be a long process.

So, what is the take-home message? First, we need more providers. We need more trained medical personnel. Dr. Cotton and I have made something of a reputation for defying the conventional wisdom, so I will defy the conventional wisdom. Because it has become almost trite to say that people should get their HIV from the primary care system. Well, the fact is these people don't have a primary care system. These are not people who have doctors. These are people who use the ER as their primary care system.

That's not, of course, universally true, and stereotypes in AIDS, as in anything else, can be dangerous. But the fact of the matter is that many of the newly diagnosed patients, newly diagnosed as sero positive or newly diagnosed with AIDS, it is not helpful to suggest that they depend on the primary care system for their care because there is none for them.

Similarly, I am aware that Hopkins has a lot of research money that we use, frankly--please don't tell our granting agencies this--but that we use to subsidize the clinical care, and I guarantee that any institution that is doing a first rate job of taking care of people in 1989 is using research money in some ways, with those economies, to take care of people. We are very concerned about what's going to happen when some of those research projects run out, as they surely will.

So, how do we provide more providers? One, we think we need to train more mid-levels. At San

Francisco General, at Johns Hopkins, many of the providers who provide the bulk of our care are nurse practitioners and physicians assistants. They do a better job than many physicians, perhaps most physicians, in providing primary care, an our care would be impossible without them.

So one answer to the question of how do you get more physicians is, well, you don't need necessarily more physicians, you need more trained mid-levels as well as more physicians.

Secondly, we think it is vitally important to do ongoing education of physicians and mid-levels. This field changes very rapidly and education is an important thing. As you know, HRSA has a system of centers to train physicians in HIV care. Our view is that that system should be evaluated very closely for the extent to which it actually is turning out more physicians prepared and competent to take care of people, and the extent to which that system is or is not closely linked to state and local health departments, we think better assessment of the need for providers.

Third is specialized regional centers for intake, assessment and consultation. That's in fact what Hopkins has become, and we think that it is worthy of investigation, the formal establishment of such specialized centers. Maryland has made that decision. New Jersey has made that decision, New York and California have made that decision, and we think it is worth looking at that as a formal program.

Fourth, the National Health Service Corps, which ought to be employed to deploy physicians in areas of high need. If not the corps, some corps like mechanism that might defray the training expenses of physicians. And fifth, incentives to physicians and other providers. I have to say here that in examining why it is we don't have enough doctors and other providers to take care of people, it again has become almost trite to talk about racism and homophobia.

Make no mistake, racism and homophobia play a role, but it is simplistic and we think not helpful to attribute the entire problem, or perhaps even a majority of the problem, to that. There are, we think, problems for providers in taking care of these patients with which we can be more sympathetic. I have mentioned the educational needs. Another one is the reimbursement. Reimbursement is lousy, and in our experience it is not helpful for government officials to pontificate about the responsibility of physicians to care for people when those same government officials are not particularly forthcoming with adequate compensation for them to do so.

In Maryland, for instance, a physician is reimbursed a nursing home visit $10.50, so now, it doesn't make sense to me for someone to say this is what we are going to pay you to take care of people in nursing homes, people who are often as sick or sicker than people we expect to find in acute care hospitals, and then say, we will not compensate you for it.

So the problem of delivering more adequately trained personnel is a multifactorial problem. It will require a variety of solutions. Not all will be the right one for a given place and a given time, but it is, we think, the most urgent and pressing problem.

Second, campaign to stress delivery of information to underserved populations about the fact that therapy is available. There is a well organized, well informed body of people with HIV infection in this country who have performed yoe-person service in making therapies more quickly and widely available, but they are not, for the most part, from low income minority communities and we see lots of folks who have delayed too long coming to a doctor because they don't know about AL-721 and Compound Q and Compound R and DDI. That is not something that is a current of conversation in those communities, so we have to let people know that therapy is available.

Third, expanded opportunities to participate in research. I'll be the first to say that our institution, like most institutions that are doing research, see a wide discrepancy between those people with AIDS and those people who have access to the latest therapies. We are not much better than anybody else in that regard, and we struggle with that every day. The recently announced program by NIAID for community based clinical trials is an important development, but I have to tell you that we are a traditional institution, and our traditional institution needs those same nontraditional services to get poor people women into trials that a community health center or a substance abuse clinic needs. Research organizations are not used to paying for daycare as part of a research trial. Well, they better get used to it. Not only do neighborhood health centers, but to the Hopkinses and the Harvards of the world too, because that's how people are going to be able to be in trials.

And fourth, and perhaps most important, if this Commission can have one lasting impact on the epidemic, in my personal view, it is to try to delineate the roles and responsibilities of different levels of government. I have worked in this epidemic in a couple of different states and cities now. There are some bright spots and there are some very, very distressing spots. My own city, Baltimore, to the best of my knowledge, spends not one red cent of its own money on any aspect of AIDS. And in my experience, different levels of government play chicken with this disease.

The city government says, we got to look to the state government to fund this. The state government says, we got to look to Washington to fund this. Washington says, this is a state and local problem. And so while everybody is pointing a finger at somebody else to do this, no one has really taken charge of delineating a strategy. It is tragic that there still is none. In my view, particularly an financing and organizational questions, this Commission has a vital role to play in trying to establish some idea of who is responsible here. Because I got to tell you, I have a son, I want good schools for my son. I want police protection. I want the potholes to be filled. I want the homeless to be housed. But I also want people with AIDS to be taken care of, and I think people have to consider that one of the legitimate responsibilities of local and state government and federal government, just like all the others.

I want to close with an anecdote. I was interviewed several days ago--more than that--by a reporter, and talking about this question of the need for someone to take charge of kind of what levels of government are going to provide for this care, are going to pay for it, are going to organize it. And I said, you know, I really think the cities--this is a problem of this city, this city has to pay more attention. And this reporter said, well, where is the money going to come from?

And frankly, I got mad. I said, that's not my job. I mean, where is the money going to come from for police or fire. I am not an expert in city finance. This a need that--this is not my problem, it is the city's problem. I didn't create this. I am trying to help deal with it.

So I think it is often the case that those people who are dealing with this newest of these large social problems and find themselves on the end of the queue, are greeted with the question, how are we going to pay for this, as if it is somehow our responsibility to figure that out because the Defense Department and Superfund and the police and fire services are already in line.

Frankly, I think it is the responsibility of this Commission to try to delineate that it is not our responsibility to deal with it, it is the society's responsibility to deal with it, and in particular, what are reasonable roles for the levels of government that exists to actually serve these needs. Because the needs are not going to get smaller, they are going to get greater.

Thank you, that's what I wanted to say.

CHAIRMAN OSBORN: Thank you very much, Dr. Smith. That is a most helpful input and we will take your suggestions very seriously.

I think Mr. Hernandez is next.

STATEMENT OF RALPH HERNANDEZ

PERSON LIVING WITH AIDS

MR. HERNANDEZ: Good afternoon. My name is Hernandez. I am going to read here my testimony, really what I have been through to--well, that's why I am still here, because of the little bit of help that I have got up to now. So I am going to read this. After this if you want to make any questions, I have a couple of things that I would like to say after this anyway. Thank you.

My name is Ralph Hernandez. I am a Vietnam vet. I am homeless and I am living with AIDS. When I went to Nam the government told me I was putting my life at risk for my country. I believed what they told me. And because I believed what they told me I became disabled and finally I got AIDS. Now that I am sick my country doesn't want to do anything for me.

This is in Spanish. Does anybody--I don't think it is necessary for the moment.

So here I was dying. I had sores all over my body so deep that I could touch my bone. My clothes stuck to my skin. No matter how many showers a took I stunk because my skin was rottening. And they told me just do stop shooting. I went to the Washington Heights shelter. When I took my clothes off in the shower, the other homeless people just kicked the living shit out of me. Then they called the guards and the guards threw me out. I went to another shelter, but I was afraid to stay there, so I started living in the tunnels of Grand Central Station. Even there I had to hide so no one would see the condition I was in.

Once * went to the Belleview Hospital in New York City. They asked me if I had any Medicaid. When they found out I didn't have any Medicaid they didn't want to help me. The nurse said, oh, your sores don't look that bad, I've seen worse. My legs hurt so bad I couldn't walk without the crutches I had stolen, but they didn't even clean my sores, they just gave me a antibiotics and put me out on the street to clean them myself. Now, I am going to keep my sores clean when I was living in the subway ditch? You know; how are they going to stay? Dirty.

A month on so later I went to Mount Sinai, another hospital. This time I realized that I was being turned away because I was homeless. So I lied. I told them I lost my Medicaid card. Then they gave me a bed, but after a week they said they have--leave me because I went through the system and they found out that I didn't have no Medicaid.

So they said, you got to go home, which was the street. Then they had to get me clothes because the old clothes have been stuck to my skin and it was all infected. So there I was, I was back in the subway system. After the Coalition for the Homeless found me in the Grand Central Station, the city did not want to help me because they said they didn't have any evidence of my illness. The VA has lost my papers. I have been tested there for AIDS three times, but because I am homeless they have lost all my records each time. Because of a lawsuit, the city finally put me in a room in a hotel that is really a shooting gallery. That was all what they wanted to help me at the moment with. That's all they gave me, too.

One day last May I went to the methadone clinic. When I said I didn't have any Medicaid they wouldn't accept me, so I went to another clinic and I lied to them. Since they thought I had a Medicaid, they looked at my sores and everything and said, okay. They medicated me then. They gave me emergency medication right away. For six months I have been in a methadone program. Now I try not to use drugs anymore, but the VA is not giving me any medical treatment yet. I still go there. They put me up like for let's say next month or month before in the Infectious Disease Department, I think that is what they call it. But still, I am still waiting.

People like me who are fighting drugs and AIDS need special help. On Friday I missed my program. I was too sick to stand up. My knees didn't have strength enough, so I missed my pickup. By Sunday I was detoxing. I called all over the emergency rooms. They wouldn't help me. Even I called an 800 number, a drug hotline. They couldn't do anything for me, so I had to shoot up. Methadone is a strong addiction. I think it is the strongest addiction in the world. To shoot up enough dope so you won't feel sick, you got to at least do $150, close to it, or $200.

So that night all night I kept on shooting and shooting. Well, I ended up selling and getting rid of things that took me months to have since I been getting help from the welfare. All of that, I just lost it in one night. So, I don't know. So what I believe is that we should get some emergency basis, some system or something for a person not just with AIDS, a person that is in a methadone program has an accident or gets arrested or his mother gets sick and he misses a program, right? Let's say you are under his pickup. What is that person going to do over the weekend? I mean, where is he going to go? what is he going to do? He is on methadone. He has to get help somewhere.

Well, there is no place to go in New York, because I tried. And I did it with legal assistance, and we didn't find nowhere, not in the 800 numbers.

We drug users need a program for people with HIV that can help people on an emergency basis. Every time we fuck up we are putting ourselves and other people on risk, so we need extra help. We need emergency methadone pickup for when we are sick, but we also need programs to get us off methadone. The purpose should be to give emergency assistance and then to make you not drug dependent.

methadone deteriorates your body. AIDS makes you tired. Methadone makes you wasted, so you can't do anything. To fight AIDS, you should be drug free. I want to be drug free, but there is nothing out there for me. I wish there was.

The welfare hotel is supposed to be an emergency only, but the city has no one to help you find an apartment, so they just leave you there. When you find an apartment on your own, you have to bring a signed lease to the case worker and wait weeks for a check. Who is going to give a lease to a homeless person with AIDS who doesn't have any money? I finally found an apartment in the Bronx, but I had to lie to the lady and make up an illness. I told her my spine was injured, and I told her a check will be issued in three days.

Then I called her before I was approved and told her it was approved and the check will come in the next week. The next week Charles King from the Coalition for the Homeless lied for me and said the building there where they cut the checks had asbestos. After three weeks I finally got my check, only they forgot to put on my furniture allowance. Where am I going to sleep, in the floor?

Two weeks later, last Friday, I got that. So this week I am no longer homeless, not because anyone helped me, but because I beat the system, just like I beat the system with the hospitals and the drug program, by lying.

Now I can move when I find a methadone program where I live. Until then I have a room on Park Avenue and an apartment in the Bronx. The city is wasting its money on things that don't help me, but it won't give me any of the things I need to live a normal life. I wish you knew how I feel when I go in the subway and I see people move away from me. It is a fucked up feeling. I served my country in time of crises. Now that I am in crises, where is my country?

I am not the only one that has this experience? There are thousands of homeless men and women with AIDS struggling to survive, not just in New York but in every city and every state. Like me, they have no place to turn to.

We are tired of being beaten up by other homeless people. I am talking about here, shelters. That's what ends up happening, and that's what happened to me and that's what happens to all of us. We are tired of being beaten up by other homeless people who think they can protect themselves from AIDS by hurting us. We are tired of not being allowed in shelters, of having to hide our illnesses to get into them, and we are tired of being treated like dogs when they find out we are sick. We are tired of living in the streets and dirty hotels. We demand housing for people with AIDS now. We demand adequate services for homeless people with AIDS now. We demand medical care and treatment for homeless people with AIDS now. We demand the right the live our lives with dignity, and we are turning our anger into direct action. Act up, fight back, fight AIDS.

So what I seen, when you go to--when anybody goes to any place to get help and you are sick, in the condition I was, I was with crutches, I had holes, I was a drug user. You know, I was destroyed completely.

I go to this welfare office. They asked me for a birth certificate. They say they have to check to see if I qualify to get some help. I'm homeless, no papers. I don't have nothing. Well, I don't know, I can't help you right now because that's another department there, they make the check, we don't have the power. The worker doesn't have the power. I have to see if they are going to approve you a check so we can get you some place to sleep. We have to check if we can approve you money to see if you can eat.

Here I am in pain, I'm sick, sores, an addict, I'm patient, waiting. You know, I am sick, I want my methadone, no Medicaid. How long you got to wait for a Medicaid card? The worker ain't going to give me the Medicaid card at the moment.

I'm there sick. I'm an addict with AIDS right there. There is nothing. I wish there was somehow some system or something, because this is just a dream. There is no such thing as help. There is nothing. Whoever goes out there right now with AIDS and an addict, to go and look for help in any government agency of the United States of America, is just alone, homeless, you ain't going to get it. You won't. And that's in New York City, a city like that. You just sit there. You are going to get impatient. You are going to stand up and leave. You going to go out there and mug somebody to get money to support your habit, keep on passing the infection to others.

I mean, there is no outreach program. They don't go out there and help and get the people. The system, I don't know. There is not even system for me. I'm living it. There is nothing. They issue a check for housing, after I go through all this, without giving me any money for a bed. Where am I going to sleep? In the bed? Because I was homeless the workers decides she is going to give me a check for rent for an apartment. You are homeless, you slept before in the floor so you sleep now in the apartment on the floor, right? I mean, that is the way I saw it.

Because what, are you going to give somebody a check without giving them the check of the furniture. Just because I am homeless, I mean, that's the way they treat us? That's the way they treated me, and that's the way they are treating all of us. I mean, I don't know what you people can do, but there is nothing out there. It is like nothing. There is nothing. Any person homeless right now with AIDS is just nobody and nobody wants to help us. And I got legal assistance behind me, I got everybody because they insisted and they chased me and they have been grabbing me to take me through the system, you understand, and still I got to struggle. And all of this is true. This is not a lie.

Even the VA throwing away my papers, and that's a federal agency. I mean, that's that. Just imagine the city or the state. I mean, I don't know. I wish--you can ask any questions. I am capable of answering them because I've been through it and I know I will answer it truthfully and with all my knowledge that I have up to now.

CHAIRMAN OSBORN: Thank you very much, Mr. Hernandez. I don't know what we can do either, but I think you have helped us to understand some of the very difficult problems that you have been facing and I hope there will be time for questions toward the end.

MR. HERNANDEZ: Not just me, the others.

There's a lot of people there. Each twelve--we figured out, each twelve and a half minutes somebody dies of AIDS. And the minutes--right here I have been spending already 20 minutes maybe, so there's two or three gone right now and I am still--you know, you got to do something. I hope God helps us or something. Somebody here on the Commission, somebody does something for us, because somebody has to. You know, I don't know when or what.

CHAIRMAN OSBORN: Thank you. let me go on to Dr. Cotton, and Mr. Welch, and then I hope there will be a bit of chance a little bit later. Thank you very much for your time.

Dr. Cotton?

STATEMENT OF DEBORAH COTTON, M.D., M.P.H.

BETH ISRAEL HOSPITAL, BOSTON, MASSACHUSETTS

DR. COTTON: Thank you. It is always difficult to follow the very powerful testimony of a person with AIDS. It is also always very difficult to follow Mark Smith as a speaker. I get this task very often. I think I am going to start demanding that I go on before him on some of these things.

As a matter of fact, my own personal idea of how we are going to solve the physician crisis in AIDS is that we are going to get some very smart basic scientist to figure can out a way to clone Mark Smith and then we'll be all set.

My name is Deborah Cotton. I am an infectious diseases physician. I am the clinical director for AIDS at the Beth Israel Hospital in Boston, which is one of the teaching hospitals of the Harvard Medical School, and I welcome the opportunity to come and speak with you today.

I am going to take Dr. Rogers' kind invitation to depart from my testimony somewhat. I would like to talk a little bit about what is in it, and then I would like to talk a little bit about a subject that isn't covered very well in it, and that's the care of women and children with AIDS.

I think that this is a particularly opportune time for the committee to start to address the issue of medical care of HIV infected people. We have seen in the last year some real progress in the treatment of this disease. We have learned that we can use the measurement of CD-4 cell number as a very sensitive way of predicting for us who among HIV infected people is at highest risk of developing AIDS in the short term.

We have also found in a large clinical trial that giving AZT to these high risk people delays progression to AIDS. In addition, in another trial, we have found that prophylaxing, that is, giving in advance the drug aerosolized pentamidine can reduce the number of case of pneumocystis pneumonia among such patients, and pneumocystis pneumonia is one of the leaders causes of death in AIDS.

We have come now this year to start to view AIDS as the terminal aspect of HIV infection, which is a chronic, progressive disease in which we believe that early intervention will make a difference. In the coming years we anticipate that we are going to see more drugs and, in fact, combinations of drugs, to treat this virus and to treat the many complications of the virus. And we are clearly excited by this progress, invigorated by this progress, and very hopeful that we are going to make more progress in the short term.

Given all this, it is really ironic that at this very hopeful time those of us who care for AIDS patients are becoming painfully aware that we do not have manpower or the resources to deliver this kind of state-of-the-art therapy to people we know would benefit from it. This is true in areas like San Francisco and New York, but it is becoming increasingly true in cities like Boston, in cities all of the country.

We know that there are too few laboratories in this country to do CD-4 testing and that we don't know what kind of quality we will get in the testing that is done. We know that many hospitals even today do not provide aerosolized pentamidine for their patients, including, I might point out, some of the major academic hospitals of this country. We know that some of those hospitals actually avoid AIDS care altogether. And perhaps most disturbingly, we know that the majority of American physicians do not yet know about these advances and in fact have no access to programs that could teach them about these advances.

So what I would like to convey to you today is that I think our science is outstripping our health care delivery, and that we are really going to be seeing a gap in what we could achieve and in fact what we are achieving. And I think the way that we can deal with this is to start thinking about managing this epidemic, about the medical care of this epidemic, in the same way that I manage an individual patient with HIV infection.

Now, to do this we are going to have to acknowledge several things. First, that the natural history of this disease is such, with a very long incubation period, that for years--I would predict for my lifetime--we will be seeing more and more patients with end-stage HIV infection. So we are going to have a crisis situation, an epidemic situation, for as long as I care to look into the future.

Secondly, we have to realize that the shape of the epidemic is indeed changing and that systems that we have created for insured, largely middle class gay and bisexual men are not necessarily going to work for women and their children and IV drug users. And finally, we have to realize that the price of our progress is that we can't always predict where the next area of progress will be. So we may invest a lot of time and energy in trying to address ways to deliver care for pneumocystis pneumonia and then have a basic advance in the treatment of another complication, like cerebral toxoplasmosis. So we have to really accept that uncertainty as we start to design systems of care.

Now, I want to expand a little bit on what Mark spoke about in terms of physician need. What kind of health care workers do we need? And I think that he outlined well our need for a variety of different health care workers. But taking into account what I have just said about some of the progress that we have seen, I think in fact that we do need AIDS specialists.

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

Now, I am an infectious diseases physician. I have been boarded in infectious diseases for many years and for many years my clinical specialty has been infectious diseases of the immuno suppressed host--cancer patients and transplant patients initially, and then when AIDS came along, AIDS patients as well. I spend really my full time taking care of AIDS patients and doing research in AIDS,. It is difficult for me to keep up with all the advances in this disease and to incorporate those advances into my practice.

So I do not believe any longer that we can expect every primary care physician in this country to deliver all of the care that we are going to need to give to people with HIV. I think they can deliver care for asymptomatics, for people with what we used to call ARC, and for early stages of AIDS, but I think we have got to have AIDS specialists.

Now, we can educate primary care physicians. I think we have to do that very quickly in a very massive way. This year, next year, I would propose that we have use of every single resource we have in terms of information transfer, that we have more continuing medical education courses, more of the programs, or an extension of the programs, such as HRSA has been conducting. But in addition, I think we have to get pretty sophisticated, and pretty quickly.

We need to use the radio and television stations that specialize in medical programming. We have to use teleconferencing. We have to achieve a certain level of understanding of this disease among primary care physicians in this country in very short order.

In terms of training AIDS specialists, I think we need to take people from a variety of backgrounds. A variety of people can be trained to become AIDS specialists. To avoid burnout, most of us feel that those people should not exclusively do AIDS, but should continue to do the other part of their training, be they pulmonary doctors or infectious disease doctors. But clearly with the changing shape of this epidemic we need to train more pediatricians, more obstetrician gynecologists, more neurologists, more psychiatrists in HIV infection so that they are a resource for their colleagues and for people in other specialties.

I think that we really have to address quickly the need for an AIDS curriculum in medical schools. My own feeling--and I haven't studied this in a rigorous way--is that there is a tremendous variation in what our medical students are being taught about HIV. I think that we would do better to efficiently have a uniform, transportable kind of curriculum that we could offer to schools throughout the country.

Now, just as we have been saying that every physician should care for AIDS patients, for many years we have been saying that we need to diffuse AIDS care across all hospital settings. I believe that there is now quite a bit to argue against this approach. First, there has been some recent research that survival among people with pneumocystis pneumonia indeed is better in hospitals that have more experience. I can attest as an AIDS researcher to the fact that the protocols that we are developing for care for drug therapy are becoming extremely sophisticated, are often requiring intravenous administration and some degree of medical supervision.

So that I think as we see that kind of sophisticated approach give to more and more people with HIV infection, we are going to have to have a care that is very, very high tech and I believe that we really have to look carefully and quickly at the option of regional AIDS centers.

I would like to emphasize that I don't mean by this merely inpatient care. I would envision this center to be very site specific, for example in New England, that it would take into account the fact that we have patients in Vermont and Maine who during the winter months cannot get to us, that we have physicians who would like to work in partnership with us in those areas in delivering state of the art care, but we have to do it with a lot of knowledge about local need and local expertise.

I think that there are many critics of this approach. I don't mean to minimize the complexity of the issue. It may be that it isn't a viable approach and we'll need alternatives, but I think we really need to think about it and discuss it very openly, very quickly, right now.

Now, we know that this epidemic has widened to include the inner city poor. Mr. Hernandez has given a very eloquent testimony to the experience of a person who has been an IVDU and dealing with this epidemic.

I would like to speak briefly about women with this disease and children with this disease, because I think many of us, including many of us in this room who have worked long and hard on AIDS, have not heard a lot from or about women with this disease. I am part of a study that is being launched by NICHD and NIAID to try study the course of this infection in women in four cities in the United States--three cities in mainland U.S. and San Juan--to try to look at how this disease impacts on pregnancy, how pregnancy impacts on the disease, and on the natural the history of this disease in children.

We know precious little about AIDS in women from a strictly medical point of view. We have no cohort studies, until this one, of a large number of women to try to see if the clinical predictors in women are the same, if their survival is different, whether pregnancy has a negative, or even a positive impact on how they do with the disease. We need that kind of data desperately.

In addition, fewer than 5 percent of the participants in clinical trials have been women. As the epidemic moves to include women, this means that we are going to test drugs in a population that is not female. We do not know whether our results, certainly in terms of toxicities, will be transportable to women.

To get women into trials, as Dr. Smith has outlined, requires viewing clinical trials in a wholly different way. We cannot expect a woman to participate in a clinical trial when she is worried about her children at home with no babysitter, when she has brought a child with her to clinic and she has had to wait four hours and she is out of diapers and she is out of formula. We cannot expect that we will not need a very high degree of social support, not only to care for women in trials, but to care for women in general.

In addition, there is a huge debate I think around women with HIV infection. I think, tragically, women with this infection have been focused on in terms of who they infect rather than on them, themselves. We have heard a lot about transmission to children, transmission to men. We need to focus on women, focus on prevention efforts that are female specific, looking at ways not only to technically use a condom, but for women, how you get a man to use the condemn, negotiation skills to do that.

These are very, very difficult issues. I don't wish to minimize them, but I think that we aren't paying any attention to them and I would urge the Commission to address the problem of women with AIDS as a very important and separate topic. We have a separate epidemic in women and it is separate and not equal.

In addition, we know now that children with HIV infection clearly survive longer than we originally thought. There was a view of AIDS in children that it was a disease of infants, that these infants died quickly. This is simply not the case. Tragically, some infants do die very quickly, but we know that we have asymptomatic children and children with mild degrees of immune impairment reaching school age now. We have to start to address the very difficult issues of how we raise these children, potentially into adolescence, and even to adulthood, in an asymptomatic state.

Finally, I would like to say that I think we are also in the country on the brink of a real revolution in American medicine, and it is a revolution that is really borne of crisis. We know that health care costs are escalating out of control. We know that they are escalating out of control to the point that it may even affect our ability to compete economically with other nations. We cannot afford to condition to introduce diagnostic technologies and therapies without a rigorous assessment of their benefit and their costs.

So I think there will be a growing emphasis on clinical effectiveness evaluation in the years to come. I can't think of a better model for trying to look at these issues than AIDS, because AIDS is an epidemic every therapy that we develop, every technology that we introduce magnifies because of the number of people that it is given to, and it magnifies in an atmosphere where we have scarce resources. So I think this is a really an excellent model for trying to look at these issues. We have spent almost $2 billion on AIDS care. Just investing a small percent of that in looking at the clinical effectiveness of what we do would pay great dividends and also, I believe, would be applicable to other diseases.

So finally, as an AIDS physician, I would like to just reiterate my hope that the therapeutic advances we have witnessed this year will spur the creation of a national, nationwide plan for AIDS care, and it is also my personal hope that physicians will be at the center of this movement. Physicians have, unfortunately, not been on the front lines of this epidemic. They have too often been on the sidelines, and sadly this has been largely their own choice.

Thank you.

CHAIRMAN OSBORN: Thank you very much, Dr. Cotton. I think I can comment parenthetically that those of you who have admired some of the style of the Institute of Medicine report of 1986 concerning AIDS will recognize some of that eloquence you have just been hearing. I think Deborah had a great deal to do with that, and not everybody here knows that, if you don't mind my mentioning it.

Next I would like to hear from Mr. Welch, and I hope you will introduce yourself fully.

STATEMENT OF JAMES C. WELCH, R.N.

AIDS PROGRAM OFFICE, DIVISION OF PUBLIC HEALTH

STATE OF DELAWARE

MR. WELCH: Thank you. I am Jim Welch. I am the AIDS Program Director for the State of Delaware for the past five years and have been a CBO volunteer of our local AIDS service organization, Delaware Lesbian and Gay Health Advocates for the past 10 years.

One of the things that is interesting to see is that there seems to be a theme that is running through a lot of our discussion this morning, and it just doesn't have to do with the care but where the care is going and where that financing is coming from. I think you all know, and in the statement I talked about how the American Nurses' Association and nurses have been on the forefront. I am proud to say that as a nurse many of us have taken it upon ourselves to get involved and stay involved with AIDS since the beginning, and I think we need to try to push all sectors of the health care community to continue to do that.

One of the problems that we see is that care for HIV infected persons is fragmented and complex and the existing health care system is very inadequate to assess and, for those people who are poor, to access that health care system.

One of the things that I really think is important is for us to provide for basic primary health care for those persons that are HIV infected. One of the things that we deal with in Delaware--which for those of you who I hope understand it is a state, I sometimes say I am from Delaware and they say what county or what state is that in, and even though it is on the East coast there are people here in Washington who forget that it is a state--but we are a very rural state and the problem that we have is the same that some of you have seen. We have one medical center in the north end of the state who accepts most of our care of people with AIDS, and two physicians in the southern end of the state who we refer in our office all of our HIV infected persons to. Ten out of the 12 of those persons in this physician's care are unable to pay, and part of that--most of that is because we are very rural and some of those people are working in the chicken farms and some of them are migrant farmers or seasonal farm workers who go up and down the East Coast.

So the problem with that physician is that she's donating a great percent of her care, and so she calls very regularly for us to make sure that we can help pay for some of the drugs that that person with AIDS and is HIV infected needs.

One of the problems that we have gotten into very much during the past month is that, as you all know, the AZT money has--the federal AZT money has run out and we are scrambling to try to fund as quickly as we can from the state perspective AZT for people who can't afford it. And I think Ralph talked very eloquently about if you don't have a Medicaid card you can't get care, and if you are homeless you can't get a Medicaid card if you don't have an address. So we see that very much in the State of Delaware where you have certain systems you must go through and if you don't follow the protocol, then you are lost within that system.

I think that everyone here has talked about a continuum of care and case management models where we try to look--and I think, Dr. Rogers, your question as to trying to move toward outpatient services is very important. Nursing has jumped in and gotten very, very involved in outpatient care. And I think this is, in my opinion, where we need to start really putting a lot of emphasis. Community based organizations are out there and have been working with those outpatient facilities. We have our local CBO that is working with hospice and with the public health nurses that are out there doing home-based care. But the problem is how to fund that care.

The nurse needs to have--you know, some of us have another job and we volunteer our time, but other ones can't raise--as single parent mothers--their children, if they are nurses, without some way to pay for their child care, especially. So that we are able to go out and treat people in the home, but there is no compensation for that and the Medicaid reimbursement system, as an earlier speaker talked about, is at best a little different and at worst, totally different and horrendous when we try to get some care in some of the states that have various types of Medicaid and Medicare reimbursement.

The other important thing that we really need to look at I feel is this piece of pie that we are all struggling to try to grab as it seems we are moving toward a chronic illness model. And yet I still believe we are in crisis and will be at least for 5 to 10 years, and as we try to say, well, we need to move toward chronic illness, that doesn't stop that we are in crisis and you have to alleviate that crisis first because you can then go to chronic illness.

So that we are asking our community based organizations, physicians and other people, to fight for a piece of the smaller pie, even though people are saying, well, there is larger financing. But now there are larger organizations and more people that we have to service, and as we look at that, we are telling our organizations out there that have spent a lot of volunteer time and money, well, I am sorry, we can't give you any more. And we have 10 CBOs that we have been funding for the past four years in Delaware and now the problem is we have about 10 other ones we would like to fund and yet our CDC funds are drying up. THey are not increasing the way they have.

HRSA has come up with some very innovative type of service and treatment plans, and I think that's one area where if this Commission can ask to put some dollars is in that area. But also not to forget those CBOs that are out there that have been waging the good fight. Many of them know where it is and what's happening and what's going on, and instead reinventing the wheel and putting money where people don't understand where the money should go, that's an issue.

Also, AIDS I think people are starting to understand, and HIV infection is no longer an urban issue. In Delaware our largest city is 85,000 and our smallest is around 20 to 30. And in some of our smallest areas we have not just an HIV epidemic, but an IV drug use epidemic and a sexually transmitted disease epidemic. And trying to get the information to persons whose first thought may not be their health but where they are beginning to get their next meal; or where their child is going to get their next meal, is very difficult. And so for those of us who may want to talk to someone about prevention and the best way to practice safer sex, it is very difficult when that is not their first priority. And then how can we make it their first priority if we are not willing to spend the dollars to help them just to live every day.

I think that NORA and the leadership that NORA has posed is very important, and I think that all the nursing associations that I represent and nurses throughout the country feel that this Commission is a step toward the solution, and I think we pledge our continued support as you deliberate and ask more of us to come and testify and talk about what is important to us and to the clients that we serve.

And I thank you for inviting me. This is not usual for a small state and a person from a small area. I really appreciate it.

CHAIRMAN OSBORN: Thank you very much, Mr. Welch. Your testimony was very large and important to us and we really appreciate your coming.

I think we do have a bit of time now for questions. I am delighted about that.

Eunice, do you want to start off? Eunice Diaz.

COMMISSIONER DIAZ: I have a question for Dr. Smith and I have a question for Dr. Cotton.

I hope I didn't hear you say that we ought to be focusing on creating more regional DEUs and forget creating the broader points of access, particularly for minorities, that are not generally going to go to academic centers or larger hospitals, or have problems in accessing care at a larger facility.

Both of you stressed the importance of building up a cadre of very trained, expert individuals in clinical centers, and I have no quarrel with that, but I did not hear either of you expand the concept of creating greater access points such as NIAID is doing right now with the community clinical trials experiment, if we may call it that, of bringing into partnership physicians, clinics and ambulatory facilities scattered throughout communities where more people can have access to care. So I would like you to comment on that.

And then, I don't think I heard either of you--particularly Dr. Cotton--stress that within this country the HIV epidemic in women and children is concentrated overwhelmingly in the Latino and black community. I have not heard that acknowledged once, and therefore it seems to me that the service delivery, the approach, the investigation, research, and the advocacy has got to be done within those communities, and I would like to hear your comments about that.

DR. SMITH: Well, on the first point, I think I agree with you, but I have to have a caveat here. I am certainly not advocating that the access be at big medical centers or academic centers, and I am not necessarily advocating that there are specialized regional centers that they necessarily need to be academic sites.

My point is this, I think part of developing and maintaining a disseminated community based system of primary care is in fact the creation of reference and consultation centers that people can feel confident can back them up. So I first don't think those things are at all mutually exclusive. I guess my problem, my fear is that I have heard for the last two years people say that so much, and it is not happening, and the question is, why isn't it happening?

It is not happening, I think, first because we haven't taken into account what the real problems are for having that done. I'll give you an example. It is has become trite to say neighborhood health centers should take care of HIV disease. Well, let's look at how many neighborhood health centers have physicians who are interested in the care of acutely ill patients. All right. Docs chose to practice in one setting or another. That is not to say that there aren't excellent, competent physicians in neighborhood health centers, but there are reasons why people have chosen that practice setting as opposed to others. And frankly, my has been to that many neighborhood health centers are not well set up to take care of people whose intensity of disease and whose volatility of disease is as these patients are.

So it is one thing to say neighborhood health centers should do this. It is another thing to say we are going to provide the funds and the infrastructure, the restructuring, if you will, in a sense, of neighborhood health centers to be able to do it, because I think there is a reason why they have not done it more. It is not just exhorting them to do it.

Similarly, I think if I look at the patients that we discussed this morning before I came up here who are new patients seen in the DEU, I can say to the private black physicians in Baltimore, you should take this patient. But I know that private black and Latino physicians are much more likely than others to be in solo or small group practice. They don't generally have social workers and phlebotomists and respiratory therapists in their office. They are not for the most part well set up in terms of ancillary and social support services, and they can't afford to subsidize the care of people who are uninsured because many of them are on the margin financially as it is.

So all I am saying is, I agree with the idea of having access where it is most convenient. We are now in the process of arranging DEU services in STD clinics, in the offices of district health centers and others. But I have also seen a phenomenon in the last few months that troubles me deeply, and that is well meaning people in local health departments and others who because of their grasp of the need are now gearing up to try to provide care for people, and I think maybe doing so overambitiously.

So that's all I am saying. I am saying it is one thing to say that the care needs to be disseminated in the community but every time I hear that I want to ask people who advocate that, are they also talking about trying to solve the very real obstacles to providing that? Because the reason people are concentrated at the Beth Israels and the Belleviews of this world is not by accident, there are some real structural reasons for it, and we have got to do more than just say go to your neighborhood health center, or call up some private doc and say take care of these patients, I'll send you a newsletter, I'll get you a teleconference. That he is not going to get it.

COMMISSIONER DIAZ: I guess my point was more in the direction of assessment and the counseling that individuals need to look at whether or not they need to be referred on to another facility.

DR. SMITH: Well, that's my point. I think there is good precedent in other branches of medicine for regionalized assessment and then re-referral back to a primary care system where that regional center can serve as a consultative backup. That is what we are struggling to do in Maryland right now, not entirely successfully.

The main reason we are having problems is because there is no place to refer them back to. It is not that we wouldn't want to. When I go through the patients we talked about this morning, if I had some place to send them, please believe me, I surely would. But we know they are going to wind up in our system. It just doesn't exist.

DR. COTTON: I would just like to reiterate what Mark said. It is true, certainly in my own city, that the care of HIV infected patients is almost exclusively in our city in academic hospitals, our public hospital. Boston City Hospital is a full teaching hospital of Boston University School of Medicine. And so we really have felt in our own city that although care has diffused out, it has diffused out solely among the academic--and major academic--institutions.

And I think that point that you raised about what sorts of care would be appropriate in community settings is absolutely essential. As I mentioned, I do think that we can deliver care up to a certain point in the community. I think that people with AIDS could be managed in regional centers with a full partnership with those community settings. And the model that I think is timely here is the hemophilia center that we heard about this morning, that we have sort of a tertiary system but that it feeds back into primary and secondary systems as well.

So I think we are all for it. We are extremely enthusiastic about the community research initiative and the whole parallel track concept of getting drugs that may be beneficial out more broadly to people. But we have to have the infrastructure to really be able to do that, and I don't want us to give lip service to this concept and then have it fail. And that's what I fear could happen if we don't really address the issue of physician education and we don't really face the fact that we are talking about a disease in which people are very, very sick and that as we develop better drugs, in essence they will become sicker. They will live longer sicker. It is the price of our progress, much as we saw in cancer.

To address your second question, your point about my lack of discussion of my minority women, women of color, Hispanic women in this epidemic. I apologize. I think it is so striking that I almost assume that everyone knows that, and I understand now that people do not.

In fact, we know that in general HIV infection disproportionately infects and affects people of color. But this is magnified among women. Black women have about 11 times as much AIDS as white women. I don't recall the exact figure for Hispanic women, but I believe it is seven or eight times as much infection as white women.

In addition, we see that the epidemic varies among women by ethnic original by age. For example, among white women with AIDS, fully 25 percent have been over the age of 40, 10 percent over the age of 65. Among black and Hispanic women too, there is a relatively large percentage of women who are over 40. This means that if we target our prevention and testing programs to prenatal clinics--which is what we are doing--and sexually transmitted disease clinics, we are going to miss a lot of women.

There are a lot of stereotypes about the women who are infected with this virus that simply are not true, and we must look at women in not a monolithic way here in terms of how we try to deal with their disease.

In terms of caring for women with AIDS, clearly the women who are coming from communities of color are far more likely not to have primary providers and have no access to primary providers and to be facing a range of social issues in which their HIV infection is the last on the list. First comes getting for themselves and for their children. Second would come getting medical care for their children who are HIV infected. Third would be with worrying about those children, and the children this in their family who are not infected, in terms of what will happen to them when the mother dies.

And I can tell you that most women I have seen with AIDS almost immediately have as number one priority what is going to happen to these children. And this is a source of tremendous psychological stress because it is not easy to help them with those issues.

So again, I am very grateful for the opportunity to depart from my comments to talk about women and children, but I think this is an area that I would hope the Commission would focus on in an extremely intensive way.

CHAIRMAN OSBORN: Scott?

COMMISSIONER ALLEN: I have a question for Ralph.

Could you go into some discussion on what type of education you have received on the street, a little about bleach, a little about cleaning the works, what kind of environment that is. What have you seen personally in education?

MR. HERNANDEZ: Okay. I am not going to say what I have seen, but what I have lived. I was working--this is just a brief, short story. I worked in the telephone company. I left ITT Caribbean in 1980 and I came over again to my home, New York. Okay.

I don't have no record of stealing. I'm

afraid of stealing or hurting anybody. So I opened up a shooting gallery in 110 and Lexington, okay. And I had that gallery for five years. Okay. And we just rinsed them out with water, and I am talking about hundreds of works in a box. Okay.

And I had that gallery there for five years, and that was all we did, rinsed them out with water. And I'm talking about 1981 to '85. And then after that my last gallery was in 105th and the middle of First Avenue and Second. I left that one three years ago. It is still there.

And there I was about three years more, and usually the addict--not even now, that incident that I have a week ago about missing my program and having to go an shoot up, when I went back to the gallery I had, they are still not using no chlorox. They know it. The outreach been out there giving out little baggies with chlorox on it and instructions of use. And the people just don't care. They just don't care.

You see, because if I got my coca and I invite you to get off, you are sick, you are an addict. I mean, you are not going to go and say, wait a minute, I am not going to do it because I got to go and get chlorox. You are sick. It is a habit. I mean, you got pain, you got this. You don't go through the system of waiting and going to the store and get 50 cents to get chlorox. I mean, that is the way people think, your know, or dreaming, because the people on the street don't do that. That's baloney.

COMMISSIONER ALLEN: But is it available?

MR. HERNANDEZ: Not no more, no. That was an outreach that came out three years ago, and that's it. Everybody forgot about it. It is not no more.

COMMISSIONER ALLEN: When it was available was it utilized?

MR. HERNANDEZ: Yes, well it was, yes. Because it was very handy, but that's stopped. There is no more. Either they don't want to give any money on it or whatever, but I haven't seen that in years.

CHAIRMAN OSBORN: Thank you. Don Goldman.

COMMISSIONER GOLDMAN: I was wondering--and you may not be able to answer this question right now, and if not I would certainly appreciate it if you would be kind enough to do so at some time in the future, if that would be at all possible.

I know that in developing and planning the comprehensive hemophilia care system, and I know the audience, Dr. McPherson from the maternal and child health program who was instrumental in together with that. We spent an awful lot of time developing an thinking very clearly as to flow charts, as to exactly where services were going to be provided, as to what kind of services were necessary at what level, what kind of patient populations were necessary to support, from a fiscal point of view, the pooling of services at each level, and how that whole thing ought to be structured and communicated.

And I am wondering whether or not you have done the same kind of thing on that kind of detailed level, determining the necessary patient populations and the mix of patients and the types of professionals that are going to be required at each level of care, ranging down from the community up to the tertiary research center, and in a very carefully defined manner of flow charting patients through that.

And I was wondering if you have done that in your communities and if you could share that with us in some way. And I realize you could spend all day on that subject, and I was wondering if you might comment on it, both of you, perhaps.

DR. COTTON: Sure. I can comment to some degree on Boston. I, myself, have not--I think we have talked, many of us informally, about it, but I think we would need certainly to do this with people who are not among our group, are not physicians, clearly with people who have a fiscal understanding of some of the constraints. We would certainly have to be working in partnership with our public health people.

We don't have, as far as I know, in my own state even an estimate for the number of people who have fewer than 500 CD-4 cells. Some states have been very proactive about this. New Jersey is certainly the model that comes to mind, and already since the developments in therapeutics this summer quickly assessing how many people would be out there who would be eligible for some of these therapies and starting, at least beginning to try to see how they could actually provide that care in the near term.

That hasn't happened in my own state. I think the reasons for that are complex and are largely, or at least partially, due to the fact that we have a real fiscal crisis in our state right now, and I think that what I would not want to convey today is that I think that the answer is simple or obviously a kind of uniform center, region to region.

But I think that it would be wise for us to do exactly what you did in setting up the hemophilia programs, and before we reject regional centers, to do that kind of analysis. What I hear now usually is just an out and out rejection of the concept when as far as I can tell that analysis hasn't been done.

DR. SMITH: First, it is not my job to do that. It is the public health department's job or--I try to run a clinic. I'm trying to take care of people. I think though that's something that we try to do to some extent in Philadelphia. I would be glad to make the report of the Philadelphia commission available. It is something that has been done by the New York City task force, which was an interdepartmental task force, and I have seen reports from Dallas and Chicago and a number of other cities in attempting to do that.

But let me tell you what the problem is. The problem is that no one really wants to do that because in doing so you create the expectation that you are going to then actually implement it. And I can tell you that every indication I have is that the Baltimore health department--I mean, they don't have the money to do any of this. So in a sense it is a waste of time.

That's what I meant when I said that some sense of the responsibilities of different levels of government is what is urgently needed. I agree with Deborah, New Jersey has, to my mind, been a leader in that. I have a little conflict of interest in saying so, but I think they have done about as good a job as you can do from the state level, but the fact is that our knowledge of the demographics, our ability to predict the therapies, their effectiveness, their cost is probably substantially less than it was in planning the hemophilia centers, and that's part of why I think people have a little reluctance in investing a lot in that process, is because you are hitting a moving target.

I know that HRSA has funded a private company, research outfit, to do the development of a microcomputer based planning model for at least out of hospital services, which is in part an effort to do that in a way that is interactive, that as you get more information about the numbers infected or what their T-4 counts are, you can then plug into a prebuilt model how to do that.

But in the case of AIDS, I think there is such a large set of social, non-acute medical services that will really determine what you need and are able to do medically, that it is important to get people from a variety of disciplines and backgrounds involved in that plan. I think it very much needs to be done. My own sense is it is probably the responsibility of state health departments to coordinate that planning process with lots of input from hospital people, physicians, community based organizations and others. That's my own thought.

COMMISSIONER GOLDMAN: But don't you have an idea from your own experience as to how many nurses, or how many social workers or for how many patients you in fact need? I mean, if you have to do some planning and say, gee, if my patient population is going to go up, you know, 200 patients, then that means I'm going to--I mean, are you going to need one more social worker, two more, three more? How many more nurses? How many respiratory therapists?

I mean, I don't think it is fair to say that you as a physician don't have say role to play in that whole process. I think you have the most vital role to play.

DR. SMITH: I have been criticized for the opposite tendency, if anything. So no, I think I have a role to play. What I am saying is, I have the ability to do that for my own system. I can tell you how many rooms I am going to need for "X" numbers of patients. But I also understand that my system is configured very differently from that of a private physician, and there are a couple of private physicians who take care of a fair number of people ion Baltimore.

So what I am saying is I can do that for my system. If anybody wants to know, I will give it to them. But I can't do that for Dr. Westric or Dr. Branson or a district health center. That's why I said someone who has a larger set of responsibilities has to be in the position of coordinating that. I have throughout my career participated in that and would be glad to do so, but no one is really coming forward to do that kind of work right now.

CHAIRMAN OSBORN: Dr. Konigsberg. And let me suggest that we are going to have to curtail our discussion pretty soon or we are going to be completely out of sync.

COMMISSIONER KONIGSBERG: Yes, I'll be very brief.

I am currently a state health official, but before that was a local health official, and I think that the comment that state health departments, and I would also add local health departments, need to be at the forefront of coordinating the system, at least I think is very valid.

I was kind of interested in the concept of raising expectations that can't be funded. I believe that may be appropriate to do. It is a form of advocacy. It is a dangerous game. I have personally played it and you can get yourself in some real trouble in raising those expectations. But by golly, somebody has got to do it. Sometimes you attract funds that way and other times you attract lots of flack, but I wanted to kind of reinforce that point.

I think that Dr. Smith and Dr. Cotton have raised an interesting point, too, about the system of health care that is going to be needed. I am trying to decide how this fits into Kansas, which is where I am currently, but Kansas is a little bit like Delaware, sometimes people don't know where we are, but unlike Delaware, it is a huge state, and how we get care to a person with symptomatic HIV disease in Atwood, Kansas is something that may be quite different than how we do it in areas near the urban centers. But I think all the speakers were excellent and raised some good points.

CHAIRMAN OSBORN: Yes, and I think * can speak for the commissioners in saying that we were quite frustrated not to be able to spend much longer with each of you, because you have really contributed a lot of food for thought.

I think since the time is so short I want to say, particularly to Mr. Welch, I want to assure you that we will be wanting to hear a great deal more from the very critical nursing profession in terms of the role that is going to be asked of them and that they will play uniquely as we develop some of these systems of better organized care. So I thank you for having initiated that discussion, but I want to assure you that that's by no means the end of it.

Thank all of you very much for your time, and very great help to the Commission. We are going to break now. I hope we are going to be able to be on schedule at 2:00 to come back. This will make it harder on the audience than it does on the commissioners because the commissioners will stay in the second floor area here for a working lunch arrangement. But I think there is a deli and a Chinese restaurant across the street, as well as some other options not too far away, and we will try and reconvene as close to 2:00 as we can. Thank you all for your attention.

[Luncheon recess.]

- - -

AFTERNOON SESSION

2:10 p.m.

CHAIRMAN OSBORN: I want to get us started again if I can.

We have a very good afternoon's additional input from some important witnesses, and I am very pleased to welcome our first panel, Theodore Hammett, Nancy Dubler and Elizabeth Barton. I hope you will tell us about yourselves as you start, instead of my taking your time to make the introduction, and then have you do that as well. Welcome and thank you for coming.

STATEMENT OF THEODORE M. HAMMETT, PH.D.

ABT ASSOCIATES, INC. CAMBRIDGE, MASSACHUSETTS

MR. HAMMETT: My name is Ted Hammett. I am a Senior Research Analyst at Abt Associates, a policy research firm in Cambridge, Massachusetts. I am pleased to appear before you this afternoon and I am extremely gratified that the Commission has shown a particular interest in addressing the difficult and complex issues regarding HIV disease in prisons and jails. I strongly believe that if we can address HIV in prisons rationally and humanely, we can do so in all settings and populations in our society.

Since 1985 I have been involved in conducting national surveys of the epidemiology and policy responses to HIV/AIDS in correctional facilities and producing annual reports of the results. I have been the principal investigator for these studies which have been carried out under contract to the National Institute of Justice, U.S. Department of Justice.

In the brief time allotted me this afternoon I will sketch two basic principles that I believe should be central to the correctional response to HIV, summarize the available data on HIV infection and AIDS in prisons and jails, and introduce some key policy issues regarding HIV in correctional facilities.

First, the two basic principles. The first of these is resisting political pressure in developing a reasonable response. In the climate of fear largely associated with the hypothesis that prisons are breeding grounds for HIV and AIDS, and misinformation, and more recently the "ghettoization" of the epidemic and all the issues that surround that, correctional officials in this climate must try to develop a rational, effective and ultimately just policy response.

It has been for some correctional systems to resist the intense political pressure for mandatory mass testing, segregation and other extreme measures, but correctional officials must attempt to base decisions on careful consideration of the facts and thorough analysis of the available policy options in terms of appropriateness, justice, compassion and effectiveness in preventing and treating HIV disease.

The second principal is that I believe that the policy response to HIV/AIDS in correctional facilities should be as close as possible to the response in the outside world. Of course, it can't be exactly the same because there are certain obvious constraints in prison that don't apply to the outside world. But principally I'm saying in this regard that prisoners should not be subjected to protection or unusual measures simply because they are prisoners. Being a prisoner is not in and of itself a risk factor for HIV infection.

In general, correctional policies addressing HIV transmission through consensual activity in prisons and jails should emphasize education, confidentiality and voluntary risk reduction. Obviously, transmission through forced means such as rape requires a very different response. I believe that this should be based on better identification and control of predatory inmates. In other words, these prevention strategies should focus on individual behavior and security needs rather than on HIV status.

As to the epidemiology of HIV and AIDS in correctional facilities, some basic statistics, and these are based on our studies between 1985 and the fall of 1988. We are currently in the process of conducting our annual survey for 1989, the results of which will be available in January and which I would be happy to share with you when they become available. So bear in mind, these figures are based on a survey that was done almost a year ago.

As of October 1988 there had been 3,136 AIDS cases among U.S. correctional inmates. And I should point out that I believe all the commissioners have received a copy of the 1988 update, and in my prepared testimony there are citations to particular tables in that report which will give you additional details.

In each year between 1985 and 1988 the cumulative total of inmate AIDS cases increased sharply. However, the corresponding increases in AIDS cases in the U.S. total population have been consistently even sharper. Thus far, in short, the predictions that the AIDS problem would grow more explosively among inmates than in the population at large have not been accurate.

The distribution of AIDS cases across

correctional systems and regions of the country has been quite uneven from the beginning of the epidemic. A relatively small number of correctional systems have accounted for the vast majority of cases, and these have been concentrated in the middle Atlantic states, principally New York and New Jersey, although California, Texas and Florida have also had relatively large numbers of cases.

Prisoner AIDS cases are predominantly associated with IV drug use. This is especially pronounced in the Mid-Atlantic region, and although our data are incomplete, the overrepresentation of blacks and Hispanics among AIDS cases in the total population appears to be replicated in the correctional population. Most correctional systems that have undertaken mass HIV antibody screening programs and blinded epidemiologic studies have found relatively low seroprevalence rates among prisoners. There are some exceptions to this, which I won't go into in detail, but it appears, again, that the variations in seroprevalence rates in prison appear to mirror variations in seroprevalence rates among IV drug users in the communities from which the inmates are drawn.

Transmission of HIV among correctional inmates is an extremely controversial issue and we do not as yet have conclusive data on this. However, the fragmentary data that we do have, primarily from Maryland, Nevada and the Federal Bureau of Prisons suggests low rates of transmission among inmates.

Finally, there have as yet been no job related cases of HIV infection or AIDS among any correctional staff, and as well there have been no job related cases of HIV infection or AIDS among other public safety workers such as police officers and firefighters.

Finally, let me turn to a few key policy issues and offer a few brief comments on each of these. I will speak about the following areas: training and education, HIV antibody testing, housing and correctional programming, confidentiality and notification issues, and precautionary measure. Medical care is, of course, a key policy issue in itself, but I will not tough on that here as it is the focus of Nancy Dubler's testimony to follow.

First, training and education. Education and training of staff and inmates on HIV is an essential component of the correctional response. I believe that all correctional systems should have mandatory regular live training on HIV for all inmates and staff. As of our 1988 survey, the vast majority of U.S. correctional systems were offering at least some live training on AIDS, but my observation suggests that these programs vary widely in quality and quantity both within and across correctional systems.

Inmate AIDS education represents not only an important responsibility of correctional systems and other criminal justice agencies, but also a unique opportunity for them to combat the spread of HIV infection. These agencies have access on a daily basis to populations with uniquely high concentrations of HIV risk factors. Failure to seize fully this opportunity to provide high quality AIDS education constitutes a profound disservice to the members of this population as well as to society at large.

Secondly, HIV antibody testing. While there is still considerable pressure on correctional systems to institute mandatory mass screening, the trend to such policies slowed appreciably between 1987 and 1988. I believe that all inmates should have access to testing on request with extensive pre and post test counseling and the latest appropriate medical interventions. However, I consider mandatory mass screening to be a misguided policy which focuses too much attention on identification of HIV infected prisoners for its own sake and detracts attention and resources from more promising prevention strategies, namely education of the entire population and controlling of the predatory inmates in that population. Mass mandatory testing has often been a simplistic, largely political response to a problem that demands a more complex, multifaceted prevention strategy.

Housing and correctional programming. In the early years of the epidemic many correctional systems decided to segregate permanently HIV infected prisoners and those with AIDS. However, over time the initial hysteria has faded somewhat, violence against HIV infected inmates has proved to be quite infrequent, and knowledge regarding the true means of transmission has spread. Consequently, there has been a trend away from blanket segregation policies and towards more case by case approaches to housing and correctional programming.

This policy focuses on each inmate's medical, security and behavioral characteristics rather than on his or her HIV status, thus insuring that prisoners will be in the least restrictive setting consistent with those individual characteristics. Most HIV infected prisoners pose no risk to others through forced activity, and I believe that transmission through consensual activity is best addressed through education.

A case by case approach means that most HIV infected inmates who are physically capable of participating in a full range of institutional programs and activities will have the opportunity to do so. This policy is also consonant with clinical observation that HIV infected persons do best psychologically and physiologically if they are able to lead as formal lives as possible for as long as possible.

Confidentiality and notification. Confidentiality of medical records and medical information related to HIV is very difficult--some would say impossible--to protect in correctional facilities. However, the effort must be made in this area. Correctional systems should establish and enforce strict controls on access to such sensitive medical information. Notification issues are troubling and complex for many public officials, including those in corrections and others who have access to individual's HIV status. There are no easy answers to these questions, but I would hold to the point that prisoners should not be subject to different and more expansive notification procedures simply because they are prisoners and because information on them may be available to officials.

Finally, precautionary measures. This policy area really comprises two issues. The first is how to prevent transmission of HIV in non-sexual encounters involving exposure to blood or other body fluids contaminated with blood. Here the best answer is clearly the establishment and enforcement of universal precautions as defined by the Centers for Disease Control.

The second issue concerns whether condoms should be made available to inmates. I omit discussion of availability of clean needles and bleach because as a practical matter correctional officials will never and probably should never permit this, regardless of its merits as an HIV prevention strategy. However, there are a few systems that make condoms available in the institutions.

Most correctional officials oppose this policy, largely on the grounds that it condones and may encourage proscribed behavior and that condoms may be used as devises to smuggle contraband and as weapons. However, I believe that correctional officials should make condoms available as a risk reduction measure, recognizing the simple fact that sexual activity occurs in prisons, whether it is prohibited or not.

In view of this fact, all reasonable steps should be taken to prevent HIV infection associated with sexual activity and to save lives.

I would like to thank you for the opportunity to appear before you today and I am available to you and the Commission staff at any time as you continue to address the serious and complex issues of HIV in prisons and jails. Thank you.

CHAIRMAN OSBORN: Thank you very much. That is a most helpful start to our discussion.

COMMISSIONER ROGERS: I want to just again respond to that elegant statement and thank you so much.

I was going to suggest that we have your written testimony. I understand from Maureen it will be available to any of you in the room who want it. Nancy, I was suggesting, if you wish speak from your heart, not your testimony. We are all good readers and will be reading it with care. You can do it either way you feel most comfortable with, but if you would rather shoot from the hip, please go ahead.

STATEMENT OF NANCY N. DUBLER, LL.B.

DEPARTMENT OF EPIDEMIOLOGY AND SOCIAL MEDICINE

DIVISION OF LAW AND ETHICS

MONTEFIORE HOSPITAL AND MEDICAL CENTER, NEW YORK

MS. DUBLER: Having never shot from the hip before.

I am Nancy Dubler. I am an attorney and the director of the Division of Law an Ethics in the Department of Epidemiology and Social Medicine at Montefiore and the Albert Einstein College of Medicine.

I am also the editor of the Standards for Health Care in Prisons and Jails of the American Public Health Association, and I actually edit a little journal on issues of health care in prisons and jails, which very few people read.

I would like to give you a sense of what it is going to mean to care for persons who are HIV positive and those who have AIDS in our prisons. I begin by saying that corrections is a growth industry. We are doing a booming business in corrections. In 1977 New York City jails were responsible for approximately 7,000 inmates. In 1987 it was about

14,000 and it has recently nudged to 20,000.

A decade ago New York State had 20,000 inmates. It now has 50,000 inmates and it is building eight new prisons. So it is in fact a system which is stressed beyond its bounds now and which will continue to grow. It is also a system that is largely a system for people of color, the poor, and drug users, the precise population that will be affected by this next wave of the epidemic.

In 1986 blacks constituted 47 percent of inmates nationally, 12.6 percent were Hispanic. The percentage of people in prison who are IV drug users is variously estimated at anywhere between 40 and 90, depending on your source. As our new drug policies come into effect, and as the police round up ever more inmates, ever more inmates are being put into ever more inefficient and inadequate systems.

We also know that the average age of an inmate is 28, that they spend about 18 months in prison, and they are back in--a very large proportion, about 50 percent of them--within three years. Therefore, people who are HIV positive on this imprisonment may not be symptomatic but may very well be symptomatic on their next visit to prison.

The enormous growth in this explosion of prisons--and it is estimated by the New York Times that we would need 800 new prison beds a week to keep pace with the imprisonment at the rate that we are now doing it, although it appears to be increasing. What that means for inmates in general is that prison services and programs become unable to cope with the needs of the population. That is not only medical care. It is educational programs. It is visiting programs. It is shop. It is work. So that more and more inmates are locked down for ever longer periods--locked in their cells with no ability to get out--for ever longer periods of time.

Therefore, men--and it is largely men, although increasingly women--are put in situations where the care is inadequate, where the housing is insufficient, and where the medical care becomes ever increasingly a problem.

Some of you may know--to turn to health care in prisons in general--that prisoners have and 8th

Amendment right to care. They are the only people in our society with a constitutional right to care under interpretations of the 8th Amendment. The 8th Amendment is the cruel and unusual punishment clause.

And the court has held--the Supreme Court in 1976 in a case called Estelle v. Gamble that, quote, "Deliberate indifference to the serious medical needs of inmates constitutes the willful and wanton infliction of pain which the 8th Amendment prohibits."

What does it mean to have a right to care which is not, quote, deliberately indifferent? Well, since 1976 when the Supreme Court decision was announced there have been hundreds of cases in lower federal courts testing the limits of that language. I can tell you the following: that a system which is systematically unable to provide adequate care--for example, a system in which individual sick inmates were locked in cells, then there was a long corridor, and the end of that corridor was another locked door, and on the outside of that locked door was a nurse and there was no way to communicate from the cell to the nurse.

That, said the Federal Court in a case called Todaro v. Ward, a Second Circuit case, is clearly a demonstration of deliberate indifference. That is a system that cannot possibly meet the needs of inmates.

Deliberate indifference has also been held to mean other things--an inmate who was eaten alive by maggots, or an inmate where surgery was done on him by other inmates.

The health care in prisons is not a matter of fine tuning. Creating a health care system in prisons has meant direct confrontation, often with state and correctional authorities. That is a critical issue when we think about the care of inmates with AIDS. We cannot even pretend, the way we do in some other areas, that if we merely set up a system for AIDS care it will be able to deliver adequate care. In prisons it must be crystal clear that unless the infrastructure exists, unless there is a system for delivering care to inmates, it will be impossible to graft upon that nonsystem any particular care for patients with AIDS.

Delivering health care in a prison or jail requires negotiating space, time, personnel and purpose. Health care providers are aliens in prisons. They are as distinct--or should be as distinct--from correctional authorities as advocates are from prosecutors. A health service in a prison or jail should be there exclusively to serve the needs of inmates, and the needs of inmates as they are self-defined are often at odds with the appropriate purposes of a correctional facility.

We have established prisons to confine and punish. A health care staff must diagnose, comfort and cure. Those are mutually incompatible perspectives and pit the medical model against a correctional model. What is required to have a decent health service has been a working cooperation between those two staffs that has permitted health care to be delivered within the confines of the prison. But also what has been required almost every time that there has been an improvement in care has been a federal lawsuit. Despite the standards, despite demonstrations of inadequate care, there are now 39 state or large systems that function under direct Federal Court supervision. Despite the fact that inmates have a right to care, it has been extraordinarily difficult to extend to them the actualities of care.

Well, what does this mean for patients with HIV infection and AIDS in prisons? Well, I think the first irony is, I would argue to you were I wearing my individual plaintiff's hat, that inmates have a clear right, constitutionally protected right at this point to be tested for HIV infection, to have their T-cell count monitored, and to be provided with prophylaxis when appropriate.

In the New York State prison system the recently appointed Deputy Commissioner for Medical Affairs and Chief Medical Officer, has estimated that one inmate a day is dying in New York of AIDS. The official estimates on the prison--and indeed they are the estimates on which my next data are based--estimated that there are 340 inmates in the prison system with AIDS. He says there a thousand.

Approximately 20 percent of the inmates coming into the New York State system were sero positive on a blinded anonymous study done a year and a half ago. Small forays, not rigorous blinded studies done into the prison system now, indicate that it is far higher than it was before.

We asked the Department of Health in New York State to give us some projections, and their projections were, based 300 symptomatic inmates now--whereas we now it is a thousand--that by 1992 there would be a cumulative index of 2,856 inmates.

The state has the ability to provide acute care, given all of its contracts and subcontracts, for perhaps 50 inmates. What will it mean, therefore, to be able to care for inmates, largely minority, people of color, IV drug users, from major urban settings, in our prison systems.

Well, I can tell you what it has meant until now. In New York State until now an inmate diagnosed with AIDS lived approximately 159 days from the diagnosis, whereas an unincarcerated person lived for 318 days, about double the time.

Twenty-five percent of the cases in the New York State system were not diagnosed until autopsy. Therefore, we are not talking about a system that needs fine tuning. We are talking in New York and in many other places about a system that must be created and taught to function.

I would like to end with two final points. Prisons are violent, horrible destructive and life-denying. They permit the powerful to pray on those who are vulnerable. AIDS patients are particularly vulnerable. To die in prison has meant until now to die alone, without family, with reasonably inadequate care. Prisoners have not been permitted access to new medical technologies. They have been denied participation in research, the second great irony. The federal regulations were designed to protect inmates from abuse, but now they prevent them from participating in precisely those protocols which would provide them with a higher standard of medical care, another problem for us to face.

However, inmates must consent to or refuse treatment or research. And the question that we all grapple with is is it possible to provide truly informed consent in a prison? Is not the structure of the prison so debilitating and the deprivation so systematic that we cannot provide inmates the opportunity to consent to or to refuse care. While I would argue to you that they are places of great deprivation, but we have no alternative than to provide inmates options for care and permit then to choose.

And I close with one final complicating point. Persons with AIDS outside of prisons devise complex systems to support their medical and their psychosocial needs as the disease progresses. Sometimes they seek out care, and sometimes they refuse care. In a prison it is never possible to tell if a particular treatment decision is a refusal or a denial. When an inmate doesn't come for care, does that mean that he or she doesn't want care, or that the prison was locked down, that a program demand changed, that a family member came to visit, or a guard decided that this was not the day for any one of a number of bases for punishment, that this inmate would be permitted to reach the medical service?

And so in order to deliver decent care not only need we an infrastructure, and particularly trained and educated practitioners able to recognize and to treat HIV infection, but we also need a system which is willing to cooperate with the medical advocacy which must be placed there.

Thank you very much.

CHAIRMAN OSBORN: Thank you very much for that most powerful statement. We'll get to questions. I think we'll have time for that, but before we do, Elizabeth Barton, welcome.

STATEMENT OF ELIZABETH BARTON, M.P.S.

SAMARITAN VILLAGE, INC., NEW YORK

MS. BARTON: Thank you. My name is Elizabeth Barton. I'm the Chief Operating Officer for Samaritan Village, which is a large, multi-site therapeutic community based in Queens, New York. I am also the Second Vice President for the state's Association for Substance Abuse Programs.

What I would like to accomplish today in the brief time allotted is to talk to you briefly about residential drug treatment, about the intravenous drug abusers in our system, and the medical management of persons with HIV infection and AIDS. And then I would like to briefly talk about a residential alternative that was undertaken by my program and another therapeutic community.

I think the main point that I am going to try and make is to tell you that the drug free therapeutic communities are now providing very effective HIV and AIDS interventions and very specialized services, because we are indeed a very special environment, and for two reasons. We are able--those programs that are larger and have enhanced medical and nursing staff--we are able to provide and continuously monitor the health status of all of our clients, and in particular the HIV infected individuals have access to primary medical care, and on a referred basis, specialized services.

And again, I want to emphasize that this is essentially only the larger programs that in New York State are certified by the Department of Health as ambulatory clinics. That it is not the case for the smaller programs that are community based.

Residential drug free treatment on the therapeutic community model is about 30 years ago old. We have been evolving steadily until today there are a wide variety of programs. There are about 14 residential therapeutic communities in New York State. We service about 4,000 of the 6,200 beds or slots in the state; 75 percent of our clients are men.

For those of you who don't know about a therapeutic community, it is a 24 hour, seven day a week environment in which those people that have chosen to stop using drugs and do something about other dysfunctional behaviors, they spend upwards of 18 to 24 months in a very rigorous and highly structured environment. There are schedules of group therapy, education, vocational preparation, and of course, work therapy.

The cost for a treatment stay is about $16,400 a per year. The therapeutic community model relies a lot on communal, nurturing, peer group role modeling, and there is a very, very strong emphasis that is placed on responsibility and accountability. The objective, obviously, is for that person to return back into society drug free, and in that sense we are talking about a recovery process that's quite in contrast to the situation with those clients that are in our programs who are HIV affected.

AIDS and HIV infection have been an issue and concern to us for about six years. It is very much an inherent part now of our treatment, and it has very, very much changed the abstinence and recovery oriented focus, as I have just mentioned.

To give you some idea of our population--and it is a very dynamic population--my program has a capacity of about well over 600 individuals, and there are about 1,500 individuals who will move through my system in a year. Of those people who are admitted, about 75 percent have had a prior treatment experience. That might be in a detox setting, it might be in methadone maintenance. I have said that about 75 percent are men. About 75 percent are self-referrals, 25 percent come from the criminal justice system, and that pretty much holds across the board for all the residential programs.

About 20 percent of those who are admitted to my program report that they are IV drug users. We did an informal survey among the 14 residential therapeutic communities, and the average is about 30 percent intravenous drug use in the residential programs. We estimate that about half of our population, somewhere over 300 individuals, probably have been exposed to the AIDS virus. I do know now that about 15 percent of our population are HIV infected. They are either asymptomatic, symptomatic, or have AIDS, and I would say probably at this point about a dozen of our direct treatment staff--which numbers about a hundred--are HIV infected.

My organization made a decision a number of years ago to furnish medical care, and we did that for two reasons. We were quick to realize that it was very essential to successful treatment of substance abuse. And secondly, basic primary medical care simply was not being delivered elsewhere to our population.

And then with the advent of AIDS, it was very clear to us that if we were going to be able to again effectively work with these individuals on their substance abuse problems, we would also have to deal with their health status. And I would say to you that along with some very carefully developed AIDS policies and procedures and, of course, a very good education program, that we probably were able to respond as promptly as we did to the HIV and AIDS crisis.

We are now seeing more and more frequently individuals presenting for admission who are diagnosed or symptomatic. This was not the case two or three years ago. We are also seeing a growing number of readmissions, persons who have successfully completed our treatment programs, and they are coming back into treatment because they need medical care, they need other psychosocial supportive services and, quite frankly, they need housing.

I can sit here and I can tell you that we are prolonging and improving the quality of their lives. We are protecting their health, and both the staff and the residents in our program alike, we are learning to live with what is indeed a chronic but a manageable condition. And I think that, again, there are probably two distinguishing characteristics of individuals in a therapeutic community different from another institutional setting. You have what is known as peer bonding and peer education, and both of those are very, very instrumental in enabling anyone who is HIV affected to cope with that situation.

I would like to stress again that really this is the empiric picture. There is very little research on the impact of HIV infection and AIDS, particularly on residential treatment settings, and that is certainly something that I would encourage in a recommendation.

I mentioned a residential alternative. There comes a point in trying to manage the HIV population in any treatment setting where you have to weigh the needs of the community as a whole against that individual's needs. And certainly our medical services are only available weekdays, primarily between 8:00 and 5:00 o'clock. We do not have any evening nursing services available, nor services on weekends, and this is pretty much the case in most of the residential programs.

Two years ago another colleague of ours and Samaritan, we sat down and we began to take a look at the more seriously ill individuals in our program who were very willing and wanted to still remain within the treatment setting, but the practicality was that they were unable to participate fully in the treatment process. And we approached both the State Health Department and our own licensing and funding agency, the Division of Substance Abuse Services, that we wanted to establish a free-standing facility for substance abusers with AIDS that would have nursing care available round the clock.

It is two years later and under construction now in the Bronx is a health related facility. It is a 66 bed facility that we expect will be operational in

June of this coming year. And it is a very modified therapeutic community, but it will have alongside it a full nursing staff and medical staff to provide the necessary health care. It is an enormous undertaking for the two drug treatment programs to do this. In addition, we have also decided that it is necessary to have some interim support of housing for our graduates, and we are currently trying to develop a housing model that would be most suitable for HIV infected individuals, and persons will be allowed to live in this supportive housing for upwards of two years.

I would like to take a few moments and suggest to you some recommendations that I think would be very helpful to free-standing community based providers like myself. In a limited study that was done at Montefiore, 80 percent of 174 IVDUs who were newly diagnosed with AIDS were not enrolled in any drug treatment program. I think that that's a very significant percentage, even though it is a very limited study.

It is absolutely important that not only linkages with hospitals and hospitals with drug treatment providers, but also entry into residential drug treatment, that that be mandated. And the New York City Health Systems Agency just issued a report, their AIDS Task Force report, and in it they called for the substance abuse programs to integrate with the health system providers, with the health care providers.

I think that that burden is not ours. I think that we are doing enough as it is right now treating these individuals. We are treating essentially the same medically needy population as the larger institutions, but I think that the formal relationships, transfer relationships, the accessibility to specialized service, I think that that is something that has to be mandated, it should not be a burden on the substance abuse program.

It is only way I think that you are going to help ensure continued stay in our programs and will help us provide better primary care services. I also think that there need to be very direct linkages with the criminal justice system and that, again, it should be mandated that upon referral to the residential treatment setting there can be a continuity of care, both their health care and the drug treatment.

And certainly in New York State right now there are some initiatives to establish drug treatment programs within the prison system. I feel very strongly that those programs should be operated by experienced providers such as the therapeutic communities.

Medicaid reimbursement is a very large issue for the free-standing programs. There are about four or five of the therapeutic communities in New York that have diagnostic and treatment center certification. Our rates are not at all based on the medical care services--I should say they are based on the medical care services, but very limited. We have been trying to get together data to establish our case, and I am hopeful that at some point in the future there will be an enhanced rate for us in providing the basic primary care to the HIV symptomatic population.

I think also that I have tried to describe to you briefly today the situation in the drug treatment programs. I think that there needs to be research done to evaluate our current drug treatment protocols. I think that we need to assess what we are doing, and certainly the impact of the health care on particularly the HIV population. The research grant process is very daunting, I mean for small free-standing programs such as ourself, and I would urge that there could be collaborative efforts. My own organization is trying to work with Montefiore or some studies. We certainly can't do that on our own.

And I also think that programs need to be more involved in clinical trials. A number of our residents take it upon themselves to seek out various clinical trials. We have encountered some difficulty in our medical clinics with individuals who want to use various experimental drugs. It would be helpful both to the individual as well as the treatment provider if there were more formal arrangements made with some of the clinical trials. The community research initiative in New York is certainly one that is encouraging more substance abusers.

And I guess lastly, it has to do with expanded funding. I feel very much that the residential programs, we have the experience, we have the resources, and we do have the growth capacity if we could get over some of the siting issues. There is very little expansion going on in New York State now within the existing systems. We need to take a look at that siting issue. But I think that we are becoming very much a key provider in not only providing substance abuse treatment, but the primary medical care. And I think that if we were given adequate resources or more expanded funding, that we could definitely develop an experiment with an even greater range of specialized services, and that expanded funding has to be not only operating funds but capital funds as well.

I thank you very much for allowing me the time to raise these issues and opportunities.

CHAIRMAN OSBORN: Thank you very much.

Now I think there will be a chance for the commissioners to bring up additional points and ask questions. Diane Ahrens.

COMMISSIONER AHRENS: I have a question, one for Ms. Dubler and one for Ms. Barton.

Let me just say, in terms of my state, we are finding that in order to not impact the state prison system dramatically there is an effort to, I guess you could call it, down commit or through regulation and policy see that the local units of government are responsible for holding people that have been committed. And, of course, that does a lot to all of the county systems out there.

And I am just wondering if you are finding that that is something that has caught on in New York and if you would want to comment on that?

MS. DUBLER: It is happening in a number of states, and what it does is shift the basis of litigation. Instead of litigating against the prison system for overcrowding, you litigate against the jail system, the county jail system, for overcrowding.

COMMISSIONER AHRENS: But the state does that for us. The state lets us know that we are out of compliance and therefore we must increase, so we don't have to rely on someone else to do the thinking.

MS. DUBLER: And do the counties when they are out of compliance, then build sufficient numbers of beds?

COMMISSIONER AHRENS: Yes, we are proceeding to do that.

MS. DUBLER: That's wonderful. I mean, that would be a tremendous example that would be an aberration in the development, but what concerns me so much is that until now change has really been the result of Federal Court intervention. I think a state government that is willing to do that should be applauded.

COMMISSIONER AHRENS: Well, yes, it can be applauded, but it also shifts the cost of those facilities from a state base to a local base, which is another issue.

I am wondering, in connection with that, if you are using, the State of New York is using any home electronics surveillance to try to take care of any of the population.

MS. DUBLER: Very little. There are a couple of states that are now experimenting with community corrections laws which were in fact much more in vogue about a decade ago than they are now.

COMMISSIONER AHRENS: We were one of the first states to have one of those laws.

MS. DUBLER: And that was just not followed by many other states after that. Basically, the new--well, it is not new, but the going correctional policy is simply to lock up as many people as can be locked up in the smallest number of institutions that that will accommodate them.

COMMISSIONER AHRENS: If I could have my next question, Madam Chair. It goes to Ms. Barton.

You speak of yours as a free-standing clinic, and I am a little puzzled by the term and I am just wondering, does that mean that you do not receive public funds, or if you do receive public funds, where do you get them from and what percentage of your funding would they represent?

MS. BARTON: By free-standing, we are a drug treatment program that is not part of an institution, another provider. For instance, most of the methadone maintenance programs are attached to or affiliated with a hospital. We do receive state funding. About 60 percent of our budget is funding from the State

Division of Substance Abuse Services. The remaining portion comes essentially from third party monies, public assistance and Medicaid.

CHAIRMAN OSBORN: Ms. Diaz.

COMMISSIONER DIAZ: I didn't hear any of you address the needs of the families of prisoners in terms of either counseling or primary prevention and health services. A number of individuals from the prison system within California have told me that any program to educate prisoners regarding HIV and their responsibilities really has to be almost done in cooperation with the families of these individuals, because of looking forward to the day when these individuals will be released, and also the situation that we have in some prisons where there are conjugal visits permitted, and certainly one in which we would want the partner certainly to know what the AIDS prevention advice may be to them.

I am a little bit confused because you say being in prison does not put anyone at risk for AIDS. Conversely, in prison we have an environment which may be somewhat associated with two of the risks of practices, and that is the sharing of limited works in IV drug use and also an opportunity for increased male to male contact.

So could you explain that, because when you said being there, obviously, doesn't put you at higher risk for AIDS, but on the other hand, we hear from people in prisons that that is an environment which is somewhat associated with two of the risks behaviors

MR. HAMMETT: Well, there are a number of issues there. But what I was trying to say was that--I was not trying to say that there is not risk behavior taking place in prison. What I was saying was, and what I believe strongly, is that the simple fact of being a prisoner is not a risk factor and therefore--because I think that that assumption becomes the basis for some of these policies which, on a sort of blanket basis take a different approach to HIV prevention and so on with prisoners from what they take with people on the outside.

Certainly risk behaviors occur in prison. I think I might disagree with the point that there is more opportunity for risk behavior in prison. I am not sure if you said more opportunity for risk behavior in prison than on the outside, but if you did say that, I would not agree with that. I mean, the notion that risk behaviors--that a sexual activity and drug activity is rampant in prisons has not been proven, certainly, and I think that perhaps it is am exaggeration. Certainly those activities occur in prison, but I think there is less opportunity for those activities to occur in prison than on the outside, simply because of the fact that at least to some extent prisons are controlled environments.

All right. The issue of family education I think is an important one, and in connection with conjugal visits and in connection with certainly prerelease education, which I believe is very important and an area which is neglected by many correctional systems, working with the families is very important.

Again though, I am somewhat concerned about the notion, or the proposal and the policy that actually exists in some correctional systems that in order to qualify for conjugal visits or work release or parole and so on that a sexual partner or spouse must be officially informed of the HIV status of the prisoner. I think that is another example of where a class of people, a different, more expansive notification policy is applied to a class of people under the assumption that prisoners as such are more at risk or more irresponsible or something of that nature. And I think that kind of policy is very troubling, but I would agree with you that the education aspect of it is very important.

COMMISSIONER DIAZ: I wanted to ask Ms. Barton if you find that the women addicts, particularly those that are Latino and Black, need, in your opinion, any specific and specially designed drug treatment interventions? Because what we hear from women who are at risk for AIDS or may be positive and are also addicts is that they would like to go into rehabilitation or drug treatment programs that, for example, allow them to come in with their children. And that is seldomly talked about, particular needs of women addicts that also need and are actively seeking drug treatment programs.

MS. BARTON: First of all, there are

specialized groups for Hispanic Latino women in the therapeutic communities. We also try and recruit staff so that there is appropriate modeling, if you will.

On the issue of access that you just raised, there are very, very few residential programs that permit women and children. There is one program in New York, one separate program which has operated by Odyssey House. There are also some other more specialized programs that focus more on your battered women and children, and there will be a program operated by Project Return in the very near future for women with AIDS and children. But on the whole, that's a tremendous gap in terms of services.

COMMISSIONER DIAZ: Thank you.

CHAIRMAN OSBORN: Larry Kessler.

COMMISSIONER KESSLER: Nancy, I would like to ask you to clarify your 800 bed a week statement. I didn't quite get that. Is that 800 new beds a week?

MS. DUBLER: We would have to build in this country 800 new prison beds a week to keep up with the increasing rates of incarceration.

COMMISSIONER KESSLER: For HIV?

MS. DUBLER: No, no, just in general.

COMMISSIONER KESSLER: In general, okay.

MS. DUBLER: The average last year was some of the larger systems increased their populations by 15 percent, some by 8 percent, so the average is about 800 beds a week.

COMMISSIONER KESSLER: To your knowledge in terms of the five or six new prisons being built, has there been any planning or anticipation of a growing number of inmates with HIV disease?

MS. DUBLER: Well, there hadn't been until now. There is some movement now to get corrections to try to renegotiate the contracts and assure that places that got prisons had a commitment to provide health care. That obviously should have been done, and perhaps it will be corrected, but it is my understanding that it has not been corrected until now.

COMMISSIONER KESSLER: And the third question I have would be for any of you, actually. Are you aware or can you tell us of some models that might exist that are working where community based groups are doing the work of education, vis-a-vis corrections or jails, in partnership with either county, state or federal authorities? Is there something that we ought to be holding up as a model that works in lieu of a more public government sponsored program?

MS. DUBLER: There are a couple of things I could note. One is a very interesting program at the women's prison in New York at Bedford Hills, which I think is the largest women's prison outside of the federal system, where they have an extensive peer counseling program which is run in conjunction with staff from the AIDS Institute, which is part of the Department of Health, but it is run with the agreement of but not with the inclusion of correctional authorities.

That has been very helpful and it is a very excellent program. The problem with CBOs and peer groups in other prisons is in the prison world it is virtually impossible to, quote, empower inmates, and as soon as you get a very active peer counseling group it becomes a security risk and all of the participants get transferred to other prisons. So when you have got one women's prison in a state you have got a shot, but otherwise it has been very hard to get stable groups of peer and CBO based. Also, CBOs are not by and large allowed to do things in the prisons.

MR. HAMMETT: I guess I am not quite so pessimistic about that approach. I mean, certainly there have been problems of the kind that Nancy describes where people have been transferred and so on, but I think this is an area that really needs to receive continuing attention, not only CBO based education but also the peer education model, which was being used in California for awhile at Vacaville, as I understand has been discontinued for a variety of reasons.

But I think the use of prisoners to do HIV and AIDS education in prisons is a particularly worthwhile endeavor and there ought to be more programs like this and they ought to be evaluated and they ought to be continued.

COMMISSIONER KESSLER: Thank you.

CHAIRMAN OSBORN: Dr. Rogers.

COMMISSIONER ROGERS: First an observation. I thought, Mr. Hammett, we heard from you a rather noble bill of rights which certainly I would adopt for how prisoners should be--prisoners who have HIV positive--should be viewed by society, and I would hope by this Commission.

I thought from Nancy Dubler, however, we were hearing that the total lack of really any decent system of medical care renders the management of people with HIV infection pretty problematic within the prisons. I am just impressed with the contrast.

A query for both of you. I have heard hair raising tales about how prisoners who are realized by other prisoners to be either HIV positive or have active disease are treated. Is this as monstrous a problem as I continue to hear it to be in terms of the treatment by other prisoners, having to be isolated, and then also some rather Catch 22 things about not being discharged, even when mortally ill, to home situations when they are obviously pretty helpless in terms of criminal behavior. What are the stories?

MR. HAMMETT: Well, as to the first point, the issue of violence against HIV infected prisoners. That certainly was a concern and continues to be a concern. However--and Nancy may have a different view of this--I think that it has not been in fact as prevalent a problem as had been feared, and I think that what you find is that in jurisdictions that have segregation policies, for example, particularly those that segregate even asymptomatically infected prisoners, those prisoners are almost unanimous in their desire to be released into the general population, and many lawsuits have ensured in this area.

COMMISSIONER ROGERS: Released into the general prison population?

MR. HAMMETT: That's right. Excuse me. I'm sure they are all anxious to be released.

But I think this is evidence of the fact that if they were convinced that they were going to be murdered the minute they got out into the general prison population, they might want to be in some kind of protected environment, and some of them do. But I think by and large they want to be released into the general prison population because there they have more opportunity to participate in programs and activities and to lead as normal lives as possible for as long as they can possibly can, and that's very important.

The second point can really cut both ways, and I think what I've seen--and Nancy again may differ--but I think there is more a problem of dumping prisoners out into society with no linkages to services or programs than there is keeping them in prison for excessively long periods of time, and the dumping is a real problem, too.

COMMISSIONER ROGERS: When they are were actively I will.

MR. HAMMETT: When they are actively ill and without any linkages and without any referrals and without any resources whatsoever to deal with their situation.

MS. DUBLER: I don't disagree on the first point. We were very concerned that HIV inmates and those with AIDS would be subject to great violence in the prison system. It pretty much has not happened, there are isolated instances.

On the second point though, I think there are very interesting phenomena at work. Number one, there is a lot of dumping. This is an expensive patient taking up a lot of service, he is ready for parole, parole him.

On the other hand, there are many inmates who are terminally ill where there is no policy of release for the terminally ill. They haven't reached their parole date and they die alone in prison. Now, that is increasingly going to be the problem, and establishing humane policies which permit clearly dying inmates to die close to their families--and remember that most inmates come from urban centers and they are imprisoned in rural communities very far away, so in fact both is a problem.

And I'll just give you the last point which I know by anecdote, which is that there are some inmates who have been refusing discharge from the prison--I have heard of maybe five or six scattered instances around the country--because they fear that they will not be able to get any care within the community, and the care they are receiving, whether it be totally adequate or not, is at least supportive of their needs.

MR. HAMMETT: Could I just add one thing, briefly as to the first point you made regarding the contrast between my presentation and Nancy's. I think that everything she says is true, and particularly perhaps in the New York system.

COMMISSIONER ROGERS: I am profoundly relieved to hear that.

MR. HAMMETT: Well, I don't think it is a great relief. But I would like to say also that I think that there are in many jurisdictions very committed and conscientious corrections people who are concerned about this issue and who are trying to do the right thing in the midst of difficult political pressure and shortage of resources and tremendous overcrowding and all the rest of it.

So I guess the thing that I would disagree with Nancy on is the impression that one might take from her testimony that corrections officials are all sort of monsters and so on--and a lot of them are, unfortunately. But there are also good corrections people--medical people and corrections people--who care about this issue and who are trying to do the right thing. And so therefore, I don't think that my bill of rights, as you called it, is entirely visionary. In fact, there are many correctional systems that I think are doing a pretty good job in this area.

MS. DUBLER: Could I just and one word, which is that all generalizations are subject to attack, whatever they be. And I think there are decent health care services and decent professionals within corrections. I think what you always have to fight against, however, is a closed system which will slip back quickly and in inexorably into the problems I describe if it is not monitored carefully all the time.

CHAIRMAN OSBORN: I want to take one more question from Don Des Jarlais, and then through the miracles of our staff plus PAHO there will be coffee downstairs as we take a somewhat belated break.

But Don, please go ahead.

COMMISSIONER DES JARLAIS: This is for Liz. One of the strong recommendations of the Watkins Commission was to greatly expand the treatment system for drug abuse treatment as a way of preventing further spread of HIV among people using drugs. You briefly just touched on siting difficulties of starting up new programs.

I would like to ask you to expand upon that, what you understand is the community dynamics. And clearly one of the issues this Commission will have to face is the realistic possibilities for expansion of the drug abuse treatment system, the stigmatization around drug abuse and the community resistance associated with that and the potential sort of double stigmatization of not only drug abuse but AIDS in terms of the siting of new programs.

MS. BARTON: Obvious is the acquisition and site control in terms of community opposition or community notification, it is never too soon to go to them, as far as they are concerned. You certainly don't want to go to the local community boards until you have essentially a property locked up, if you will.

The community boards also are very much aware that they have very little power. Indeed, the local officials have very little say in the siting issue. That determination is made by the state licensing agency.

My organization is currently enmeshed in a battle in Queens in an attempt to open an outpatient program, a 150 slot outpatient program, in a community that we have been operating in for 24 years. The difficulty was that the site was too close to the local parochial school, and as far as the community is concerned, you have to be well away from any school. And if you with familiar with Queens, Queens has a lot of schools.

It was an ideal site for us. It was very close to two existing facilities. We had been in the board for 24 years. It seemed very logical. We underestimated the response. As far as they were concerned we were going to be bringing in active drug abusers, we were going to be the problem instead of we know that we take care of the problem, that crime is reduced and et cetera.

We have been three years trying to first acquire, in terms of purchasing through bank loans, a site in Manhattan on East 53rd Street. And first it was the acquisition problem, then it was the community opposition problem, then it was a question of going through the building department. It was an SRO and we had to get a waiver. Then there was a question at the last minute of handicapped access, and then finally you get to do we or do we not have the capital funding from our licensing agency, and that is finally in place.

So three years later we are just beginning to alter a site for 80 individuals. Just about every program that I know of is at this point expanded as far as they can within their existing treatment system. You then run into issues of do you have enough square footage per resident? Do you have enough fixtures per resident?

So that if you attempt to operate at over your capacity you are almost going to be penalized from your own licensing agency. I don't know if that sort of covers it, Don.

CHAIRMAN OSBORN: Once again, it seems like we are just beginning a discussion instead of ending it, and I want to thank all three of you for giving us a very profound beginning to what will obviously need to capture some more of our attention. But thank you so much for your important testimony.

We will now take a 15 minute break, and if you go down to the lower level I think there is supposed to be coffee in the lobby there, and we will reconvene in 15 minutes, please.

[Brief recess.]

CHAIRMAN OSBORN: I am going to reconvene the Commission even though some people are still coming in from the back, because Dr. Oleske has a very tight travel schedule and we would like to make sure that we take advantage of his efforts to come and be with us today.

I am sorry that Dr. Novello is not going to be with us. She had a sudden change of plans, and so we will hope to talk to her at a future meeting.

But I am personally very pleased to have with us two people who make me very proud to be a pediatrician, Jim Oleske and Cathy Wilfert. I think we'll change our style slightly and ask Jim to speak first and take questions so that he can make his way back to an important function that he has to attend an a remarkably early hour of the evening. In fact, I sort of hope it works. The east coast sometimes doesn't work as well as all that, but we'll wish you well. And then Cathy can stay with us and go seriatim this time.

Welcome, Jim.

STATEMENT OF JAMES M. OLESKE, M.D.

DIVISION OF ALLERGY, IMMUNOLOGY AND INFECTIOUS DISEASES

DEPARTMENT OF PEDIATRICS AND PREVENTATIVE MEDICINE

UNIVERSITY OF MEDICINE AND DENTISTRY OF NEW JERSEY

NEWARK, NEW JERSEY

DR. OLESKE: Thank you very much. I would light to prefix my remarks by stating that besides my written statement I have given to the Commission Generations in Jeopardy, which is a report that was commissioned by the New Jersey State Department of Health to look at issues of children, women and adolescents in New Jersey, and since New Jersey is somewhat of a bellwether state for this disease in many areas, especially heterosexual transmission and, unfortunately, in women and children, I think this is an important statement that is relatively up to date--it is only a week old--and I think relevant to the Commission's duties, and I would suggest that be added to the reference material, besides just my written report, which is rather small.

I guess I hope that this Commission is the beginning of the band striking up the chord so we can begin to march on this disease, because I, like many other people, have been overwhelmed and somewhat tired by reports and commissions and groups that have looked and studied this problem of HIV infection. I think it is time many of us stayed busy in taking care of the patients who have this disease.

Perhaps the greatest difficulty facing those committed to the care of children with HIV infection is the alarming numbers of new cases. In 1987 at the initial Surgeon General Workshop on HIV Infection in Women and Children and Adolescents, I had estimated that by 1991 there will be 20,000 children with HIV infection in this country. At that time many felt that that was an exaggerated figure, but unfortunately today it is clearly probably and underestimation.

Over 11 percent of all pregnant women in the United States engage in substance abuse. If just 1 percent are HIV infected, there would be almost 4,000 infants born each year at risk of HIV infection to this population alone, which would not include the 10 percent of pregnant women who do not use drugs but are sexual contacts of men who use drugs.

Based on nationwide anonymous newborn seroprevalence studies, the CDC has estimated that there are 5,000 HIV infected infants born each year right now in the United States. These independent estimates--

COMMISSIONER ROGERS: Jim, excuse me. Let me just interrupt. Did I get your figure correctly? You said 11 percent of pregnant women?

DR. OLESKE: Engage in substance abuse in this country.

COMMISSIONER ROGERS: Are you including alcohol, cigarettes, or are you talking about--

DR. OLESKE: I'm talking about crack, alcohol, heroin.

COMMISSIONER ROGERS: Thank you.

DR. OLESKE: For every 1 percent increase in the drug using population of pregnant women who becomes HIV positive, there would be an additional 4,000 HIV exposed infants each year. In the high prevalence areas like Newark, New Jersey, greater than 60 percent of such women are positive for HIV.

As HIV spreads into our country's drug using population, the potential increase in the number of HIV infected children becomes catastrophic. If there are no effective preventive strategies developed by the year 2000, there will be over, in my opinion, 10 to 20 million HIV infected Americans, many of them women and children.

Who will take care of these children? Unfortunately, most HIV infected infants are born to HIV infected mothers. Both the HIV infected child and their uninfected sibs, are at risk of being orphaned besides becoming sick. In our Newark program over 40 percent of the infants eventually become orphaned and require foster care, including extended families. The social setting typical of most perinatally acquired HIV infection is not conducive to the provision of even the minimum standards of health care.

The minority group most affected by the HIV epidemic consist of poor people living in communities where drug use and its consequence not only encourages HIV spread but also destroys the social structure of those communities so that effective preventive programs and access to health care is severely limited.

Women with a perinatally infected child are usually not able to function as advocates and have the most limited access to health care for themselves as any group who are infected with HIV. There needs to be availability or health services to HIV infected women and children under one roof. As a society we claim to protect and cherish our children, but in fact we have placed women and children squarely in front of the onrushing HIV epidemic.

Although we must insist that all children have access to investigational drugs and new therapies at the same time as adults, we must also recognize the ethical dilemma posed by the coercion of poverty. In our urban centers where the epidemic is now concentrated, health facilities that have the expertise to provide the care to HIV infected children are usually the same centers that offer access to investigational drugs.

The poor, frequently ill, caretaker of an HIV infected child may well perceive that the only option to obtain good health care for a child is also to participate in an investigational drug trial. This places an extra burden on the health care team to ensure provision of equal clinical care regardless of a particular child's participation or not in an investigational drugs trial.

As investigational drug trials are increasingly performed in population groups that do not have the ability to access new drugs by other means, it is an imperative that as such drugs are approved, the disadvantaged pediatric population and those populations in which those studies are done must have assured access. If not, IRB approval would be inappropriate, since the principle of justice would not have been met by these studies.

The presence of transplacental antibodies for up to 15 months, and the immune dysfunction characteristic of HIV, makes the diagnosis in infants of the primary HIV infection, as well as the opportunistic infection and co-factor infections in these children difficult. It is vital that we develop and apply laboratory diagnostic assays to identify the HIV infected children as close to birth as possible. Such early diagnosis will allow more aggressive specific anti-viral therapy to be offered to such infants, as well as identify those requiring prophylaxis of opportunistic infections.

Since 1983 when pediatric HIV infection was first recognized, it became evident that the most appropriate model of care was to have considered these children to have a chronic disease that requires comprehensive care which includes the family. In addition, however, we have now recognized that besides considering these children having a chronic disease, we must now consider them to have a multi-organ system disease.

In the very first group of patients described, besides overwhelming PCP infection, failure to thrive, encephalopathy, and lymphocytic interstitial pneumonia, LIP, was noted. Our ability to provide strong supportive care, including nutritional support, and the aggressive therapy and prophylaxis of infections has increased the longevity and quality of life in children.

Although specific therapy of HIV infection with antivirals is needed to be a priority in children, we must continue to develop appropriate regimens to treat the more immediate life threatening and morbidity causing opportunistic infections in our patients. It is unfortunate that opportunistic infections such as MAI and disseminated cytomegalovirus, common in children with AIDS, have no effective therapy available.

The multi-organ system involvement, the chronic disease nature of pediatric HIV, frequently requires the consultation of multiple specialists in the care of the single child with HIV infection. As we improve longevity with both supportive and specific therapy we will be seeing a greater number of older children with previously unrecognized manifestations and complications, including renal, cardiac and neoplastic diseases.

The primary care provider is frequently responsible for a child who requires multiple medications. Many of them aren't familiar to that physician. The potential for drug adverse interactions has become a real problem in the care of such children. It can be expected as the number of adolescent patients with HIV infection increases, they will have disease manifestations different from the younger child. The pediatric specialist caring for these adolescents will need to be able to coordinate the complex care and counseling required by this group. We must develop training programs for the various health care professionals that are to provide the clinical and social care needs of children and families with HIV infection.

The experience of centers now providing services and care to HIV infected children and their families affirms that early detection of HIV infection cases results in improved care, including developmental intervention and early access to investigational drugs. While this supports the need for routine HIV screening of childbearing age women and children and adolescents in high risk settings, such screening must be linked to appropriate services for the cares of those identified. Routine prenatal screening should not be replaced by newborn screening programs. Analogous to syphilis, HIV infection should be diagnosed before birth if optimum care is to be provide for the infant.

It is alarming that in high prevalence areas for HIV, previously well controlled disease like congenital syphilis has shown an alarming resurgence. In Newark, New Jersey alone there has been a 200 percent increase in congenital syphilis in the last four years. Besides the development of novel organ system diseases and the reappearance and resurgence of older, previously controlled disease, children with HIV infection have presented new challenges not previously encountered by the health care provider.

These children of the '80s AIDS epidemic develop stroke syndromes related to their hyperviscosity; the usual manifestations of common diseases are exaggerated or altered, making clinical diagnosis difficult. Dental disease is universal but corresponding availability of dental care is not. Multiple family members have the same fatal disease. And most unfortunately, society as a whole, reflected in our government's inconsistent allocation of resources, either does not recognize the enormity of the threat of this disease, or worse, does not yet care.

We need to mobilize the resources necessary to provide care to those already infected, to develop effective strategies to prevent those not yet infected from becoming infected, and we need to do that now. Remember that not just poor people use drugs nor have sex. Although it may take longer for HIV to manifest and establish itself in non-urban poor communities, it is already happening.

HIV infection is considered by many to be a disease of other people. Those other peoples are ourselves and our children. We cannot allow compassion and provision of health care to be replaced by anger, contempt and unneeded punitive laws. The wolf is truly at everyone's door. The efforts needed may at times seen unachievable, but we should keep the words of Robert Browning always in mind, "Ah, but a man's reach should exceed his grasp or what's a heaven for."

Thank you very much.

CHAIRMAN OSBORN: Thank you very much, Jim. Very eloquent and wonderfully put.

Are there questions for Dr. Oleske? As I mention, he will have to leave us as soon as we have had a chance to ask him questions because of the urgency of his schedule.

Mr. Goldman.

COMMISSIONER GOLDMAN: Dr. Oleske, would you describe just briefly how many patients you are treating in your program and what kind of staffing requirements there are to provide the level of care that you are providing, and also what kind of staffing requirements would be required to provide the level of care that you think ought to be provided?

DR. OLESKE: We provide ongoing active care for about now 200 children who are activity HIV infected and symptomatic. We have provided care for about a hundred children who have subsequently died.

The staffing requirements to provide care to those 200 children usually includes three physicians, a staff nurse, a nurse practitioner, two social workers, and the administrative support staff. That would be the sort of minimum staff for a large group of patients like that.

We have additional staff because we serve as a regional program to provide outreach education to other programs in New Jersey who are experiencing HIV cases. The biggest need, as I see it, as far as the numbers as they increase are case management individuals. All too often the case manager in the family's eyes is the most important individual. It is the individual who makes sure that those patients and their family have access to the services available.

In New Jersey right now there are 12 case managers for HIV infected patients. It is estimated by the State Department of Health that they need at least a hundred. So that we are already very short in the numbers of people who are willing to do case management. That is complicated by the fact that we tend to pay case managers very small amounts of money and there is rapid turnovers in that field of health care delivery.

So if you asked me what probably was the single greatest need, although I would like to say physicians--and there is a need for physicians who are trained to take care of HIV infected patients--it is really case managers who know the system and are able to provide the services to patients as they need them.

And we have to pay them enough that they stay in the job long enough to be effective.

Did I answer all your question?

COMMISSIONER GOLDMAN: You basically did. I assume you also have consultants in other sub-specialties?

DR. OLESKE: Yes. The issue I tried to bring out in my presentation is that that one child who you provide good service and support to may have an improved quality of life and may live longer and as we use drugs like AZT that is certainly going to be true. But the dilemma you run into is that this disease, despite AZT, remember is still probably progressive, chronic, multi-organ system and still fatal. So that in the care of these children we require during the course of illness any one of a number of specialists, the dentists, who are very difficult to entrap into the program, neurologists, endocrinologists, pulmonologists, gastroenterologists, surgeons to put in lines, and so that the care can be very, very difficult as the child becomes more and more symptomatic.

It is still important though to recognize that early in the course of the disease and late in the course of the disease when it is clear to everyone that no further advantage can be given to a child with illness, it is important though that the primary care provider, whoever that may be, assume care so that children have the right of a dignified death. And we have had at least a dozen children die at home with no respirators and with no extraordinary procedures done.

Now, that does require a social worker, frequently, or a nurse to help the family do that. But families can be helped in that dying process, and although as a physician I tend not to like to think about most of my patients die, helping the family cope with that dying process and helping the child and his other siblings cope with that dying process becomes also very important, and that requires people with different type of expertise.

COMMISSIONER GOLDMAN: Can I follow-up on that. Earlier we heard some testimony which suggested that the complexities of treating HIV disease, at least I think in adults, is such that the argument can be made that in order to really and truly provide the greatest opportunities for longevity and quality of life, that a level of expertise is required in terms of treatment and care that may well be beyond the ken of the community based private practitioner.

Would you agree or disagree? What would your views be in that kind of--

DR. OLESKE: I think that a decently trained health care provider physician or dentist could provide most of the care required by a symptomatic HIV infected adult or child if--and that it is a big if--that individual is willing to expend the effort that it requires to provide those services. So that I do not think every patient with HIV should, or even is it conceivable that we could provide those services at our major centers, we are overwhelmed already. So that I think one of the things we have to do is to train people and make them feel comfortable, obviously serve backup and provide the care when they do get in trouble. But I think a lot of care that we provide, for example, right now could be provided by others if they were trained and willing to do that care

COMMISSIONER GOLDMAN: But does that change when patients become symptomatic and you are talking about activated--

DR. OLESKE: I think that even with symptomatic care, after decisions are made about certain drugs or programs, that monitoring can be done in the physician's office most of the time. So that I do think we should rethink where patients with HIV infection receive their care, and a lot of that care could be received based in the communities.

Now, there are some practical problems with that, so that for the present time many patients with HIV do go to specialty services and clinics that provide that care. That doesn't mean that's the best answer though, or the most effective answer, or what is best for the patients, that's what's happening.

CHAIRMAN OSBORN: David Rogers, and then Diane Ahrens.

COMMISSIONER ROGERS: Dr. Oleske, you made the point that to take the best care of your youngsters really required knowing--really picking it up prenatally. Would you tell us what the ground rules are for testing and counseling in our own obstetrical services in Newark now?

DR. OLESKE: Well, to be quite honest, the hardest part of pediatric AIDS over the last four years have been trying to get the obstetrical community involved. And I am not laying a blame at them. It is just that it was difficult to mobilize their resources, so in Newark, New Jersey where one in 20 to one in 22 women who deliver at our University Hospital are infected. That's about 5 percent. Less than 25 percent ever got any prenatal care, so they weren't offered testing and they found out they were infected after I had to tell them that they had an infant who was infected. Testing a woman and talking with her in the immediate postpartum period is probably the worst timing you can have.

When you don't test a woman before she becomes pregnant or early in the course of her pregnancy, you offer no options, no counseling, and it becomes after the fact. That's why I am fairly much against neonatal screening as a technique to capture, if you will, women. Remembering--and it is a very important concept--testing the newborn is akin to testing the mother.

So that if we could mobilize our obstetrical communities to offer prenatal testing, identify women with voluntary programs as part of what is good obstetrical care in a state like New Jersey, I think we would be able to identify women early enough that they could make choices, early enough that they could be counseled and prepare, if they so choose, for the birth of a child who may or may not be sick. Remember, 25 to 50 percent of children who are born to such a woman will be infected, the rest are not.

So that in coordinating and planning for the care of that child, knowing the child is infected is much better than finding out at three months when he comes in with PCP pneumonia. So that I would make a very strong argument, and one of my strongest please, is that one of the recommendations that needs to be developed is that HIV testing, at least in high risk areas, and maybe nationwide, of women as part of their care, whether it is before they become pregnant or when they become pregnant, should be a routine recognized standard of care.

So that there is no question then so the obstetrician is not having to guess whether he should or shouldn't do it, it is like doing a CBC or a test for serology or for syphillis or anything else that has been routine or standardized in our society. A woman comes in a physician and as part of the screening and HIV is done. Now, he has to know how to do counseling and has to be aware that if he identifies a positive, where those services are if he cannot provide them.

But most of the time, again, going back to your question, I think it is certainly in the purview and the expertise of any physician trained in this country to be able to test, counsel and provide services to an asymptomatic HIV identified individual. There is no excuse for physicians saying they cannot take care of an asymptomatic HIV had infected woman or adult.

COMMISSIONER ROGERS: Let me just punch this home for a moment. You are saying that within your institution where you are noted for the care of youngsters with HIV infection, your obstetrical department has no routine testing, counseling procedures?

DR. OLESKE: Until February of '89 they did not. It took us until February of '89 to convince our department of the need for those kind of services.

CHAIRMAN OSBORN: Diane, Don, Charles, and then I think we'll probably have to let Jim catch his plane. Let's see if we can do that much, and then Cathy I think can follow through with some of these points as well.

COMMISSIONER AHRENS: Dr. Oleske, my question really refers to what happens to children with AIDS and orphaned. There is such a dearth of foster care parents across this country now, and particularly in minority communities, very difficult in terms of getting adoption in those communities.

I am wondering what your experience is in providing placement of children with AIDS or children orphaned because of AIDS?

DR. OLESKE: I'll disagree just a little bit. As it turns out, our Newark community has been wonderful. I have fallen in love with grandmothers and great aunts in taking up the burden of providing services, extended family services, to children with HIV infection. In fact, in Newark we don't have a boarder baby problem as in New York.

I think the reasons for this is we have worked very closely with our Division of Youth and Family Services and our adoptive services to educate very early on potentially foster care families and adoptive families. Also, it is very important, as pointed out by Dr. Novello in her report, that extended families should receive the same support if they take on the responsibility of an HIV infected child as if a foster care family did it.

With those provisos you usually can find extended families frequently that will take on that burden--grandmothers and aunts and people like that. We have in New Jersey I think 87 HIV infected symptomatic children in foster care. The numbers game though are going to catch up to us and we are going to run out of those types of people, and I'm not sure what the answer is. I would hope we can avoid large residential communities. That bothers me as a pediatrician. The thought of another Woodbridge bothers me.

And I think what needs to be done is a continued education of extended families and other people in communities that have high case loads of HIV infected children of the need for their services. For example, I met just three days ago with a program called the National Association of Aging. I found out that you don't call them old people, they like the term "mature Americans." And there is a whole voluntarily force of mature Americans out there and they have this program called Family Friends. And I was so impressed with this program called Family Friends, and I looked on the back of the cover where Family Friends programs were. Salt Lake City, Utah, Omaha, Nebraska. No Newark, New Jersey, no Bronx, New York, no Miami Florida. You know, no Los Angeles, California.

And so what my response was, that program, Family Friends, would be wonderful in Newark. And I think we sell our minority poor communities short. If we develop Family Friends in Newark, I would think there would be an outpouring and a mobilization of a lot of senior mature Americans, both Black and Hispanic and White, living in those poor communities who would in fact probably step forward. But in many ways we don't give them that opportunity because those programs, those voluntary agencies, or even the agencies that are funded through public funds, don't try to capture that resource. And so I think it is a capturable resource that we need to look into.

COMMISSIONER DES JARLAIS: You mentioned about the difficulties in getting obstetricians to provide routine HIV counseling and testing. But you also mentioned, I believe, in your institution that only 25 percent of the women giving birth had any prenatal care at all.

It would seem that the real problem may be in this large group of women who are just--they are not going to get counseling and testing because they are not getting any other form of prenatal care, and that you can't just change what the obstetricians are doing with the small group of women coming in, that you have got to go out into the community or do something really radically different.

DR. OLESKE: I think it is fair to say that

AIDS has just focused, if you will, a spotlight on problems that have long existed in Newark. Poor women don't have very good access to health care. A poor woman who gets pregnant has less access to care, and a poor woman who is pregnant and gets HIV infected in Newark has literally no access to care. So that you are absolutely right. The problem has been preexisting AIDS. AIDS just makes it so much more evident.

What we need to do in approaching HIV infection--and Dr. Osborn and I have talked about this in the past--from my point of view as a Humphrey liberal, Hubert Humphrey is my political hero--is to do something about poverty. And until we recognize that we have to do something about poverty and drugs, we are running in circles. And so that in my community in Newark, New Jersey you are absolutely right. Even if my obstetricians were the most dedicated, loyal, hard working, committed HIV infection advocates there were, they still probably wouldn't be able to reach many of the women.

Unless we do something about a system where poor women do not have access to health care, whether they are HIV infected or not it is not going to change. You could say the same thing about drug use in our poor communities. I think that a lot of people used to think that I exaggerated the numbers, and I am sure that a lot of you think that the 10 million to 20 million figure is a gross exaggeration of the problem and I am just trying to scare you so that eventually my program and other programs get more money, et cetera, et cetera, et cetera.

I don't think that the people who have made the numbers have ever considered implications like crack is having on our adolescent population in places like Newark. Crack and this new drug, ice, are going to be two drugs, combined with an HIV virus, that is going to--and I promise you this is going to happen--take a tremendous toll on our adolescent population. And again, we can talk a lot about how we change the system, but it is going to have to be some very fundamental changes in how we deal with the whole issue of poverty and drug abuse. So you are really absolutely right, we can't blame obstetricians, that's like blaming the wrong people.

CHAIRMAN OSBORN: Dr. Konigsberg, one last question and then I think we have to let Jim go.

COMMISSIONER KONIGSBERG: Well, Don Des Jarlais picked up on the point that I was going to make about prenatal care, and I think what I would like to do is reinforce very strongly that what you just described, Dr. Oleske, is an example of difficulties in the public care system that we find in many urban communities. To be more specific, in my previous experience in Fort Lauderdale the problem with HIV infected babies was presaged, if you will, by a congenital syphilis outbreak, a thoroughly preventable disease in every way.

Again, mothers not coming in for prenatal care, a prenatal system where we had 17 week backlogs in our particular clinic, which was in and of itself a barrier, then compounded by crack cocaine. So my point here is to try to really reinforce how all these factors interact and that this is being seen I think in many of our urban communities.

CHAIRMAN OSBORN: Jim, thank you so much for being with us and taking the extra effort with a tight schedule.

DR. OLESKE: Well, I really appreciate the Commission's hearing our story from Newark, New Jersey, and any of you who want to come up to Newark, we would be happy to have you come up. Come up on a Friday, that's when our big clinic is, and if any of you know how to start an IV, that's even an added bonus.

Thank you very much.

CHAIRMAN OSBORN: Dr. Cathy Wilfert from Duke University, welcome.

STATEMENT OF CATHERINE WILFERT, M.D.

DUKE UNIVERSITY SCHOOL OF MEDICINE

DURHAM, NORTH CAROLINA

DR. WILFERT: Thank you, June. It is a pleasure and a privilege to be here.

Dr. Oleske as always has articulated common concerns from the group of us who care for children with HIV infection, and I would like to take the opportunity to expand on some areas and to contrast, if you will, an experience from an area which is not Newark, New Jersey, hoping that I can underscore some of the same points.

First of all, I am sure that most of you know that the reported numbers of children under the age of 13 with HIV infection are about 1 percent of the total population. Now, at this point in time that is reported AIDS, not infected persons.

I think probably most of you know that the adolescents by and large are included with the young adults, so that the risk to the adolescent population is hidden, because if you develop AIDS when you are 25, it is not immediately obvious that you contracted the infection when you were a teenager. So that the prevalence of the infection or the acquisition of infection amongst adolescents is underestimated.

We do have, roughly, a thousand adolescents reported to have AIDS, but rest assured that unfortunately there are many more acquiring infection. So I would like to point out that the problems are--I mean, there are two childhood populations, one of which is increasingly well enumerated and one of which is still hidden in the other statistics.

Recognize that 80 percent of babies who acquire HIV infection do so from infected mothers, and that this proportion of infection will only increase because we have successfully diminished transmission by blood transfusion and blood products. So by definition, as Dr. Oleske has said, there is another infected person in the infant's family, an infected person who may be ill or who may not be ill, but that is a unique situation, because, as you can readily appreciate, as with every other childhood illness, the children are not taking themselves to physicians. They are dependent upon their caretakers to take them to physicians. Their problems may be but may not be uppermost in the minds of their caretakers for a variety of reasons.

I think it is important to point out at this juncture that we speak a lot about education, but there is no education of a child which can protect them from acquiring AIDS, because it is always after the fact. The education of the adult is the way in which transmission might be interrupted, and that is the only way in which that kind of education can benefit a child or in which education can benefit a child.

Now let me say that the grim part of the picture which Dr. Oleske has alluded to I am going to make grimmer by telling you that untreated children--that is, without anti-retroviral therapy--will develop symptoms and die--at least half of them--by two years from the time of onset of the symptoms, and 80 percent of them by four years from the onset of symptoms. If you say from the onset of birth, you can add on two years. That is, from birth to onset of symptoms for 80 percent of the children the time is going to be roughly by the time they are four years old, but 80 percent of them will have died by the time they are six years old. So that the whole disease process is telescoped.

Now, let me also point out that one of the features of caring for these children is that in our best attempts to protect children from therapy which might be harmful, we have evolved through a system that has delayed therapy of children. It is only this past week that AZT has reached any sort of approval for administration to children, three years after it was proven to be efficacious in adults. This is the same disease, it is just as fatal. And it is important for everyone to appreciate that our evolution in thinking about therapeutic trials of children is incredibly important to making progress.

They die faster. They are dependent upon other people making their decisions from the standpoint of consent for serological testing to consent for clinic trials, and they deserve access to any form of approved therapeutic protocol in record time; that is, in parallel with adults, and we have evolved towards that. I do not intend this to be an indictment but rather a statement of progress and a need to appreciate that those of us who care for children are in favor of this kind of progress.

And I'm now going to make a very giant leap, because I think it is so terribly important and has been so controversial that it is I think of some urgency. If there is any chance at all that we can by intervention prevent transmission of infection from mothers to babies--and by that I mean animal models suggest that the administration of drug, AZT in this case, can prevent transmission of infection from the maternal animal to the fetal animal--the leap which I think we must take is that it is at least theoretically possible that we can interrupt transmission of virus from infected women to their babies, and those protocols are actually nearing completion.

That involves an ethical step which is, we will administer a drug to a newborn baby who is at risk from acquiring infection. That is, the baby's mother is known to be infected, but we do not know if the baby is infected. And we are willing to take that step. That is, we can justify the administration of a drug which actually is very well tolerated in newborn babies, if we can establish that we interrupt transmission and stop babies from acquiring infection.

And also, I want to apologize, I don't mean this to be a platform. This is an issue which will come up with the Commission and will come up in the newspapers from the standpoint of better diagnostic tools so you don't have to give drug to babies unless you can prove that they are infected. And the step which I think is so terribly important is to consider that we might prevent the infection by an intervention with appropriate therapy.

Now, let me speak to our population at Duke, because I think that North Carolina is a rural state, happily so I might add. The population of the state is probably about seven million people. We follow in our center approximately one hundred children who are infected with HIV. The number has doubled in the last year. We see a new child every Monday and Thursday in clinic, so that we see one to two new children who have never been identified before per week. We have a drug using population in a county of 160 thousand that numbers approximately 3,000. We have 15 percent sero positivity in the drug using population.

Durham is a wonderful place to live. I do not believe that our community is unique. I believe that this is an example of infection outside of the recognized epicenters that exists all over this country.

We have been providing care for these children, and I would like to expand just a bit on supportive care. Once you know that an infant is born to a sero positive mother, although somewhere in the neighborhood of 30 percent of those children will actually acquire infection, all of the babies require extra medical care. You need to be able to determine who is infected and who isn't. You need to treat each possible infection as though the infant does have HIV infection. So that the numbers of children that require extra care are larger than the actual numbers who end up being infected.

I would echo Dr. Oleske's call for prenatal care, for support for women in prenatal clinics. We have a unique clinic in the public sector, the Durham

County clinic, which happens to be called Lincoln Community Health Center, where 90 percent of the women come in and receive their care before the third trimester. There are no funds and no way in that community to support the appropriate intervention, serological testing and/or counseling, and/or all of the time and extra effort it takes in that community of women to deal with HIV infection.

They are receiving excellent medical care. There just is no way to add on what is essential if there is HIV infection in the community, and that situation certainly must be existing in numerous other places. For the children I believe, as Dr. Oleske has said, the key is going to be obtaining support for care of women with HIV infection, which is at least equal to the care of others with HIV infection, and is, with regard to their pregnancies, at least equal to other pregnancies. And that's a need which I see for this country in particular.

Let me deal with foster care briefly. Twenty-two percent of our children are in foster care. There are no boarder babies. Every child has been placed in a home situation. An additional 15 percent of our children are living in extended families, great grandmothers and great aunts, uncles, whoever assumes responsibility for these children.

We have not been overwhelmed by--we continue to be able to place children, as Dr. Oleske has suggested, but the need to help agencies train parents or educate people who would be willing to become parents is one which extends across the country. It has been solved in our location by Lutheran Family Services, who has taken on the entire state as well as the State of South Carolina and some other southeastern states. But it needs to be approached in every community, because that's how we will be able to provide homes for these infants.

Let me just say finally, and then leave the floor open for questions, that I believe that it is possible for pediatricians and family practitioners to care for children with HIV infection within the framework of their usual practice setting. I think, as is the case with many complicated illnesses, those individuals will call upon the resources available to them, whether it is a university or whether it is another medical center nearby that has multi-specialties, and I believe that it is possible to meet the needs of the mothers and children who are infected, many of them within their home community.

I think it is exceedingly important, since right this minute the numbers are proportionally small of children--that is, the numbers, as I have said, approach 2,000--that any study which is designed to investigate the care of these children and therapeutic results be carefully considered and collaborated across the board nationally.

We conserve lots of our national resources. I don't regard AIDS infected children as a national resource, but I think that it is foolish to think that you can do uncoordinated studies in a population which is both scattered and very different, and that you must have coordination of the investigative studies to obtain answers as rapidly as possible. And that is happening now, thanks to the AIDS clinical trial program, but it continues to be a very urgent need.

If the study which I described to you to intervene with transmission of infection from mothers to infants takes place, it will require enrollment of some 700 women and children, and it is immediately obvious that every center in the United States who is caring for mothers and babies would need to have access to the study to enroll their mothers, because you must administer drug we think within the first 24 hours. So if you identify a baby at a week of age, the baby is not eligible.

And that I would use as the ultimate example of how important the coordination of these kinds of resources are if we are to obtain answers which are ultimately useful for the entire population.

I think I'll just stop right there and say I will be glad to answer questions.

CHAIRMAN OSBORN: Thank you very much. Are there questions for Dr. Wilfert?

Dr. Konigsberg?

COMMISSIONER KONIGSBERG: Dr. Wilfert, you mentioned I believe that there was an underestimate of the prevalence of HIV infection in adolescents, and I was wondering if you would elaborate on that a little bit and what you saw as some possible solutions to getting a better handle on the prevalence of HIV infection, particularly in that population or in people in general.

DR. WILFERT: I think there are some people who are approaching it, actually. Here in Washington Georgetown has done a prevalence study, and I can't remember the number, but it was teenagers in their emergency room. And I believe that in New York there has been a study in a population of adolescents, particularly drug using adolescents, but there needs to be additional information gained. So that it is being approached, it is just now beginning to open up, I think.

CHAIRMAN OSBORN: Dr. Rogers?

COMMISSIONER ROGERS: I could add one figure there. In homeless youth in New York City, ages 13 to 18, HIV positivity in boys about 6.9, in women almost the same, almost 6 percent. That certainly shouts for heterosexual transmission.

I much enjoyed your testimony. Educate me once again on--and I like your gutsy suggestion that we begin to think about treating mothers to prevent the infection or their newborns. I didn't quite understand your last statement in terms of--and I gather you are extrapolating from the animal system--when do you need to start treatment of the mother to prevent it in the fetus?

DR. WILFERT: Well, I sort of skipped over that much too fast, Dr. Rogers. The animal studies suggest that if you are giving it after the fact that you need to have drug on board as quickly as possible. So that if the infant is being exposed to virus primarily during the process of delivery, having drug available within the first 24 hours or so is ideal. And the animal studies--

COMMISSIONER ROGERS: Post-delivery, you mean?

DR. WILFERT: Yes, postpartum. The next phase of the study would be administration of drug to pregnant women, and the FDA has in fact approved a pharmacokinetic study to do that, because it is possible that administration of the drug in the immediate postpartum period will not succeed, and then it will be do you administer drug in the last trimester of pregnancy. I no longer regard that as brave but probably essential and am preparing the way for people to learn that we are proposing to give a drug to pregnant women.

Let me make one last point which I should have made at the very beginning, and that is that most of you probably are aware that nationally children are underinsured with regard to health care. Many of their parents are insured, but they are not included in the insurance policies. Two-thirds of our children have Medicaid only and nothing else. I am sure that some populations--it may be 80 percent or 90 percent--but I wish the Commission to pay attention to the fact that this highlights a problem which exists for children, and the disease itself is calling to the surface the major deficit in health care coverage for children with severe illness.

CHAIRMAN OSBORN: Mr. Goldman?

COMMISSIONER GOLDMAN: Is there any consensus in the medical community as to when the transmission from mother to child in fact takes place?

DR. WILFERT: Well, I think the answer is going to be that it is variable. The fact that transmission occurs probably 30 percent of the time and not 100 percent of the time strongly suggests that it isn't just in utero. The fact that infants can't be identified in the immediate postpartum period, or that only a proportion of them, roughly 20 percent, can be identified in the immediate postpartum period, suggests that some infection occurs across the placenta. If we are lucky it will be in a minority of babies, and that the majority of infection is in fact occurring at the time of delivery. We don't know that, that is strictly a guess.

CHAIRMAN OSBORN: Cathy, could I ask a question. You have a somewhat different population and setup to deliver care than Jim was talking about. But I wonder if you would like to comment about the coordination of care of sick mothers and sick children, because that, in addition to the fact that there are problems with mothers being brought in, that those are two dynamics that can be quite associated. And do you in your clinical setup have a way of coordinating awareness and care delivery for the mothers and children in those situations where both are actively progressing in their disease?

DR. WILFERT: The area where we do least well, June, is in the prenatal situation. That is, oftentimes we are seeing infants because they have been identified and then begin to provide care for both the mother and the child. In that setting we provide care for both at one institution.

I am sort of embarrassed to say this out loud, but the average length of time that a child travels to our clinic with the mother or responsible caretaker is two and a half hours across the state. I wish to say that the compliance for those who are in studies has been better than 95 percent. So while I describe a population which for all practical purposes is severely disadvantaged, not totally, but many of them in lower socioeconomic status, who haven't been able to mobilize resources, when the means is provided for the care to become available, we have amazing compliance with the most intricate of protocols under circumstances which I think would tax most of us, weekly to monthly trips to a clinic across the state.

CHAIRMAN OSBORN: The other thing I wondered if you would bring out, and I think that you and I in private conversation have talked about the increasingly rural nature of the infection and drug use in North Carolina, and other states, of course. But if you could bring that point out, I think that belies some people's conception of rural versus urban in this epidemic and is helpful to see the future.

DR. WILFERT: I already said, our county has a population of 160,000, but our patient population is scattered throughout the state, and the most rural areas where the communities probably have a couple thousand people have significant amounts of drug use.

Part of it may be because I-95 runs from north to south and cuts across our state, and the distribution of drugs does tend to follow some of those pathways. But it has certainly reached the rural corners of our community with no difficulty at all, sad to say.

CHAIRMAN OSBORN: Are there other questions for Dr. Wilfert?

Thank you very much for taking the time to talk with us. We appreciate it.

We have an opportunity here to have some general discussion for a short while, if the commissioners wish. It has been a long day and we have another day tomorrow, so I don't think this needs to be profound or detailed. But on the other hand, if there are points that people would like to highlight or raise now about what's happened today, this is a time to do so. I think there is a lot to absorb.

Dr. Rogers?

COMMISSIONER ROGERS: I'll try and get the group going. I think it was said many times today that--and Diane and I talked a bit about it--AIDS has certainly put the spotlight on an enormous number of really tragic deficits we have in our health care system. We are, obviously, charged with trying to put this together in ways that will be helpful for people with AIDS, but I hope we are smart enough to do it in ways that will help improve the lot of all of the "have nots" in our society. I think to bring them aboard, perhaps using the vehicle of this particular tragedy, would be very worthwhile.

I guess the thing which I find deeply troubling after three years in this business, June, is the stories are as tragic as they were three years ago. We continue to be a country that is sort of business as usual, the same bureaucratic nonsense put in front of programs that seem to me you ought to be able to get done in a couple of weeks, no one really acting as though this is the catastrophe which every person before us has outlined.

The question which is continuously in my mind is why the hell does it take us as a nation so long to do the things which I bet we could design on the back of an old envelope in about 20 minutes if we took the time to do so. I'll just be that provocative to get the Commission going.

COMMISSIONER AHRENS: Well, since we had our conversation, let me just say a few things, and they will have to sort of come from experience where I live. But it just seems to me when we look at the health care system--and it really isn't a system, or whatever we have out there--that whatever we have is really broke.

And one of the illustrations that I see of this, we heard today from several people--and I think it was Dr. Smith that talked about the fact that the people that were now--the ones that we are now seeing, that are coming in with AIDS and increasingly being affected, were not people who had a primary care physician. Their primary care physician is the emergency room, and generally in the public hospital.

Now, our public hospital in Ramsey County, Minnesota, the county provides $1.6 million a year for the hospital to draw down for indigent care. Now, we have a very good system called Medical Assistance, which is Medicaid, and we also have a general assistance system that provides good health care for people eligible for that program, General Assistance.

So the people that come in that are the indigents into that hospital and into that emergency room are the working poor, primarily. That's who those folks are. In 1988 that hospital ran out of its $1.6 million in November, and they just ate it from November through January 1. This year they ran out in September, and so they are eating it from September to

December 31.

Now, that just seems to me to indicate how the system is not only broke but it is getting broker. And either the county increases what we are giving that hospital or the hospital will soon be belly-up, because they just simply cannot continue to absorb that.

That is just sort of one aspect of, and I think illustrative, of the breakdown. There are all kinds of other illustrations I think we can give. We can talk about the number of people who are uninsured, the 13 million children uninsured. We can talk about what is happening to doctors, and doctors are even saying now we have got to fix the system.

I just think there are a lot of interests in the health care industry, including I think people out there who have private insurance, that are beginning to realize there is something really the matter with the system. And I think they are beginning to coalesce. I think this is going to be the domestic issue of the early '90s in the Congress, and we are part of that whole issue.

In fact, I think we can almost be the

facilitating issue that can highlight how bad out off we are. And it is clearly only going to get worse. If AIDS wasn't even a part of it, it would get worse, but with AIDS it is going just to be devastating. So I just I think we have to take at a real good look at how we approach the whole issue of financing of AIDS.

CHAIRMAN OSBORN: Eunice Diaz?

COMMISSIONER DIAZ: I had just three thoughts after sitting here all day listening to some really wonderful testimony. But this is what I've gotten out of it, adding a few thoughts of mine.

I really think that when we look at what we have today in terms of treatment and care issues and access and delivery issues, we have really got to focus very clearly on the fact that AIDS in this country--and you will hear me repeat it every Commission meeting--is a problem heavily impacting the ethnic and racial minority communities. Today, other than one individual, all of the presenters, we have had to draw that aspect, but I don't think that too many of them have focused on the particular problems faced by Hispanic and Black communities in this nation.

And in order to do that we would have to have individuals who can offer that perspective, almost through the various subjects--prison, women, certainly the public hospitals--because we do have people there that are from these groups that are doing work and can see the perspective as to how the various issues affect ethnic and racial minorities.

I discussed with one of you over lunch that I personally have known 300 persons that have AIDS, personally. I wrote their names down. Over 200 of these individuals have died. I have yet to find anyone of those 300 individuals who has told me that what they needed from the medical care system or health care system was high tech, more treatment within those facilities. But I have found, probably overwhelmingly, all of them have told me what they needed was high touch. I think we talked very little about that today.

And finally, in the treatment and care arena and financing, although I agree with what Diane Ahrens has said so eloquently, really we probably need to begin to look more--and I know we will tomorrow--at creative ways of organizing what we have. There just seems to be so much relationship to how services are organized, how they are delivered in terms of making those dollars stretch, and creative partnerships between public and private funding.

And I think we are going to have to look very much in terms of utilizing what there is there and reorganizing it for the betterment of providing patient care and services to our populations. And that goes right across the board. Our community health centers that were mentioned this morning, if they are not doing the job for our people, why aren't they?

We have heard today again kind of a very stimulating discussion of the need to create regional centers that are highly specialized, and some of us who feel that perhaps at least in the area of providing care to racial and ethnic minorities that creating access points, multiple access points in the community is really the way to go. We just have not done well at being able to get our community people into major centers or very specialized centers.

I think we have to learn a lot from that experience. Why is it we are eight years into this epidemic and that does not seem to be? It is not a matter of transportation. Or do we have psychological barriers that prevent people from accessing care at these very beautiful, specialized places we have now?

So in creating systems that we can suggest, I think let's look at reorganizing and creative ways of approaching what there is now out there, and always keep in mind that in this country 42 percent of the people that have AIDS are definitely from racial and ethnic minorities. That has to be an overriding concern in every single one of our discussions and I am not going to let any of us forget it.

CHAIRMAN OSBORN: Thank you for not letting us forget it. I think that many of us have it in the back of our minds, but I think it is very helpful that you keep bringing it to the front.

COMMISSIONER KONIGSBERG: I would like to expand the discussion a little bit from comments that Diane Ahrens and Eunice Diaz both just made in terms of system problems, and I agree with all of their points. I would like to expand it a little bit to the public health system. If you will recall, I attempted to get

Dr. Koop to give me an answer as to what he thought about the public health system in this country in terms of its ability to respond to an epidemic. And there is something in our charge from Congress about at least the Federal Government's ability to respond not only to AIDS but other epidemics. But I would like to think of that in terms also of state and local governments.

Another IOM report, which June is also very familiar with, is the recently published report on the future of public health. And there were many serious concerns raised in that report about the public health system in this country which, like the rest of our health care system, is pluralistic. I mean, it varies widely from state and local levels in terms of consistency, and in terms of what it does, et cetera.

And the three major functions that were outlined for public health in that report were assessment, policy development and assurance. And I guess as we go along in our deliberations over a couple of years, as a state health official and formerly a local public health official, I hope that we'll avail ourselves of the opportunity to look not only at the medical care system which we have been looking at today, but the public health system at the federal, state and local level in terms of its ability to respond, because not only is there that health care function, but this assessment function.

For example, seroprevalence is a good example of an assessment function in the policy development, which is often the function of health departments. We heard one speaker indicate, I think correctly in my view, that the state health department should be taking some leadership. And we need to examine those points, and I would certainly urge in future deliberations that we get some state and local health officers--both, not just state--to come in and talk to us about the system, the things that they are doing right, the things that trouble them.

I predict it will be just as frustrating as the rest of it. They will also echo much of what we heard today in terms of the medical care system. But I want us to look at it in the broader context of the nation's public health system because, again, in a couple of talks I have given recently I've made comment that to the extent feasible to do so, other diseases known and unknown in the future that we are supposed to look at. That's a real scary charge. As if AIDS weren't scary enough, what happens with the next? And were we really prepared?

We may be better prepared for earthquakes in this country than we were for an epidemic like AIDS, and what happens with the next one? Thank you.

CHAIRMAN OSBORN: Don Goldman?

COMMISSIONER GOLDMAN: I worry about whether or not and what we as this Commission can do to deal with obvious defects and deficiencies in our health care delivery system. But one thing is clear, it seems to me, and that is that, I think as one of the speakers tomorrow pointed out in a recent JAMA article, rather than a full fulminant illness treated primarily inside the hospital, the disease will largely become a chronic condition requiring years of outpatient monitoring and pharmacological intervention.

And I think that is as clear as the handwriting on the wall and we ought to keep our eyes on, not to ignore their needs, certainly, but that if this Commission is to do its job we have to keep our eyes on the ball. The ball is 5 or 10 years down the road, and 5 or 10 years down the road we are going to have a massive problem in terms of available treatment for people with HIV disease, that is, a system that is simply not capable or able to cope with it.

I think in that context we have two charges that have to deal with that issue. One of them is that I think we do have to address the total system, but I think we also have to address the system of care delivery for people with AIDS and HIV disease. And in a world not necessarily the way it is today, but in a world that is likely to be 5 or 10 years from now, what are the kinds of systems, what are the kinds of programs, what are the kinds structures that ought to be in place in order to deal with HIV disease at that point in time in the future?

And those are awesome challenges. I frankly find my mind to a large extent at this point of the day a piece of mush, and as much as I deal with AIDS and HIV disease, as much as I mourn when friends of mine die, as much as I think I intellectually understand the problems that exist, when I hear them again from panelists as eloquent as we had here today, I feel so helpless and I feel so inadequate and I feel so overwhelmed.

I am looking forward to tomorrow, but I would certainly like to thank you, Madam Chairman, and the staff for putting together an inspiring group of presenters for us today.

CHAIRMAN OSBORN: Well, I think the staff did a heroic job of putting things together. I think one thought I had in listening to your comment Don, that it doesn't make this seem any easier, but it does make it seem, if anything, more important. And perhaps as a helpful insight, those of you who have not had a recent chance to look at demographic statistics about AIDS distribution in this country, or for that matter, health care needs of elderly and now--earlier it was mature adults--but we also are developing terms such as older older, and oldest older, and things like that in health care--that those trends are timed in such a way that if we did our work awfully well we would be just in the nick of time.

And as such I think we will certainly be only one group focusing on this. Certainly the Pepper Commission has been looking at very much related needs. The thing that drives the need is quite different, really, and yet the needs come out looking similar.

Now, that's on the one hand to the extent that the system is broke, and as Diane is pointing out, needs a lot of fixing, that's scary. That sort of more than doubles the load. On the other hand, it also makes it more likely that if we join forces that we may be participants in a very important systemic change and one that would be just in the nick of time for people well beyond HIV.

So I think that is good news and bad news wrapped up in one perception. But it certainly adds to the rationale for tackling what seems an impossible task.

COMMISSIONER GOLDMAN: And the one hope that I have is that perhaps in the year 2125 we will be able to meld those two and have programs and seminars and perhaps commissions on geriatric problems in patients with HIV disease, and that's not beyond the ken of hope, it is not beyond the ken of what is foreseeable, if we do our job right now and provide the kind of systems, it is possible.

CHAIRMAN OSBORN: Don Des Jarlais?

COMMISSIONER DES JARLAIS: We seem to be having a developing consensus of AIDS throwing a spotlight on a health care system that is breaking down anyway, and there is clearly lots of evidence above and beyond HIV that the system is running into real problems.

I think also though in our deliberations as a Commission we need to identify special areas that can be done immediately at no cost and may have a large effect. And maybe even areas where we say, start doing this, but stop doing that; where there are even counterproductive efforts currently underway that could be stopped and would save money and probably reduce the spread of HIV.

Second, on the sort of long term issue, the sense I have of Cain's remark that in the long term we are all dead, and I really worry about HIV in a long term, that we really need to focus on things that really could be done quickly and at minimal cost, and that this Commission I am sure can have a major effect in the ongoing restructuring of the health care industry in this country, but there are a lot of other things that we need to do about people who are either in immediate need of treatment for HIV related disease or who are at very high risk for becoming infected with HIV, and we simply can't wait in terms of providing some immediately needed treatment and reinforcing prevention.

An additional comment, picking up on what Eunice is saying, and going back to some of the things John Mann was saying this morning, there are many countries in this world where people with HIV infection and at risk for HIV infection are not members of ethnic minority groups, and I think that some examination of those health systems and the prevention programs in those areas could perhaps teach our country many valuable lessons of what can be done for meaningful HIV prevention when there is perhaps real empathy between the people at risk for HIV and the people who control resources. And that we may want to think in terms of not just having all of our hearings and all of our witnesses be people from the United States, but to also look at health and social systems that are tackling the HIV problem without a collective burden of racism overlapping the problem, and get some idea of what could be done if we are willing to break some of the mindsets associated with racism and say, look here, you could be doing this, and if you got away from your historical blinders you may without any massive increase of money just be able to go out and do some things that could be very effective in the short run.

CHAIRMAN OSBORN: Thank you very much.

Suzanne Neeme?

MS. NEEME: As the PWA observer I would be remiss in not noticing that I think a very important issue that really hasn't been spoken very much about is the empowerment of the PWAs to do things for themselves, and to work within the community and the medical community to do more for themselves and to get more involved in their medical care, which would relieve some burdens of the public hospital and the physician's care. As a person with AIDS can learn more and more about their medical care and do more and more, the chronic care management becomes much more reasonable, as they can do more and more care at home and not have to be hospitalized so often.

I think that is something that we really need to focus on, and especially in the minority communities where there isn't as much focus on empowerment as there has been in the Gay community. And I think it is very important that we all work very hard to help the organizations within the minority communities that are working towards empowering their population towards better care and better health, and I think that it is something that is very important, is PWA empowerment.

Thank you.

CHAIRMAN OSBORN: Thank you. That was a wonderful contribution to give us something to think about and factor into today's ruminations between now and tomorrow morning.

I think with that perhaps we should adjourn for today, and we will be reconvening tomorrow morning with I think an equally articulate and daunting group of witnesses.

Thank you for today's hearing.

[Whereupon, at 5:00 p.m., the hearing was recessed to reconvene the following morning at 9:00 a.m.]