ORIGINAL

TRANSCRIPT OF PROCEEDINGS

NATIONAL COMMISSION ON

ACQUIRED IMMUNE DEFICIENCY SYNDROME

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HEARING

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Denver, Colorado
June 5, 1991

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NATIONAL COMMISSION

ON

ACQUIRED IMMUNE DEFICIENCY SYNDROME

HEARING

Wednesday, June 5, 1991

8:40 a.m.

Stapleton Plaza Hotel
Denver, Colorado

COMMISSIONERS PRESENT:

June E. Osborn, M.D.
David E. Rogers, M.D.
Harlon L. Dalton
Michael R. Peterson
Larry Kessler
Diane Ahrens
Scott Allen
Donald S. Goldman
Valerie P. Setlow

STAFF PRESENT:

Frank Arcari
Tom Brandt
Joan Piemme
Karen Porter
Jane Silver
Patricia Sosa
Tracey Bush
Nicole

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P R O C E E D I N G S

DR. ROGERS: Good morning, and welcome to all of you. I think it is entirely appropriate on this tenth anniversary of the AIDS epidemic to hear from a group who have been neglected in many instances, women and children. We are really quite well-briefed, but we are enormously anxious to hear from you.

Those of you who are not from the East Coast have probably not seen what I thought was just an elegant op-ed piece this morning, and I'm going to read you a few sentences from it. This is by Michael Gottleib, who some of you will recall was the doctor who first saw cases of what we now call AIDS on the West Coast. June 5th was the date that it was first reported in the MMWR.

This is what Michael Gottleib says, among other things.

"As we enter the second decade of AIDS, the question that haunts me must haunt everyone. How did this epidemic happen? Why wasn't every possible step taken to halt the spread of this virus? And, perhaps most importantly, why is there no comprehensive national plan to address the most costly epidemic of our time?

"The tragedy, of course, is that the AIDS epidemic was preventable. The war could have been won early if there had been a commitment at the highest levels of the government.

"We need a battle plan for AIDS in the 1990s. Mine would aim to do the following: Persuade President Bush to take charge of the crisis by putting AIDS at the top of his domestic agenda.

"Revive the prevention message first voiced by Surgeon General C. Everett Koop. It has been neglected since he left the government in 1988. He made condoms a household word. Because of inadequate prevention strategies, 40,000 to 50,000 Americans are newly infected each year.

"Prevent the spread of the virus among drug users, their sexual partners and babies. This strategy must include distributing free clean needles to addicts, and expanding methadone programs and basic health care for this impoverished population.

"Increase access to prenatal care and testing for the 80,000 or so women of child-bearing age who are infected with the HIV virus.

"Expand financing for research on treatment and vaccines. AIDS is still a medical emergency and warrants urgent expenditures."

I had the feeling in reading this that he had written our National Commission report for us. I think that is a fine message for us to start the day.

If the first panel would come up to the table, we will begin the proceedings. Those of you who have seen the schedule will I am sure recognize that we are trying to hear from a great many of you this morning, and consequently I would ask that you stay meticulously within your time. Each of you will really have a 15-minute crack. But you will find, I think, that the commissioners love to ask questions, so if you can keep your statements fairly brief and then interact with the commission, I think that will be most productive -- and I will warn you when time is running out.

We are privileged to have Lorelei Estrada, Frankie Mason, and JoAnne Suiter with us this morning.

Lorelei, are you kicking it off?

MS. ESTRADA: Yes, I am.

DR. ROGERS: It is a privilege to have you here.

STATEMENT OF MS. LORELEI ESTRADA

MS. ESTRADA: Nice being here, thank you.

Growing up, I had a fairly good childhood. My parents were well-off. But my downfall was my boyfriend, who turned out to be my husband of 18 years. He was an IV drug user. We had our ups and downs, but he was my addiction. I didn't use drugs. I went on to school. I was even a police officer for seven years. I've raised three wonderful children. In fact, my oldest is graduating from high school tomorrow.

Unfortunately, the last time my husband got out of jail, or prison, I should say, he was infected with the virus, but he didn't tell me. We had these big plans that we were going to leave California and go to Arizona and start a new life, and he was going to stay off drugs and get a full-time job, which he actually did do. The only thing is, he didn't tell me he was infected.

Two years later, I was five months pregnant and I became deathly ill. I didn't know what was wrong with me. I couldn't stand up. And so I went to the hospital. And that's when they told me, we can't find anything wrong with you, Mrs. Estrada, but there's two more tests that we can give you. One was the syphilis, and the other was HTLV, which is now the HIV test. Christmas Day, three-and-a-half years ago, it came back positive.

A lot of people don't like me for what I did, but I opted to abort the child immediately, and I did it because of the fact that I was sick. I knew that my body was saying hey, there's something wrong, get this out of you. And I felt really awful about it at the time, but I know I made the right decision. A lot of people disagree.

I couldn't go home at first, because I figured my husband hasn't even come to talk to me yet. He hasn't said anything. And so I called my mom, and she hung up and says, oh, Lorelei, you've always got something wrong with you.

And I went home, and I tried to talk to him, but he wouldn't listen to me, and so I started throwing things. In fact, I threw my plant so hard that when it hit the wall, it didn't even shatter, it stuck in the wall.

Ironically, two weeks later, my husband came down with his first case of pneumocystis pneumonia. I called the ambulance to transport him to the hospital. They refused, so I drove him to the hospital. They refused to admit him, and so I didn't know what was going on.

I was scared to death. I had just been told I was going to die within a year, eat vegetables and meat and get your will together and find out who you're going to give your kids to.

And so I called the woman who had given me my test result, and she was very gracious and came to our house and she said, Lorelei, I don't know where I'm going and I don't know when I'll be back, but I will be back. Apparently, this woman drove all night long. She couldn't find a place at that time that would take him in.

At ten of ten the next morning, she called me and told me that she was at St. John's Hospital, and that they had agreed to keep him for three days. The three days were over, I brought him home, and we hadn't been there a half-an-hour and there's a knock at the door, and we were asked to leave the community. We were told that they didn't want our kind there.

So, naturally, because we were scared and frightened, we left, and we came back to California, and my husband was immediately put in the hospital, and he spent 30 days--that's how ill he was.

As soon as he got back, he started using drugs again, and continued to use drugs. When he died, he was on 150 milligrams of morphine an hour. He died last July 16th, and he never did tell me, I'm sorry, or why he didn't tell me or anything.

Since the time I was diagnosed, I've had numerous yeast infections, I have had numerous ovarian cysts, where there's one with another one inside bleeding. They won't treat me. They won't let me into a hospital. They don't want to do anything.

The last time, they finally told me, Lorelei, well, come back in--this was a week later, in unbearable pain--they said, well, we'll try and stabilize your pain. And just as they got with the inner ultra-sound, the thing went poof on the screen, and I turned around and I said, now can I sue you? I didn't of course. I wasn't going to gain anything out of it.

But from the public I haven't, you know, gotten any real discrimination. It's just been from treatment. Right now, I'm at--I don't have a doctor. My doctor has quit.

In our North County, I do almost all the education that is done. Our funding was cut, so there's no money left. The doctor quit three months ago and has still not been replaced. A few months ago, we had eight new cases of women turn up positive, but there was nowhere for them to turn. I have had three rape cases that just turned up positive in the last month.

There's nowhere for them to go, because there's no doctor. And the doctors that are there won't treat us. They say, oh, you can find a primary. Well, if the primary's don't want to treat us, who do we go to? There's nobody for us to go to.

I know I'm going to die, but I don't know when. But until then, I want to have somebody that's going to take care of me, that's going to be there when I turn around and say, I've got an infection. That commercial on the TV's got to go.

I mean, those of us that know that we have yeast infections but were infected, okay, fine. But a lot of these women, they might be getting these yeast infections, and they don't know that they're infected. And then what's the good of this medicine? It's just going to take the itch away? So, I don't know.

I'm just privileged you guys even let me come here and speak. I just wish there was some way we could get these infections put on the definition. Something has got to be done. Something has got to be changed. Thank you.

DR. ROGERS: Ms. Estrada, thank you. I think we'll hear from your colleagues, and then I'm sure the commissioners are going to want to ask you all questions.

Mrs. Mason? Could we hear from you?

STATEMENT OF MS. FRANKIE MASON

MS. MASON: Hi. I'm Frankie, and I've already written testimony that's placed in your packets. One of the reasons for that is because there may be some areas I might not be able to touch because of my commitment to this disease in women and teenagers.

DR. ROGERS: Be assured, we will read your testimony carefully, so just free-wheel on the major points you'd like to have us know about.

MS. MASON: Thank you. I'm a recovering addict of four years. During my addiction, I had a blood transfusion after having a miscarriage with a baby in '81. After having the miscarriage, I ended up getting married and having my husband, who wasn't worth nothing, and going on into a life of prostitution and still intravenous drug use. This went on for 18 years for me.

When I found out anything about AIDS, I was pregnant with my baby. My baby was born full-blown withdrawals from methadone, cocaine, heroin, alcohol. She was born HIV-positive. She wasn't breathing.

When I found out I was pregnant, they told me to abort my baby. And the lifestyle that I lived, I needed this baby in my life to make me feel like I was somebody, because I always felt less there. My self-esteem was not there, because I always looked back at what my mother did or my father did, or, you know, somebody always did something to Frankie.

So I had this baby, and I had this man that loved me. And to come up diagnosed with AIDS was real devastating for me, because I just knew my life was over. I would sit around the house and listen to the media. The media would always talk about Ryan White, how people discriminated against this kid, this kid that had a blood transfusion--didn't have a mother like me.

And I would start beating on myself, because I didn't feel worthy of having this child. I didn't feel worthy of living a life, and I went back out and continued on my mission, which was a mission of suicide.

I decided that the baby and I needed to die because people did not want us around. They weren't going to treat us like human beings. Once they found out about my past, the poor baby was never going to be accepted in society.

So, in my mission of hope trying to succeed, I did not. And one of the reasons I also like to talk about is the behavior that I had when I was in this denial, this anger of being rejected by society was I'll hurt anybody and everybody, and if you hurt me, that's okay, because I'm going to die anyway.

I did not tell people I was infected with the HIV virus. I didn't care if they knew, and after the baby was born, I was real--I was more angry then, because I was still alive. My mission was not completed. I really wanted to die. I didn't know anything about AIDS, all I knew was my past wasn't going to help me, and AIDS was going to kill me.

After I'm going through the feelings and the fear of the baby being born and being in the hospital with labels all over the hospital talking about infected blood fluids and all of these things, I just knew I was doomed.

So I went on out and continued to do the same behavior that I did when I was pregnant. Thank God they didn't lock me up. I have girlfriends that are in jail for child abuse. I wasn't locked up. They just took my kid. My baby grew up in a very happy home, but I ended up homeless.

And when I ended up homeless, the courts found me and gave me my summons to court, and the judge stipulated me to a long-term program. In this program, this program taught me that HIV was not my problem, substance abuse was my problem. If I got a handle on that, maybe my life would get a little better.

They allowed me to get into support groups that had heterosexual females and males in it, because I wanted to compare out with the gay community at the time. After finding out the heterosexual community didn't have as much information as the gay community, I went into the gay community and asked for help.

Something happened to me, because they told me that AIDS was a diagnosis. All this time I carried my baby, I thought I had AIDS. I did not know that I had the antibodies for AIDS. Information was not very clear. The doctors told me I had AIDS, you know, and that I would die and so would my baby, so I was already doomed.

After getting with the gay community and getting all the support and the help, I ended up going to find me a doctor. When I went to find a doctor, they told me I didn't meet the sliding scale. I worked a job. My job was paying me too much to get AZT or medical help, so I ended up doing some lying. I ended up doing some manipulating. I ended up doing a lot of things to help me to be able to survive in the society.

I am an example of a fighter, but I have a lot of female friends that have given up that are doing the same behaviors that I have done in the past.

Today, I work for a national association, and they also help me with a lot of medical information. They help me to find protocols. They're helping me to find out how I can get medicine on my sliding scale. A lot of people are not being given this opportunity that I'm given.

I'm a screamer. I yell real loud. I'm trying to sit here and be as composed as possible, you know, and one of the reasons is because media said this morning that they had 100 teenage boys diagnosed here in Denver, and the reason they were infected was because of the gay community, and that's a lie.

I do a lot of teenage outreach. The teenagers are still in denial. They are being misinformed about the AIDS virus. They're dying, and I'm afraid. I'm afraid, because I have a daughter 19, I have a son 16, and my little girl was born HIV-positive.

I'm sitting here with a full heart and real heavy, because like my peer said, I'm going to die one day, but I'm not sick yet. I have a lot of friends that cannot walk. I have friends that can't get Medicaid because they had to leave from one State to another and wait on the medical help, and you know, it's just--I'm--

DR. ROGERS: Take your time.

MS. MASON: Most of it is fear. I sit here and I look like this too, because people have this description of a person with the virus, and I'm getting ready to get married. We don't look a certain way. We are all human beings. We feel.

The gay community has really been supportive of me, and when I came here to Denver, it hurt me so bad to know that there's so much abuse still being done to people that have this virus.

Basically, what I want to say to you all is a lot of people cannot keep this hope alive if they don't get the information that has been given to me.

I feel no problem with you all supporting to give condoms to save lives. Teenagers have choices. If they are held back, knowing that they can't get condoms because their parents say, I don't think you should use them, they're going to die. Our future is going to die just because of a letter with a big A to it, you know.

And I'm concerned, not so much now for me, because I've found a lot of ways to get what I need, but there's a lot of people coming behind me that does not know how to do this. They're afraid to do this. You know, most of the abuse that I suffered is, you is a dope fiend. What right do you have to go around telling people how you infected other people. I said, well, there's a lot of Frankies still out there, and it takes me to let you all know that it has not stopped.

I think I'd better be quiet right now, because I'm getting ready to attack. I'm sorry. Thank you for listening to me.

DR. ROGERS: Thank you for talking with us, a very powerful message. We appreciate your coming.

MS. MASON: Thank you.

DR. ROGERS: Let's hear from Ms. Suiter.

STATEMENT OF MS. JOANNE SUITER

MS. SUITER: I've been a drug addict for over 20 years, an alcoholic. I came out here a year-and-a-half ago to go into a behavior modification treatment center, from Detroit. I was kicking methadone and heroin. I was very sick. They put me in the hospital the second week I was there. They asked me if I wanted the test run again. I said sure, why not.

Two weeks later, I went back to University, and found out I was positive. And it--I don't know, it was like the biggest pain I've ever had and the biggest anger. And I'd been looking for an excuse like that my whole life, to shoot dope, to finish myself off. And here I have the perfect excuse.

I stayed in the treatment center another week, and I could not deal with what was happening, and I walked out. I have a 15-year-old son and an ex-husband that live in Colorado. I went there for about a week, but my ex-husband and I didn't get along, so I went to a shelter.

I have a lot of internal problems from drug addiction besides the virus. I blew all my veins out, and I have to take Comadin, I have to take Flaxis, I have to take potassium. I take Sinaquon for depression. I'm on methadone.

And you're right. There do need to be more methadone clinics. The problem is, they're cutting back on them. And methadone does take the edge off that a drug addict needs to go out and support his habit. If nothing else, it slows him down.

I had a choice when I walked out of whether to just polish myself off, because they told me I hard to get this, and that at this point in my life, I probably wouldn't last two more years. And if I'd been in Detroit, I would have.

But I was here in Denver, and it's a lot--it was like a culture shock from Detroit to be here. People were nice. The bus driver talks to you.

[Laughter.]

MS. SUITER: I mean, it was an entirely different scenario. You could make eye contact on the street, and somebody wasn't going to ask you for money. People were nice. Even at the hospital, the nurses were nice.

In Detroit, they hated junkies, you know. They gowned up, they gloved up, they put on all these suits and gas masks if you were a junkie, regardless of whether you had the virus or not. They just assumed you did.

So I found that actually the personnel out here were pretty nice. And I, for once, made a choice, and in all that anger, I used it for myself instead of against myself. I got put in a shelter. I got AND from social services. I got food stamps. I was in the shelter for six months.

I moved into a place through Denver Housing Authority, and I've been there a year. I applied for SSI, and I'm still messing around with them. Every month, I worry about whether I'm going to get my rent paid, or whether I'm going to have to go back out and be what I was before.

I don't want to be what I was when I came out here. I was inhuman. I didn't care about anyone. I was dangerous to myself and other human beings. You know, a life in and out of jail, in and out of hospitals--and I don't have--that's what I have to look forward to if I go back to what I was.

I have been messed around with so much. I want to go to school. I want to be a drug and alcohol abuse counselor, and I think I'll be a good one. I want my son, who has a lot of the same problems that I do, I want to help him. I want to give him the opportunity to not turn out like his mother.

And for a 15-year-old that has had a mother like myself, he loves me. He really loves me. I didn't even love my parents at 15. And he thinks I'm wonderful when I'm clean. It's like the first time he's ever seen me like this.

I don't--I guess my basic grievances are the things that we have to go through, the stress of what's going to happen to us. My rent is only $59, but I don't know--I didn't work for the last 22 years, and I'm not proud of this, but the fact of the matter is the only thing I know how to do is be a drug addict.

And the past year-and-a-half, it's been very hard for me to learn how not to be one. I'm stuck between a rock and a hard place. When I came out here, I wanted to die. They shoot horses, don't they? Can't you just put a bullet through my head and let it go?

And God's chosen not to let me go. I mean, I'm 38 years old. I'm burnt out. I should be dead. Most of the people I started out with are dead, or they're doing life in the penitentiary. There must be a reason why I'm still here.

My mother has got cancer. My brother's got lupus. And this sounds like a goddamn nightmare. It doesn't sound like it's even factual, and it's true. Real life is like nothing I've ever read in a book. And for all these years, I've been getting high, so I never had to look at it.

It's not so much--I think there are times I've thought about killing myself because it got too goddamn hard to hustle up this money to get by on every month, and I just thought it would be so easy to die. But--and my parents would understand. My family would understand. I think my counselors would understand.

But my 15-year-old son wouldn't. He would take it personally, and he would never, never understand, and he'd never forgive me. And one thing that I do have, after all these years, is my kid. And now that I'm clean, we've gotten really close, and I love him very much.

And thank you for the kleenex. I was a fool to put on make-up today.

[Laughter.]

MS. SUITER: Thank you very much.

DR. ROGERS: Thank you for your statement. I think we can see why your son loves you.

MS. SUITER: Thank you.

DR. ROGERS: Questions from the Commissioners? Mr. Kessler?

QUESTIONS AND ANSWERS

MR. KESSLER: Ms. Estrada, I just wanted to fill in some missing blanks here. The discrimination in terms of the treatment occurred in Arizona?

MS. ESTRADA: Yes, but in Santa Barbara County, also.

MR. KESSLER: And that's where you are now, Santa Barbara?

MS. ESTRADA: Yes, Santa Barbara County.

MR. KESSLER: Can you just fill me in, and probably some of the other Commissioners, about the yeast commercial that you referred to?

MS. ESTRADA: The Gyne-Lotrimin and the--what's the other one--the Monistat.

MR. KESSLER: And they're just being promoted as across-the-counter--

MS. ESTRADA: Yes. I think it's ridiculous. It's absolutely ridiculous.

DR. ROGERS: Those of us who are TV watchers have seen it all the time. It's directed at women, and says it's real easy, and--

MS. ESTRADA: I'd rather they put a condom commercial on.

DR. ROGERS: So would we.

MS. ESTRADA: In fact, day before yesterday, they had these special--we were watching TNT, the Trials of Life program, and they kept putting on these commercials about AIDS and condoms, and every time it came on, they bleeped out the sound. They bleeped out the sound. And my kids went, and they looked at me, and they said, oh Mom, don't get mad, calm down.

[Laughter.]

MS. ESTRADA: Because we've been fighting really hard. We just passed a condom bill in Santa Barbara. We fought real hard. And wherever condoms are sold, there has to be a sign stating the difference between the lambskin and the latex. And if the sign is not put up, they are going to be fined, which is really wonderful. I think it's about time. I hope other counties follow us.

DR. ROGERS: Mr. Dalton?

MR. DALTON: JoAnne, I actually grew up in Denver, and when I was 17, I moved back East, and I had the opposite experience of yours. I mean, I would say hi to people on the street, and they would jump six feet off the ground--

[Laughter.]

MR. DALTON: --so I know exactly what you're talking about, about culture shock. I just happened the other direction.

In order to really deal with this epidemic, I think all of us need to learn about just how complicated human beings are. And I thought you all were really very helpful in that way.

JoAnne, when you talked about how you have to learn not to be a drug addict, I think that's really important. I mean, not only is "just say no" ridiculous, but most ideas about how to deal with addiction don't really take into account how much addiction becomes a person's life, and how you have to unlearn it over time, and how hard that is. And so I appreciate that.

Frankie, when she talked about how there was a point in her life when she was so angry that, you said I'll hurt anybody and everybody. And I really could have hugged you when you said that, because that's such a natural, it seems to me, a normal human reaction. And yet we act as if people are supposed to find out that you're diagnosed and then suddenly become Mother Teresa or something. And that's just not human nature. I appreciate just the honesty with which you all talked about those things.

I was struck that Lorelei said that you, in fact, had an abortion of the child you were carrying when you found out you were diagnosed, and a lot of people have gotten on you about that. Frankie said that people pressured her to have an abortion. It seems to me in each case, people ought to get out of your life and let you make that decision.

[Laughter.]

MR. DALTON: But, I guess, Frankie, I was curious who--was it people in the hospital who were urging you to have an abortion, or family or friends, or--

MS. MASON: It was the people in the methadone clinic and the hospital, the doctor, the nurses. And as I wrote in the testimony, the results they told me would be my baby would stand a 50-50 chance of surviving with the virus and living three to five years or dying and coming in the world full-blown with AIDS within weeks of their life.

And in my anger, I asked is that all, you know, and they said, well, you know, we don't have a lot of answers. And I said, well, I'm not aborting my baby. You know, I attacked these people verbally. I wanted to attack them physically, but it wasn't in my nature to attack people physically.

Really, what I always did was hurt me. I always hurt me because I was always the victim. I always felt like somebody's doing something to me. And this time, I attacked me again, because I was hurting this little person, you know, my selfish reasons, I should not have kept this baby.

I went into the understanding of where she was at. Maybe I shouldn't have kept this baby. Maybe what they say is right. Maybe I shouldn't subject this baby to coming into life suffering this disease.

Because the only description they gave you of AIDS back in '86 and '87 was these people laying in the bed, looking like a skeleton or something out of the twilight zone, or, you know, somebody really scary looking. And I couldn't see me or my baby looking like that.

Look at me. Can you--I mean no, no. I look at me as a sensuous woman, and to die like that, being virtuous and energetic as I am, no. I couldn't see that, and not for that baby. So I figured, you know, the best thing for us was to die. Nobody understood anything.

MR. DALTON: But one thing that you just told us is that you thought about all sides of this issue with very poor information. And it seems that somehow there's this notion that women are incapable of thinking through this choice. And you've just, at least convinced me, that you gave this as much serious thought as any human being could.

MS. MASON: One of the reasons why I feel a little different is a lot of--women have always been attacked through--all the way back. They shouldn't smoke. They shouldn't wear their dresses too high.

Okay, now I'm a woman that's smoked, shot dope, I prostituted, I did everything. What right did I have to be accepted in society? I had no right. And a lot of the women that I know that are still out there are feeling that same feeling. Women aren't supposed to be this certain way, you know. We are supposed to be--I don't know.

They've got this person, this lady that stays at home with her husband and does what he wants her to do, or the woman that goes out and beats the pavement every day and goes to work. She does not feel. She does not think. All she does is survive. That's a lie.

I feel, I hurt, I think, I cry. Now a lot of my friends aren't strong survivors, you know, and the only way to survive is to think. And if we keep thinking negative about our future and us, we're going to die too, you know, and that's what made me want to die. I only had negative thoughts like her.

All I knew how to do was shoot dope and prostitute. Today, I don't know how to shoot dope or prostitute. Today, I know how to take care of me. I want to live, and I want other people to live with me.

DR. ROGERS: Mr. Allen?

MR. ALLEN: I have a couple of questions, one for JoAnne. You mentioned you were fighting SSI. How long have you been fighting it, and why has it stalled? Is it medical diagnosis, is it sociological reasons?

DR. ROGERS: You might give us a time table on that too.

MS. SUITER: Okay.

DR. ROGERS: How long have you been holding your breath?

MS. SUITER: I applied when I applied for A&D. I applied for SSI then, in November of '89.

DR. ROGERS: November of '89?

MS. SUITER: I have been--yes. Besides the problems that I have with my legs and my hands from lack of circulation and being depressed, I had PCP in March of '90, and I got very sick. And at one point with SSI, they mistook me for somebody else. They had me as a waitress that worked for 15 years. I would have liked to have claimed that, too.

But I was trying to be honest about it. And the thing is, the last time I got turned down, they didn't even have my last hearing on the turn-down, the last hearing I had in front of the judge. They didn't even have it down there.

I took my counselor from Empowerment with me. They decided to call her a paralegal, and they said that I chose not to represent myself with a lawyer. Well, at $229 a month, I had no idea where I was going to get a lawyer.

Since then, this last turn-down, I was [inaudible] appeal. I'm going to try legal aid, I'm going to try everything I can possibly do to get some legal representation with this. I had no idea, having not dealt with social services or SSI in all the time that I was strung out, because, you know, they make you go to appointments. That was something I was incapable of doing as a drug addict.

So I was not really familiar with any of the things that I had to do. So part of it was a learning process on my part.

MR. ALLEN: Are you on Medicaid?

MS. SUITER: No.

MR. ALLEN: Because SSI is--

MS. SUITER: SSI--yes, I will.

MR. ALLEN: So you don't have--

MS. SUITER: I don't have--no, see, I have no insurance. When I get sick, they get me out of the hospital as quick as possible.

MR. ALLEN: So in your testimony you mentioned that you were on several medications and also some vitamins and so forth. How do you get the--

MS. SUITER: Okay. I am a client of CAP, the Colorado AIDS Project.

MR. ALLEN: Okay. So that's the help, and I assume they--

MS. SUITER: Yes. I'm on AZT also.

MR. ALLEN: Okay.

MS. SUITER: I pay them $10 a month, and I can get my medications and see the doctor. I have to have blood tests once a month because of the Coumadin that I take for the problems with my veins. And then I have to have my T-4 cell count done, and all that.

And I don't have any veins. They hand me the stuff, and lock me in a little room and let me go find them.

MR. ALLEN: That's probably better than under some circumstances.

MS. SUITER: Well, actually it is, you know. I'm not fighting it.

[Laughter.]

MR. ALLEN: I have one more question. I'm assuming you're under the CDC diagnosis as full-blown due to the pneumocystis, full-blown AIDS?

MS. SUITER: I'm a PW ARC.

MR. ALLEN: You're a PW ARC, even with pneumocystis?

MS. SUITER: Yes. That's what the Med-9 says, is ARC.

MR. ALLEN: Okay. My question for the other panelists is what is your CDC definition? You mentioned earlier about the yeast infections and not being on--

MS. ESTRADA: I'm still HIV-positive. They won't diagnose me with anything, because there's nothing on the list.

MR. ALLEN: Okay, but--

MS. ESTRADA: I keep getting reoccurring infections, but I can't get it since I get $800 a month from my job. I have no health insurance. I can't get any. I had to deny them with my job in order to get my job.

MR. ALLEN: And your T-cell count?

MS. ESTRADA: It started out at 760, and I put on 80 pounds, and it went up to 1100.

MR. ALLEN: That's great.

MS. ESTRADA: So, something's going on in my body, but still the fact is, the virus is still there. The infections are still happening, and there's nothing there for me.

MR. ALLEN: How about you, Frankie?

MS. MASON: I'm diagnosed as ARC symptomatic. My T-cell count is 242, and I don't feel, you know, anything. My doctor always insists that I do not worry about the count. The doctor that I have now is through a hospital clinic, and that's because I'm a female, and they started this female clinic, and I had to be on the waiting list for three months to get into this clinic.

It's really for people that are on welfare and Social Security, but like I say, I do a lot of stuff to get what I need in order to survive.

MR. ALLEN: So really, the only reason I was asking about T-cell is because of CDC and so forth and jumping through the hoops.

MS. MASON: I'm just on AZT. The doctor's looking into DDI for me, because I've been on AZT for three years now. They don't want the toxic to start doing any damage to my body since I've been so strong.

MR. ALLEN: But none of you are a full-blown under the CDC diagnosis, and with all the frenzy you're dealing with?

MS. MASON: No, thank God, we're lucky.

MS. ESTRADA: No.

MS. SUITER: No.

DR. ROGERS: Ms. Estrada, you mentioned no doctors--a tough time getting doctors in your area. Could you expand a little bit on that? Doctors unwilling in your area to take care of people who are HIV-positive?

MS. ESTRADA: What's happened, number one, I believe that we've probably got one of probably the top ten doctors in California, or if not the United States, in our area, Dr. Josea, and he has my assistant, Andy Gershoff. The problem is, he's the only one that's seeing all these doctors. But I live in the North County. Our county is divided in half, and it's a 110-mile round trip for me to get there.

DR. ROGERS: And he's the only doctor--

MS. ESTRADA: And I'm in the middle, so that means that the people that are above me have close to a 200-mile round trip just to see that one doctor.

DR. ROGERS: How many doctors would you say are close by?

MS. ESTRADA: Well, there's doctors everywhere.

DR. ROGERS: There's doctors everywhere.

MS. ESTRADA: But that doesn't mean we want to see us. Because we're HIV-positive, they don't' want to have anything to do with us, so they've even offered to pay more money to the doctors, whatever, just to get them in our North County. Nobody wants to do it.

They've said that there's a man, Dr. Koons, that may do it, except that he's never worked with HIV-patients, and so he wants a year of training before he will take anybody on. He has taken one patient, but he's using him as a guinea pig. And already he has diagnosed him wrong twice.

DR. ROGERS: Could you give me any idea, just roughly, how many doctors in your area that are not taking care of AIDS patients that are in general practice? Are there--

MS. ESTRADA: There's only three that I know of--

DR. ROGERS: No, I wanted it the other way around. Are there 20 doctors, are there 50, are there 3--

MS. ESTRADA: There's more than that--I don't even know what the population is. I know that we have 214 full-blown cases--

DR. ROGERS: Of AIDS in your North County area.

MS. ESTRADA: Yes.

DR. ROGERS: And no doctors?

MS. ESTRADA: Plus 65 that have been diagnosed in other counties that we do take care of, so it's the 214 plus the 65. And I'm giving out positive--I do HIV testing also, and I'm giving out positive results every week, so the rise, it's just--it's almost all women lately.

DR. ROGERS: Other questions?

MS. MASON: Could I say one last thing?

DR. ROGERS: You may say one last thing.

MS. MASON: Okay, because the gentleman asked about all of us being diagnosed as full-blown. I have a girlfriend that was not able to attend this because she's full-blown and she's too weak to sit up here and tell you all about what she's going through.

But I am a living witness to what she has been through. You know, if there are some questions about, have you had experience with other people, and what are their experiences, I'll be glad to help you. I work in a national association, and people are part of my life that have the AIDS virus, okay?

DR. ROGERS: Okay.

MS. MASON: So, you know, it's not so much as, am I full-blown--

MR. ALLEN: I need a point of clarification. The reason I was asking is not because of lack of experience of understanding, it was because of the bureaucratic issues of CDC. And that's frustrating, and that's unjust, and that's why I was asking, not because I didn't think that you all could not share with us--and you have eloquently shared with us the dilemmas that you're going through, and it's been very powerful, and I'm very grateful.

But that was why I was asking, because we're frustrated. I will speak for myself. I am frustrated by

CDC's leaving out women in the time of the greatest need, and also with the structures, financial support and so forth. So that's why I was asking.

DR. ROGERS: Mr. Dalton?

MR. DALTON: Money to help provide treatment for AIDS only goes to people who have a full-blown diagnosis, and a lot of women ought to have a diagnosis of full-blown AIDS so that they can get Medicaid and other forms of--and yet, there are a lot of infections and things that women have that men don't have that don't count for an AIDS diagnosis.

MS. ESTRADA: Can I add to that real fast? I--this last year, I've tried to get a fund going for people, especially women, who are HIV-positive and still working or not working, because there are no benefits for us. We were laughed at. They laughed at me. They thought I was trying to do it for my own gain. It's ridiculous.

If we're able to work, if there is a fund there and we need that money and there's no other resource, hopefully maybe we will be able to put some of that money back in for somebody else. If not, we know that it is there for us. But they laughed at us. They laughed at ever single one of us.

And the other thing I want to say is thank God we're still well, because with us still being well, we're able to get out here and talk to the people and be able to reach the people and say, hey, this is what's going on, and hopefully we're going to do something so our future's not going to die, because our future's going downhill because of this.

DR. ROGERS: We thank you all very much, and we will do our very best to articulate some of the things you've taught us. It's been a privilege to listen to all of you.

MS. ESTRADA: Thank you.

MS. MASON: Thank you.

MS. SUITER: Thank you.

DR. ROGERS: Thank you so much.

We're going to hear from another troop of three, if they would come up to the table. We're privileged to have before us Kathryn Anastos--am I pronouncing that right?

DR. ANASTOS: Anastos.

DR. ROGERS: Anastos, thank you, who's the Medical Director of HIV Primary Care Services at Bronx-Lebanon, my territory, and Mary Young, who's also a physician who's Director of the HIV Women's Program at Georgetown, and Carmen Zorrilla, who's in the Obstetrics and Gynecological Department of the University of Puerto Rico in San Juan.

I bet you are all thinking, can you top the last one, at the moment. Please go ahead.

STATEMENT OF DR. KATHRYN ANASTOS

DR. ANASTOS: In fact, I'd like to express my thanks to the last group of women, in spite of the fact that it makes it a little harder for me.

I know the doctors are expected not to cry up here, but what you all did for me, the women who preceded me, was to once again push me past the barriers I set up, as does every provider so that we can continue to provide care, and look for that middle ground where we know that we're all human beings, and yet we must keep going on with our work.

Some of what I have to say was expressed far more eloquently by the women who have had to live with this. Whatever our pain is as providers, and it's real, it is small compared to the pain of the women who themselves have to live with this disease.

What I do is I'm basically a clinician and a medical administrator. I see patients about half the time. I provide care to HIV-infected patients. About half of my patients are women. There's some mutual self-selection there.

The rest of my time I spend trying to organize services, trying to hire and retain the physicians and other medical providers so that the patients who live in my community, the South Bronx, do not experience what has been described to us by Lorelei.

It is our goal to provide adequate, comprehensive, state-of-the art health care to everyone in the community who needs it, including HIV-infected people. We currently care for 2,000 patients who are HIV-infected in continuity, comprehensive primary care. About 600 of those patients are women.

Our numbers are in a very rapid rise. I think--we run a large clinic. It's huge by some standards. It's going to grow even larger.

We provide very good care. We provide access to clinical trials, even though we're working against very heavy odds in terms of lack of resources, both of our own lack of resources, as well as my patients' lack of resources.

And it's from that perspective, both as a clinician and as someone who desperately tries to keep up with the need--and we don't meet the need. No matter how much we're doing, we always have a wait. Sometimes it's one week, and that's where we try to keep it.

A lot of times it's a month. It's never gone over a month. But if I can't hire more doctors, it will go over a month within a month from now. This is the perspective I bring to my testimony.

Because I only have a few minutes, I'm really going to try to identify the major issues without providing a lot of the substantiating data. It does exist. I know that Dr. Young and Dr. Zorrilla will also address some of the substantiating data and some of the same issues.

DR. ROGERS: Do we have some written testimony from you, Dr. Anastos?

DR. ANASTOS: You don't yet, but I can provide it.

DR. ROGERS: Okay, fine.

DR. ANASTOS: We think of AIDS in women--I think the public perception of AIDS in women as not being so important rests on the fact that only ten or 11 percent of diagnosed cases are in women. But the real way to look at it is the impact on morbidity and mortality.

Even with the current case definition, AIDS is a leading cause of death for young women in New York City and

New York State and New Jersey and for all African-American young women in the entire United States.

This is a public health problem of enormous magnitude, and it's not getting smaller. It's getting bigger. We're on the steep part of the curve in terms of rising rate of disease in women.

The medical issues in women are very real. The underlying theme is that we don't know what we're doing. We've had ten years of taking care of HIV infection in women, and in the first eight years, the only studies that we saw related to whether we could give it to anybody else.

It was woman as vector. Can we give it to a fetus or a baby, can we give it to our client if we're a prostitute.

Nobody addressed how women get sick, and there is a growing body of evidence that indicates women get sick in a different way with HIV infection. If that's true, it means we will provide care in a different way.

Basically, a few of the issues are these. One is, how do you measure disease progression in women? What do T-cells mean? We know that T-cells vary with the large hormonal changes of pregnancy. Do they vary with the smaller hormonal changes of menses? How come we don't know that yet?

That's something that could be relatively easily studied.

In the absence of that information, we take care of women based on the information that we have in men, which frankly is what we do in almost every medical illness, including hypertension and heart disease and cholesterol, but this is very difficult when you're talking about a disease with a rapid progression to very serious illness the way that HIV infection is.

A second question is, do women have different opportunistic infections than men do? And that matters, because you provide different prophylaxis. That if you're providing a prophylactic therapy for something they don't get but not for the thing they will get, you're not altering their disease course. You're not prolonging their longevity or decreasing their morbidity.

There's some evidence--and my opinion is the answers clearly are not in on this. We do not know, and we need to fund studies that look at this. Maybe women get more candida esophagus. Maybe women get more MAI, a form of bacteria that's like tuberculosis. And maybe they get more CNV infections.

If that's true, we need to prophylax in a different way. It takes years to develop a prophylactic therapy. If we haven't even identified the ways women are getting sick, we are years away from preventing significant morbidity and mortality from those infections.

Another major issue is survival. Every single study, whether it's aggregate public health data or a better-controlled cohort study that looks at survival data shows that women survive shorter periods of time. Sometimes it's only a third as long, like four months compared to 12 months from the time of diagnosis of AIDS. Sometimes it's longer, ten months versus 12 months. But it's always shorter.

For every other group of people, if you look at survival data, the data's all over the map. Sometimes gay men do better, sometimes they do worse. Sometimes drug users do better, sometimes they do worse, although most studies that control for socio-economic status are now demonstrating that it seems like drug users to better--meaning people who acquired their infection through intravenous drug use, not whether or not they're actively using drugs.

But the common theme around women, there is no study that shows that women do better. That is, they always do worse. Is that delayed diagnosis? Is that because we don't diagnose the disease?

There's a lot of evidence recently that indicates it's not just delayed diagnosis. If it's a physiologically mediated difference, then maybe we could find a way to figure out what that is and prevent it.

A third issue is gynecologic manifestations of disease. It does seem, and has actually been described by the women who preceded me--it is real clear, although it's not well documented in the literature, because the studies are only now being done, that even life-threatening infections like cervical cytologic abnormalities which may progress to cervical cancer, are more frequent and probably progress more rapidly in women who are HIV infected, and it's more so as they become more immune suppressed.

There are other very significant infections, for example, vaginal yeast infections, which is not a trivial infection if you have it and it can't be treated. It's a very disabling infection if you can't get rid of it. That occurs much earlier in the course of disease. And yet as providers--providers frequently aren't even diagnosing it, because we don't ask women. This is one of the "we's" I don't include myself in. I do ask women.

We don't know what the response is to anti-retroviral therapy in women. We don't know what the complications are of anti-retroviral therapy in women. These are questions that alter the way we take care of patients, and where we really need to have more information.

The last area I want to address with a little bit of depth is the societal response to HIV infection in women, which is not a response that I--I am not proud of our country's response in this respect.

The first thing, as I've previously stated, is that we've only studied women as vectors. We haven't looked at women as people who get sick with a disease process, what is the impact of that on their lives, how does it alter the way they're able to care for their children or for the other people in their lives.

A second issue, which is frequently discussed, has to do with how do any women decide whether or not they're going to have children? And we have a stated public policy in this country that comes from the CDC that as a provider, when I sit in a room with a patient, what I'm supposed to say to her is, well, I advise you to delay having children. What does delay mean? Delay means I'm asking her not to have children at all, because we do not have a cure on the horizon for this disease.

I resent such a stated public policy. I cannot sit in a room with a woman and tell her that. As I think is much better described by the women who preceded me, having children is a part of being human, and it's certainly a big part of being a woman.

It is not my role to tell somebody else how to decide, or how to define her life, or how to define her own humanity. It is my role to be a consultant. It is my role to give her as much information as I can. That information includes whether or not there--what is the likelihood that the HIV will be transmitted to the fetus or to the baby, and the likelihood is much smaller than what is usually talked about.

In the beginning of this epidemic, we only studied people who had late-stage disease. And the one thing we are finding out now is that the later the stage of the disease for the mother, the more likely it is that the fetus will be infected.

The most recent study and the best study gives a 13 percent rate of transmission to the child. That's children followed for 15 months. That's a European cooperative study. It's the biggest and it's the best. It's probably also the most comparable to our own circumstances as a developed nation.

But if you look back over studies for the last few years, the highest transmission rate is 39 percent, and that was in Zambia. The highest transmission rate in the developed world was 33 percent.

For a woman making a decision about whether to have a child, a 13 percent transmission rate means an 87 percent chance that the child will be uninfected. I don't know what I would do in that circumstance. I don't feel that we should have a public policy that tries to tell me I should tell her to go have an abortion or to prevent pregnancy. I think it's a decision she has to make with her family.

And the last area I want to touch on in brief is the issue of mandatory testing for "women of childbearing age". This is becoming a much bigger and bigger topic, and its recent discussion in the <u>New England Journal of Medicine</u> gives it more cogency.

I do not believe we should be doing mandatory or so-called routinized testing of anybody. I think that what we're forced to do as providers, when we adhere to a public health law that says you have to give pre- and post-test counseling, and you have to have voluntary informed consent, is that basically it's just making us do what we ought to do anyway about any disease, is that the patient should be provided with education.

The patient should get information from me that lets her understand what is her likelihood of being infected with this disease, including the fact that it's normal human behavior that puts us all at risk, that the only way you're not at risk is if you haven't had sex since '75, if you weren't transfused during the period of risk, and if you've never used injection drugs. Almost nobody fits that category, so in some way, each of us is at some small risk.

And the information should be provided in a way that lets the woman believe that this is--whether she chooses to be tested has to do with her own health and her own life and the provision of early care. And I am a big believer in early care.

But what we ought to be mandating here is not testing, but primary care services. What are we trying to encourage? We are trying to improve the quality and the length of life for people who are infected. To do that, you have to provide care. Just testing people doesn't do that. In fact, forcing testing people will drive them away from care.

The other side of it is that saying we should have mandatory testing of what is, in fact, a low-prevalence population, women of childbearing age, is setting up a false dichotomy between mother and child. In fact, most mothers are the protectors of their children. Most mothers and most parents think that one of the greatest pains we would have to endure is losing a child, or by dying ourselves, failing to be present to protect that child into adulthood.

In summary, let me say, clearly HIV infection is a public health problem that may reach staggering magnitudes for women. That in terms of public health policy, there are things that we should be doing that we are not currently doing. One is we have to fund adequate research that lets us as medical providers know, what does this disease do in women? How can we best take care of women?

I think we do have to address the CDC case definition, but I think we should separate the case definition from the awarding of disability benefits. The case definition is an epidemiologic definition. It helps us understand the disease.

AIDS itself is just a clinical marker for immune suppression, but it's a marker we should never let go of, because T-cells clearly doesn't tell us the whole story. We will probably never measure laboratory-wise the ways that our body prevents us from getting sick with infections.

I do think we should include some more gynecologic conditions specifically as either HIV-related symptomatic, and a couple of them as AIDS-defining.

I think we can't go any longer in trying to provide care here without addressing the underlying failures of our health care system. It's a national shame that we do not guarantee health care to all of our people. We are strugglin now against enormous odds, both for the acute care needs of people with HIV infection as well as the long-term needs of people with HIV infection. We're not going to improve longevity if people can't get into care.

I think we need to improve our education efforts, echoing Michael Gottleib. I cannot believe that we have not put better--more resources into education at the community level so that both women and men will recognize that they are at some risk for HIV infection and can make some kind of informed choice about whether to access health care, if it exists, in their community.

And finally, I think that we as a nation must acknowledge and we must address the fact that both the cause for where this epidemic sits, in women, at least, among communities of color, as well as the societal response to that, has been heavily determined by our historical legacy of racism and also of sexism, which basically are ways that allow us to separate from another group of people.

We have to address this and prevent it from heaping on women who are infected the additional burdens that really were described by the women who preceded me, and allow us to provide--to know what we're doing, to provide access to care to everybody, and to provide that care in a compassionate and humane way.

Thank you.

DR. ROGERS: Thank you so much.

Dr. Young, I've seen you nodding vigorously with almost every comment.

[Laughter.]

DR. YOUNG: I have nothing to say now.

[Laughter.]

DR. YOUNG: Dr. Anastos says--

DR. ROGERS: Or shorten your remarks slightly, and then we'll be able to ask you all lots of questions.

STATEMENT OF DR. MARY YOUNG

DR. YOUNG: Dr. Anastos, I think, has really eloquently stated many of the major points that I would also like to cover, so what I'd like to do is really just use this time to highlight several of the things that I think she has pointed out.

I'm Dr. Mary Young. I work in Georgetown University Medical Center's HIV Clinical Center. I direct the women's component of the care there.

We've currently followed probably over 100 women over the course of the last three to four years, and currently have 80 women. We could follow more if we had additional funding and additional help.

I remember Michael Gottleib's article in Morbidity and Mortality Weekly Review, those first five cases of pneumocystis. Little did we know that ten years later, we'd be sitting with 170,000 people infected, with another maybe million-and-a-half who are HIV-infected, with women now and

IV drug users becoming a growing component of this epidemic.

The women that I follow range in age from 16 years to 62 years of age. Many of them, about 50 percent, have a history of former IV drug use or current IV drug use, but a growing majority are giving me histories of heterosexual transmission. Some of these women, particularly the young ones, have had maybe two to three sexual partners.

Again, underlying a comment that I've heard before, which is that in this epidemic, geography is destiny. Where you live, where you practice risky behavior can put you at much higher risk of coming in contact with this virus.

Currently, young urban African-American and Hispanic women, particularly adolescent women in certain areas of this country, New York City, Newark, New Jersey, Washington, D.C., Miami, et cetera, are at very high risk with unprotected sexual intercourse of coming in contact with this virus.

As Dr. Anastos pointed out, although we're ten years into this epidemic, the medical knowledge that we have about how women have been affected by the virus is really quite slim. There've been very few published reports of natural history studies, and the ones that have been done, I think, are limited geographically and by small numbers, and you really can't draw many large conclusions from them.

I think that most of us would agree that pneumocystis creneii pneumonia remains the main AIDS-defining illness for women, although as with other groups, as we become better at prophylaxing, that number will continue to go down.

Whether other opportunistic infections like MAI or candida are going to have a higher incidence in women, I think are going to have to be borne out by larger studies, although indications would look like MAI in particular should be a problem for women.

Kaposi's sarcoma, as we know, is a very rare occurrence in women, making up less than one percent of cases. Again, gynecologic manifestations are a very important aspect of HIV in women, and little information is available.

Two areas, I think, of concern--one is PID. Certainly everyone is used to treating PID and knows when it's a simple case and it resolves with typical antibiotic therapy. But a case that's quite recurrent or refractory to treatment is a different animal.

I think as Dr. Anastos pointed out, also recurrent vaginal candidiasis. We all work with women who have candidiasis who respond quickly to therapy. But when those therapies stop working, you know you're dealing in a different aspect. So I think there are ways to delineate between simple cases of bacterial infections and more complicated that probably imply underlying immune deficiency.

Also, the whole question of cervical cancers. Currently in the CDC definition, as you know, there are no gender-specific cancers for women listed. Lymphoma is listed, Kaposi's sarcoma is listed, but cervical carcinoma is left off.

Again, social issues are clearly different for women. When I looked in 1989 at our 56 women we had followed to date, they were responsible at that time for the care of 66 children. Those children are, by and large, uninfected with this virus, but still have very special needs as regards living in a household where the mother is infected, is often ill.

Yesterday in my office, a young woman came who had spent an hour-and-a-half on a bus with a temperature of 102, a hematocrit of 25, and a very active six-year-old in tow. She refused hospital admission because she is the sole responsibility of this child, and would not come in until better arrangements could be made. We basically babysat her child and let her sleep in the office until she could regain her strength.

This is not an uncommon problem, so that women are often subrogating their own care to the care of children or, in some cases, other infected spouses.

Again, I think the good news with women is that by and large, women have not yet been touched by the HIV virus. We're still making up only 11 percent of the case definition, and that's good news, which means that if we could get preventative strategies into appropriate communities in ways that could be used by young women and are culturally appropriate for these young women, that we could prevent further spread of this virus.

On the other hand, one area that I'd like to touch on before I end is that, again that Dr. Anastos spoke about, is that of mandatory testing. As the women on this panel preceding me, I think, testified to, and if you asked any HIV-infected woman in this audience, the moment at which you receive that diagnosis is a very emotionally tense moment. I've best heard it described as stepping off a cliff.

If you step off that cliff with your eyes open, willingly, if you request testing, if there's a safety net of good counseling and appropriate care below you, then it's a livable experience.

However, if you're shoved off that cliff, without any counseling, without any appropriate care available, sometimes even without your knowledge that you're being tested, then this is a very devastating experience, and as a practitioner, we can spend months trying to correct that kind of misinformation, the fear that's been engendered, the, as some people said, often suicidal thoughts that come up at that time.

So that I think to do testing without adequate counseling and adequate health care available once testing has been done is truly a disservice and is also just very inappropriate in terms of what we would hope to gain out of that information. So that I think in an age of mandatory testing, we really need to be aware of these issues.

DR. ROGERS: Dr. Young, thank you. Very fine.

Dr. Zorrilla, I think we met you in Puerto Rico--

DR. ZORRILLA: Yes.

DR. ROGERS: --it's a pleasure to see you again.

DR. ZORRILLA: Thank you. You have my written statement, so I will just make some comments about it.

DR. ROGERS: Thank you. You might pull your microphone just a little bit closer.

STATEMENT OF DR. CARMEN D. ZORRILLA

DR. ZORRILLA: As you all know, the Commonwealth of Puerto Rico is the second jurisdiction in the United States in cases of AIDS per capita. If we were an independent nation, we would be the fourth nation in the world in cases of AIDS per capita, so as to give you an idea of the scope of the problem in Puerto Rico.

I started to work with AIDS in 1986 when we developed a prenatal screening program, which is a universal offering of counseling and testing. Since then, I've had the privilege of having interviewed and treated more than 250 women, which I consider my friends and not my patients.

The mean age of this population is around 26 years old, and most of them, 86 percent, acquired the infection by heterosexual contact, mostly from an IV drug user, but an alarming 17 percent of them did not acknowledge any risk behavior in their partners. They were unaware of the risk.

They were identified because of our universal offering of counseling and testing. Our prevalence rate is around 2.2 percent.

Most of the women that we have [inaudible] are asymptomatic, but we are noticing a disturbing pattern. We are noticing people that come to us referred from other hospitals with different diseases, and it is not until we evaluate them that the issue of the possibility of AIDS is being raised.

The latest example is a 21-year-old female on her 27 weeks pregnancy that she was admitted to another hospital with a kidney infection. Then she developed rubella, measles, and then she had a pneumonia. And the physicians said that she had a measles pneumonia. It was not until we evaluated her that we felt she had PCP, and we started her on antimicrobials. She's on a respirator, but she's improving after the medications.

So this case illustrates the point that women with AIDS may go undiagnosed and often mismanaged until late in their disease process.

Seventeen percent of our population have--the most common AIDS-defining condition in our population is PCP, with a 17 percent mortality. But I want to comment, again, on the other manifestations that are gender-specific.

This disease originated in men, and as such the conditions that were prevalent and served as the basis for the definition of the syndrome were in part diseases common to male homosexuals. When the infection affected children, then some conditions that were common in children but were not seen in others were included into the case definition, as for example bacterial infections, such as otitis media.

Two weeks ago, I was asked whether I thought the case definition was appropriate for women. At that point, I said that we needed more information and we needed large cohort studies to answer that question. After that, I made a search in the literature, and I re-evaluated our data base, and I have changed my mind.

HIV-infected women have been reported to have an increasing seriousness and severity of human papilloma virus, which is an infection that has been blamed as a cofactor or as an initiating factor into the development of cervical dysplasias and cancer.

HIV-infected women have been reported to have increased risk for development of cervical cancer and present with advanced stages of cancer at a younger age.

We have corroborated this with our own group of patients, and in summary we have found that they have more risk of developing HPV, developing dysplasias, and developing cancer.

In just three articles in the literature, at least eight invasive cancers of the cervix have been described, more than 50 cases of co-infection with HPV have been reported, and more than 40 cases of cervical inter-[inaudible]plasias have been described.

We have to remember that the original description of the syndrome was based on 36 male homosexuals, so we don't need to add more cases of cancer, of dysplasias to the series. It is time to reassess this case definition with the knowledge and experience that we have now in 1991.

I emphasize cancer of the cervix, because preliminary stages can be detected with mass screening programs, and therefore it is a preventable condition. It is opportunistic in that it occurs in immunosuppressed patients.

The other issue that I want to mention is, again, the society's repose, and I have coined two definitions--consumerism sexuality, which is the sexuality that we're seeing in the media that is associated to business and to selling products, and I have contrasted it with responsible sexuality, which is associated with more of these healthy attitudes, knowledge, and respect for the sexual partner.

We accept consumer sexuality, but we do not accept responsible sexuality. We do not teach our youngsters responsible sexuality. Our society still believes that knowledge of our sexuality will lead to promiscuity.

Studies of this issue, in particular the one done by the Alan Guttmacher Institute, have shown that knowledge and availability of preventive measures decreases the incidence of adolescent pregnancy and, by the same standards, the incidence of sexually transmitted diseases in other countries.

This is why I brought this issue of sexuality and societal attitudes. Prevention of AIDS will not be a reality for women, and probably will not be a reality for any sexually active person, until society, including all of us, accepts the concept of responsible sexuality.

If the rate of unwanted pregnancy among adolescents, which, by the way in Puerto Rico is 20 percent, and also among others is considered as a failure of our society to teach or make available preventive measures, then we can conclude that the task ahead of us is difficult but not impossible, and the challenge is big but it is worth the extra effort.

Women are the basis of the society. We are the caregivers, nurturers, educators, and many times the economic supporters of a vast segment of our population. Let's all recognize that the health of women will impact in one way or another the health of the society, and this is the issue of the '90s. Thank you.

DR. ROGERS: Dr. Zorrilla, thank you very much. Very elegant. You may have not quite equalled, but you did very, very well, all three of you.

Mr. Goldman?

QUESTIONS AND ANSWERS

MR. GOLDMAN: Thank you. Maybe--I don't know whether what I'm going to say is a question or a comment, and if it is the latter, then take it as my question is, would you comment on my comment.

One of the things that both panels, I think, have demonstrated in a way which demonstrates both the personal impact as well as the perspective of the view as providers is the consequences of the lack of a national plan that we have.

Last night on Nightline, Dr. Fauci, commenting on Dr. Gottleib's comments, said that there was a national plan, referring of course to the Public Health Service plan. What clearly is the case is that a Public Health Service plan is not a national plan.

The Public Health Service is not the country. The Public Health Service for the country wouldn't have the Justice Department trying to make medical policy on immigration issues.

We wouldn't have the CDC sitting there saying what the definition of AIDS ought to be, and saying that for disability and other determination purposes is the problem of SSI, and SSI saying it's the problem of CDC, and neither of them talking to each other about what the nature of the problem is, and that's because the SSI, Social Security Administration, is not part of the Public Health Service, and therefore is not part of the same plan that the CDC is part of. And what we need is a national plan.

There's a national plan in which we have housing available to people who need it, and that people with AIDS by virtue of their condition, by the discrimination that exists, and by in some cases the limited life span, are virtually denied access to low-income housing, and yet if I recall correctly, the last time we had hearings, we invited people from HUD to our Commission hearings, and they did not even bother to show up and choose not to come. They're not part of the Public Health Service's plan on AIDS.

I just find it extraordinarily frustrating to see some very good people--and I don't say that in criticism of Dr. Fauci, who's done a wonderful job. I certainly don't say it in criticism of my colleague on the Commission, Dr. Sullivan, that HHS in many cases has done a wonderful job, but it can't do it all itself, particularly when there are people outside of HHS and people outside of the Public Health Service who perhaps do not understand that unless and until we can stop being punitive about people with AIDS and HIV infection and instead care for them, that we'll never solve the problem.

DR. ROGERS: Mr. Goldman's writing a report for us here. Would you like to comment on his report? Dr. Zorrilla?

DR. ZORRILLA: I'd like just to make one comment or idea, and that's my late realization in my career that health is not a constitutional right, and health is a business, and that's why we don't have access to health to everyone.

DR. ROGERS: That's a powerful statement. Mr. Allen?

MR. ALLEN: I have a question for all three of you. Are any of you a part of any CRIs, community research initiatives, anything dealing with the community-based research?

DR. ANASTOS: Bronx-Lebanon is a CPCRA, an NIAID-funded--

DR. ROGERS: Why don't you translate all those initials--

DR. ANASTOS: Part of the NIH, the National Institute of Allergy--

[Simultaneous discussion and laughter.]

DR. ROGERS: We don't know what it is.

DR. ANASTOS: A community program for clinical research on AIDS, which is supposed to be comparable--basically, it's supposed to take clinical trials and place them into settings like mine. My setting is not--I work in a service-based institution. This is what we do: We provide health care services. But we provide a lot of health care services, and we do a better and better and better job of it.

We have an enormous base of patients who ought to have access to clinical trials for two reasons. One is, first, it really is state-of-the-art care, that patients need access to clinical trials in terms of available therapies for HIV-related disease. The second is, it's a wealth of information that we should not let go of.

And I think it's a very important initiative. But I would also add, sort of tied in to what Mr. Goldman said, I don't think that Anthony Fauci is the enemy either, but I do think that the observational data base study, for example, which is a national natural history study that comes out of these community-based programs, is not the answer to defining the disease course in women nor in intravenous drug users.

And the reason it's not the answer is that there's inadequate funding for it. And in spite of the fact that we are in a time of limited resources, we're going to have to acknowledge that we can't get this information without a little bit more money than what we've had so far.

I run a reimbursement-based system. We get reimbursed for our care--not all of it, but a lot of it, enough that, you know, if I can find doctors to hire, we can hire them. We can get salary lines for them. And that in providing services, that is the most important thing and must be the most important thing for us. I can't break the back of my clinic by trying to load on a research program with nobody to collect the data.

DR. ROGERS: Mr. Dalton?

MR. ALLEN: Well, I had a second part of that question, which was, are there any studies that you know of that are dealing with opportunistic infections on the CRIs for women?

DR. ANASTOS: I believe they don't exist. There is currently a funding initiative coming through the CDC that has to do with the natural history of women, but because of limited funding, the control group is limited to uninfected women. Now you really can't answer the questions about gender differences and opportunistic infections and disease progression of HIV without a control group of HIV-infected men.

I desperately hope that enough funding will be made available that control groups of men can be added to whatever sites do those studies. And we have applied as a site to do that study.

DR. ROGERS: Dr. Young?

DR. YOUNG: We are neither an ACTG, which is the AIDS clinical treatment group, nor a CRC, but we have over 400 people involved in studies, most of those funded either through drug companies, through private grants, or through stealing from Peter to pay Paul. We kind of shuffle things around, or sometimes just on sheer labor.

One of the problems that face particularly women, I'd like to address, in clinical trials, because clinical trials have provided a great opportunity for people to get state-of-the-art care, particularly those who have limited resources. But one of the problems has been that these studies do not take into account special needs of women, particularly those regarding child care, and prolonged time.

And these studies take enormous amounts of time. We sometimes drag people in on a weekly basis. We're doing one PK study. It's a pharmacokinetic study where people need to be there for 12 hours on several days. Unless you provide child care or make provisions, women are not going to be a part, and I think it's why women are under-represented.

But a greater issue is you cannot have studies without having adequate care. And as the treatment groups are currently set up, primary care is not provided. Gynecologic care is not provided. And until you combine those two, you can't ask people to enroll in a clinical trial and then tell them when something goes wrong, I'm sorry, there's nothing that can be done.

So it has to be connected. There have to be funds made available to provide adequate primary care before we can worry about enrolling people in clinical trials.

DR. ROGERS: Mr. Dalton? Let's make our questions short, because we've only got about five minutes left.

MR. DALTON: Your timing is auspicious, David.

[Laughter.]

DR. ROGERS: Harlon is so eloquent, he always writes our reports.

MR. DALTON: You notice David has several times referred to writing a report. It's clearly on our minds, as the end of our two years. And not only has Dr. Gottleib helped us and not only has Don Gold, but this panel has helped us, each one of two.

Dr. Anastos, the series of questions that you listed that would not get answered so long as we focus on women as vectors, it seems to me, deserves a prominent place in our report.

Dr. Young, your description of the woman who came to see you who wouldn't let herself be admitted because of wanting to take care of her child, who had no one else to take care of it, I think needs a place in our report, as does that metaphor of stepping off a cliff versus being pushed off a cliff.

Dr. Zorrilla, your, in a sense, new founded recent research with respect to the data already present with respect to HPV and cervical cancer and dysplasia, I think, deserves a place in our report.

So I just wanted to thank you all for helping us.

As for specific questions, Dr. Anastos, we both really know you're not going to really write up your testimony, and that's fine. But could you at least send us the cites with respect to--actually, I wrote this down so I won't strain my brain--a couple of things--the survival studies that you talked about and also with respect to the likelihood of rate of transmission from mother to child

And of course specifically with respect to the survival studies, you said that women survive less long than men in every study. I was wondering whether any of those studies control for race, because it is also true that African-Americans and Latinos survive less long, and most women infected with AIDS are black or brown, so I was just curious about whether that--

DR. ANASTOS: There is some aggregate public health data that can be separated by race and ethnicity in terms of survival data. It also is surprising. I will preface this by saying this was hard information to come by. I called everybody I could think of in both the United States and the world. The rest of the world has very little survival data, and that the results were very surprising.

One surprising result was that in some cohort studies, drug users do much, much better, and that was very surprising to me. It was against every piece of common wisdom I had ever heard or thought.

The other is that for people of color, the same is true. There are some studies where they do better, and some studies where they do worse. And that shocked me. For example, in aggregate public health data from Michigan, and I believe I'm quoting this correctly, but I haven't looked at it recently, among drug-using men, the white men do much worse than the black men.

You know, what does this mean? Is it real? Is it just because of some funny way the data--

DR. ROGERS: Black men in New York should move to Michigan, then.

DR. ANASTOS: Because it is so hard to tease out economic status, compared to everything else--gender, race ethnicity. I think all we can do at this point is look at the information, and then try to have it guide us in the way we should design a study that would help us answer the questions.

DR. ROGERS: Mr. Peterson, last question.

MR. PETERSON: Actually, Harlon lent me three seconds for my question here--and it is a quick question.

DR. ROGERS: Talk a little bit louder, sir.

MR. PETERSON: Dr. Young, you made specific reference to the lack of counseling associated with the diagnosis of HIV infection, and that's one thing I'm not familiar with in the literature in terms of putting a magnitude on that. I'm not really sure it's been addressed in the literature specifically with women.

Do you have any idea, just anecdotally, or any other panel members, how much lack of counseling there is associated with the diagnosis in women?

DR. YOUNG: It's going to be anecdotal. I haven't seen any studies that have really addressed this, and maybe some of the epidemiologists in the audience can help us with, at later times, testimony.

But anecdotally, from the women I'm seeing, a number of them--and I think it's motivated sometimes by good concerns on the part of often gynecologists and obstetricians--will test women, sometimes even without their knowledge. But then because they're not equipped to actually--it's a very difficult thing to tell somebody that they're HIV-positive. It requires a--it's just difficult, and it requires time.

And often because they don't have that time nor the expertise, and because I think sometimes frankly they're frightened--they're not sure how to tell people that they're HIV-positive--they'll often say to the woman, well, you have AIDS, as you've heard before, not you're HIV-positive, but you have AIDS and you better find a physician. So that it's in settings where people are not used to dealing with this disease.

We get calls every week from small outlying hospitals or outlying physicians' offices who say, we just tested our first person and they're positive and we don't know what to do. In some cases, those test results have not even been correct. But I think that people who cannot counsel should not be testing.

DR. ZORRILLA: I want to make a comment regarding counseling, and that is that the traditional way to counsel a person regarding the HIV test will not work for women, because at least most of the women that I know are not aware of any risk behavior because they don't engage in risk behavior. So counseling a person, and telling them have you ever done this, this, this, this, then you should do this test will not work for women.

DR. ROGERS: Very important.

DR. ZORRILLA: So that is why I agree on universal offering of counseling and testing to women in particular, because risk to women is not associated to their behavior.

DR. ROGERS: Mr. Kessler is pleading for a last comment.

DR. KESSLER: Yes. I just wanted to answer your question, Dr. Peterson. On our hotline, which gets about 5,000 calls a month, I would say at least twice a day--and this has been going on for eight-and-a-half years now--at least twice a day we will get a call from someone who's been told by a physician, you're HIV-positive, but I don't have time to tell you what it means. Call this number.

And in more cases than not, one of those two calls are in an absolute panic or crisis situation, and the other half is so scared that they don't even know how to pose it, because they're afraid that someone else is going to refer them yet down the line.

And the other thing that's going on often, especially with male physicians, male physicians bump the decision to tell to someone in the office, their nurse, their receptionist, people like that. They are absolutely not trained in counseling, and they're afraid to counsel women more than men.

DR. ANASTOS: In fact, doctors aren't even trained to talk to a patient in language that is understandable, so that some of the time, I think the doctors actually think that they have counseled and told the patient that there's an HIV test being done, but the patient has zero comprehension that that's what they're talking about, and that is compounded if there's a language barrier.

DR. KESSLER: They throw it all in the alphabet soup, and who knows.

DR. ROGERS: One last query to all of you. In thinking about what all six of you have said, wouldn't one problem be solved by simply indicating that HIV positivity qualified you for treatment?

DR. ZORRILLA: Definitely.

DR. YOUNG: Definitely.

DR. ANASTOS: Absolutely.

DR. ROGERS: Many, many--yes, Mary?

DR. YOUNG: The better care we provide, and the better care our patients provide themselves--this is a very patient-active disease--the more they're penalized. You know, it takes a lot of work to stay healthy when your CD-4 count is 50. But a number of women and physicians work very hard to maintain that state. But the better we do that, the less entitlements there are available for these women, the more fatigue really does not fit in.

You know, if you get to women early, if you're treating them appropriately, if you're preventing the opportunistic infections, in the long run you can actually be penalizing them from having access to entitlements. It should not be working that way.

DR. ANASTOS: Can I make one more comment?

DR. ROGERS: Of course.

DR. ANASTOS: Relating to disability benefits, I mean, I think the other thing that we have to acknowledge is that if you're a young woman who's infected and you are responsible for the care of your children, that it is almost cruel--in fact, it is cruel--to say, well, if you're--we're not going to give you disability benefits if you don't meet such and such a definition.

You cannot stay home and spend your last years with your children, the way that all of us would probably want to do. You must go out and work a menial job, even though it won't pay for the child care you need to get, even though all of us who work full time know that the child care falls through a lot and you are desperately afraid some of the time for the safety of your children.

What are we doing, asking women to do that, when they only have a few years to live?

DR. ROGERS: Thank you all very much. We're most grateful to you. I'm ignoring Mr. Goldman.

[Laughter.]

DR. ROGERS: He can talk to you during the break. We will have a ten-minute break, and then we will reconvene.

[Short break.]

DR. ROGERS: I think we'll go ahead and get started. We've got all the brains of the Commission here.

[Laughter.]

DR. ROGERS: We're missing a few of the others, but those who make a difference are here.

[Laughter.]

DR. ROGERS: We're going to talk a little bit about psychosocial issues, and we're privileged to have Inca Mohamed, from the Adolescent Program at the YWCA in New York, and Alva Moreno, who is from the UCSF California Partner Study in Alhambra. We do not have Veneita Porter. Unfortunately, she's had a death in the family.

We have La Francis Rodgers-Rose, who's President of the International Black Women's Congress from Newark, New Jersey--my territory, and we have Ruth Slaughter also, who's Director of the AIDS Division of Women and AIDS Risk Network in Los Angeles.

Thank you all for being with us. Ms. Mohamed, we will hear from you.

STATEMENT OF MS. INCA MOHAMED

MS. MOHAMED: At the first offering, saying that I'm a trainer, I'm so used to standing in front of people and getting the group to talk that I always have to psych myself up when I'm making a presentation. So be prepared if I ask you a question--it will be my nervousness coming out.

[Laughter.]

MS. MOHAMED: One of the things, when I was telling someone that I was going to be coming here to talk about women and HIV disease, and I told the people that specifically the only group I can really talk about are adolescent women, because that has been my focus, is working with adolescents for the last 20 years, the person commented to me, but why? That's not really a big problem. Prevention is really the issue there.

And as I've been sitting here listening to people talk, what came to me was the fact that that's what people were saying about women before, and hopefully we will learn something from this so that five years from now that statement will still be true that that person made.

The focus of my work in HIV has been primarily prevention. And in a desire to bring you the most current information, I felt that it was important to talk to some providers in New York City who are providing services to young women between the ages of 13 and 21 who are either HIV-positive, or because of their behavior, and as it was mentioned earlier that geography is destiny when it comes to this disease, they are living in the path of the epidemic and therefore are at high risk for HIV disease.

These programs include an adolescent clinic, which provides primary care, and two clinics which specialize in HIV and adolescents, one of them being in King's County Hospital, which is a county hospital.

My training in public health has taught me to not look at health problems in isolation, but to locate the problem within an economic, political, and social context, regardless of how overwhelmed I might feel after I get the big picture. The same approach needs to be employed when looking at HIV disease in young women.

First we need to take into consideration their developmental stage. Whether one subscribes to the idea that adolescence is a turbulent and problematic period or simply another period of transition in a life, we know that it is characterized by certain behaviors and beliefs which do not promote an adolescent to protect or care for themselves adequately--such feelings of invulnerability, present thinking, a natural desire to experiment, and ongoing sexual development, to name a few.

Secondly, a large percentage of the young women who are HIV-positive are young women who live in economically depressed communities and lack adequate education, medical, and social services.

Third, these young women often have histories of drug abuse, primarily crack, sexual abuse, family problems, and inadequate personal and social support to effectively make the transition to adulthood. In essence, these are young women who already had their plates full, and now HIV disease has been added to the menu.

As is often the case in a crisis, people either mobilize themselves and handle it or they throw their hands up in futility. For most people, the process of survival is a combination of the two. A key factor for all people, but especially for young people, is what are the resources they will be able to rely upon to assist them.

With that in mind, I would like to highlight eight major psychosocial issues that come up for adolescent women who are HIV-positive, and the main thing--my purpose in setting up that picture is that it really will repeat a lot of what we've heard about adult women, but needing to keep in mind that we are talking about young women who are between the ages of 13 and 21.

DR. ROGERS: Ms. Mohamed, why don't you pinpoint those so that--as you know, the Commissioners love to interact, and I realize--

MS. MOHAMED: Right. That's exactly--

DR. ROGERS: Good.

MS. MOHAMED: I'll just hit them very quickly.

DR. ROGERS: Please do.

MS. MOHAMED: The first one is denial, and part of that denial is even further reinforced because of the sense of invulnerability. I'm not going to die. I'm a young person. What do you mean?

The next is the difficulty in notifying parents and partners, and that difficulty is based a lot on fear--fear of violence, fear of being abandoned. A lot of times when young women find out they are HIV-positive is also when they're finding out that they're pregnant. Teenagers are not supposed to be having sex anyway, so here you have the proof that you have been having sex twice.

Feelings of stigmatization--we all know adolescence, everything is very "me" focused, and on top of it you now have a disease.

Lack of peer support--one of the things that we're finding is that with young men, gay and bisexual men, there is at least an adult gay male community that is dealing with the issue of AIDS. So that however tenuous, there is a community that they can attach themselves to. There is no community for these young women to attach themselves to.

Anger and what was mentioned before, a lot of these young women are parents with very little resources, so there is trying to be a parent, trying to take care of your child and take care of yourself at the same time.

Difficulty in developing trusting relationships--most of these young women have not seen the best sides of adults, and now they have to rely upon adults.

And the last thing is that the major focus in working with these young women is to one, build the self-esteem, increase their sense of personal power, and to establish trusting relationships which fosters compliance, and all of that takes a tremendous amount of time and money to do.

DR. ROGERS: Thank you very much. That's very helpful. Ms. Moreno?

STATEMENT OF MS. ALVA A. MORENO

MS. MORENO: Thank you. I am with the California

Partner Study that is being done throughout the State of California, and I will have the opportunity to work which is compromised of Southern California. If you could cut the State in half and imagine from Bakersfield to the Tijuana border, that is the area that myself and another woman by the name of Rosemarie Ramos cover in the recruitment of couples who will qualify into our study.

The success of the study, in my opinion, has been that we are able to go into the privacy of these individuals' homes and provide them with actual information. And even though it is a research study, we are actually a service in many eyes of the providers who will refer to us.

One, we are bilingual. We can go into the homes of individuals who do not have the language skills or the economic facilities to be able to go into the services that are being provided.

What we are seeing is--the whole concept of the study is that it is looking at the sexual transmission of the virus. Because I am in the homes of these individuals, I have been able to look at some of the psychosocial implications that the virus is having on these families.

For many of these couples, I am their sole source of support. They are very afraid to go out and get any information. These couples are married. The women range from the ages of 18 to 51 years old.

Of the 307 women that we have participating in the study, 61 are infected. Of the 61 women who are infected, probably I would venture to say that about 22 are Latino women. And because, again, language is such a barrier in the southern part of California, for many of the providers, they will refer them to me because of the language skill.

And for many of these Latino women, they are here undocumented, so right there that is one major fear. A lot of these couples, or the Latino couples I should say, that I am working with have found out their status through the mandatory testing that amnesty has imposed on them. And again, that has caused more stress and most fear.

I can say that for these men, I would say three of the men that found out they were HIV-positive through amnesty, three of them died within the year of the diagnosis, and I can honestly say they did not die of AIDS. They died of the stress, of the guilt, the fear, and the shame that they felt of this virus, or having been infected and not being able to go anywhere and talk about it.

The women, though, who are HIV-infected that I'm working with, and again predominately Latino women, I am watching them deteriorate little-by-little because of the fact that they're putting themselves second. We're hearing a lot of the same stuff, and it makes me feel good, because a lot of the stuff that I have seen has definitely been validated here, and I don't feel alone.

These women are leaving themselves for last as a result of having to take care of their husbands and their children. Their biggest fear is what's going to happen to my children when I no longer here are able to provide for them. Many who are here from other countries who have no family support here, again, are fearing, what am I going to do, where am I going to go, what is going to happen to my children?

They do not want to go back home to their prospective countries, because again, they've come here to prosper and look at the land of--what did we call it last night--milk and honey, and are definitely not finding it.

Fifty-two percent of the men who have become infected have done so through bisexual activity in our study. We have very few, if not almost--I would probably--of the women that I'm working with, of the couples, I probably only have like four of the men who actually became infected through intravenous drug use. The rest are through sexual activity, bisexual activity.

These women do not know that their husbands are participating in this kind of activity. These women are, unfortunately, your typical female who's home taking care of her children, does not consider herself at risk, knows and accepts that for possible cultural reasons that her role is to stay home and endure whatever her husband is doing.

For many of these women, there is already dysfunction in their relationships. They are already living through domestic violence. There has already been a series of spousal rape that they do not identify that they've had to deal with. For many of these women, they are the survivors of rape and incest, and now all we have here is AIDS.

So for many of them, the issue of HIV and AIDS is secondary. It's like their self-esteem and their idea of who they are is already way down, and so to now be diagnosed with HIV, it's just another blow to my life. So what? I just go one. It's very unfortunate.

Many of these women do not have the resources to be able to seek psychosocial services counseling. Many of these women, again, are very afraid to go out and see it, to try to find out. They fear--again, the fear is what is definitely deteriorating their health--the fear that they're going to be found out, that they're going to be ostracized, that their children are going to be kicked out of school, that they're going to be rejected.

There are still very many myths. When we talk about women who are HIV-infected, especially Latinos, we have--I have a real problem when we talk about negotiating safe sex or continued use of condoms, because for many women of color, we're just now learning how to negotiate for jobs, and to talk to us about negotiating for safe sex is sort of a problem for me personally, but then again.

And we cannot forget the female partner who is not infected, because this virus is definitely having an impact on that women too. She's having to endure the same psychosocial issues, but at a different scale. She is having to leave in secrecy. She is having to stay, possibly, in a relationship because again, she does not want to leave her partner, who needs her very much and who in leaving will cause some stress in that family members or friends are going to want to find out, why are all of the sudden you leaving?

For example, I have a female, 50 years old, she's been married 25 years, and her husband was diagnosed in 1986. She is not infected, but she is having to endure all that responsibility.

I have a young woman who is 33 years old. She found out she was HIV-infected when she and her husband, after being married only four months, tried to purchase some life insurance, and she found out through her agent that there was something wrong with her blood. She had bad blood, she better go see a doctor immediately.

And she is having to deal with amnesty issues. This is a woman from England. We always assume that when we talk about amnesty issues, we consider the Latin American woman or the Mexican woman. But this is a woman who is having to deal with amnesty issues or immigration issues who is here from England.

Fortunately, she is better off than some of the other women I'm working with. Her husband is quite capable of taking care of her. She does not have to work. They live in a very prominent area of Southern California, in Laguna Beach, so she's quite well--but--

DR. ROGERS: Will she be deported because she--

MS. MORENO: She could be, yes. She tried to apply, or she started to apply. She had a lawyer, and she was applying through her husband. She doesn't qualify through the amnesty, because she has married to an American citizen, and her lawyer told her to just let go of the papers, don't do anything. But she's always in fear that she's going to be stopped or be questioned about her status.

And the stresses that are affecting her is that she cannot go and see her family. The idea that maybe she'll never see her family again, she'll never see her country. And that's basically so of the other women in Mexico who have their parents, their family members there.

A lot of these women who are in Latin American countries have left the children behind to come here and work ahead of time, and are now not able to go back for their children or able to see their children. That is definitely a stressor and an impact.

The women I'm working with, the only difference--the emotions, in my opinion, are the same--the fear, the sense of isolation, the guilt, the anger, it's the same. The only difference that I'm seeing is the economic differences.

For those women who are quite well off and can be provided for, I mean they can get away for the weekend, they don't have to worry about their children not being cared for appropriately, they do not have to work, they can get medical care, versus the woman that does not have those resources, definitely the stresses are in higher quantity.

We have been hearing how physicians do not want to take responsibility, or that we do not have enough physicians taking responsibility. I am seeing that, too.

I have another woman that I will refer to as Anna, who is 33 years old also. She found out she was HIV-infected about a year-and-a-half after she married her second husband, and in the process of just trying to possibly being pregnant, she just took her responsibility to get tested. She found out she was HIV-positive.

When she went to the doctor, to a private physician to get the test, and he gave her the results, he told her that she just as well go home, pack, and just accept the fact that she was going to die and make arrangements for her one child, and that anything and everything she touched, she needed to clean with Clorox.

And she left just in total distress, went home, cleaned everything with Clorox, got obsessed with the whole issue of bleach and Clorox. She actually douched with Clorox.

When the call came to me, she, in desperation because of the injuries that she had caused to herself in doing so, she in desperation called the Spanish-speaking AIDS hotline, which then referred her to me because then they knew that I could go see her in her home and blah, blah, blah.

I had a heck of a time trying to find a gynecologist or a physician who would see her. By the grace of God, I finally did, who took her in and treated her.

But those are some of the--they seem extreme stories, but they're true. These are true stories. These are the kind of stuff that I am seeing and looking at in these peoples' homes.

Again, I just feel that these women need a place to go. They need people to talk to. They need to feel safe. They need to feel comfortable. We need to be able to provide them with language at the level that they're going to understand.

We also need to be supportive of their male partners. We cannot isolate the women from the men, especially women of color, and I can honestly testify for Latino women. They're not going to leave their partners. You know, historically, our role has been that we are to care for our men and our children, and to death do us part, and in sickness and in health. And again values, religious values, definitely have a major role in that.

And even though these women want to leave, would like to leave, want to find themselves, want to be able to leave and live whatever time they have left in peace, they cannot do so. And so on and on and on. And I could share with you all day long some of these stories.

I again thank you for allowing me to come and share with you and be an advocate for these most wonderful women who have definitely impacted my life and are my friends too. Thank you.

DR. ROGERS: Thank you very much, Ms. Moreno. Dr. Rodgers-Rose?

STATEMENT OF MS. LA FRANCIS RODGERS-ROSE

MS. RODGERS-ROSE: Thank you very much for inviting me. Much of what I have to say has, I think, already been said, but I think one of the good things about being here this morning is to see that one's perspective on the subject is within the realms of what other women have said.

Despite women's vulnerability to AIDS, there has been a lack of attention to the seriousness of the problem. Data on women and AIDS are not routinely collected or reported, although they represent the fastest growing group with AIDS.

In the May 1991 CDC reports, there were 174-and-some-odd thousand known cases of AIDS, and of that number, 17,000 were women. Black women account for a little more than half, 8,990, while Hispanic women represented about 25 percent, 4,527.

Much of the preventative materials that we see about AIDS usually show middle-class white women dealing with this subject. And that's missing the vast majority of women who are affected with AIDS in the United States.

It seems that AIDS must be addresed from a holistic perspective, and must be addressed from the perspective of the women who are indeed affected with the disease. We cannot separate AIDS from the everyday lives of women.

Some of the social issues, very briefly, that women confront with AIDS are issues that are compounded because of the position that women find themselves in in the larger society. And that is that women invariably are found in subordinate positions in society. They have less education, and because of having less education, have less access to some of the materials about AIDS and the prevention of AIDS.

But in this country, we have witnessed in the last 15 years a growing feminization of poverty. And with that feminization of poverty has come increased homelessness among women and their children. And many of these women have no access to health care. Then you add on top of that women who now have AIDS, and you put the picture being very, very bleak.

These women also quite often are the main supporters and providers of their families, and when they cannot work, then it means that their children suffer and they suffer.

Women suffer heavy social responsibilities, so that when they get sick, they still have to do certain things, and that is, they still have to cook, they still have to shop, and they still have to wash, and they still have to raise their children.

They do not have the support mechanisms that I think men have, because men are not given the responsibility of shopping for foods and taking care of the family, and so women find themselves sick but still having to take care of the growing responsibilities of their families.

And also we know that women are the caregivers in their families, and so that when we look at not only in the families, but in social service agencies, it is the women who are giving the care. And although they may be sick, they must still give the care.

So women have this low social status, which gives them a social vulnerability to the HIV infections.

There is a growing incidence, and I think you see it in the videos, particularly on TV, of women seeing more today, I think, in the last--than what was true say in the early '70s as sex objects. And being seen as sex objects, it has an impact on women's perceptions of themselves, but also men's perceptions of themselves.

And so when we talk about responsibility and responsible sexual behavior and you still have women barely clad--and I'm sure you see some of these videos. Some of the latest kinds of issues that videos deal with say nothing about taking responsibility for one's sexual behavior and taking--and being accountable for sexual acts.

So women, then, when we talk about AIDS and women and AIDS, women are seen as infecting men, rather than the other way around. And however, we know, with best reliable data that it is usually the men who have infected the women.

And then we see the pitch for women being responsible for the whole use of condoms. And I would just echo what you have said, is that it takes a whole another kind of negotiation. Women are not socialized nor raised to be the aggressor in sexual behavior, and so that means we have to talk about writing different kinds of scripts if we want to talk about women being responsible in terms of being the person to say that you now have to wear the condom.

I think we need much more research in terms of coming up with some kind of condoms for women, which we are not putting that kind of effort into that kind of research.

And when women suggest that men use condoms, they are confronted with sexual violence. Women are being beat up because the men think that they are messing around with them if they say that, I think you ought to wear a condom. And so some of the things that we are pitching out for women to do are not things that we can do just based on the kinds of socio-economic political kind of a climate that we live in.

I would echo some of the psychological things that have already been talked about. Women growing today still see themselves as sex objects, their self-esteem being related to sex. Young women feel that I'm not anybody if I don't have a man, and so you see television shows like Oprah Winfrey the other day about how do you keep your son away from these women who are like all after them, et cetera.

It kind of goes on and on, and we're really talking about changing lifestyles, and in order to change lifestyles, we must be talking about changing very crucial issues in the society and how the society has defined women's roles.

I know my time is up. I just suggest that we need more research on how women can manage with AIDS based on the kinds of social responsibilities that they have. Thank you very much.

DR. ROGERS: Thank you very much, Dr. Rodgers-Rose. Ms. Slaughter?

STATEMENT OF MS. RUTH SLAUGHTER

MS. SLAUGHTER: Good morning. My name is Ruth Slaughter. I'm from the Women and AIDS Risk Network in Los Angeles.

WARN is a three-city project that has been providing AIDS education, information to women in Los Angeles, Boston, and Phoenix. We are now in five cities doing research and service in San Diego, Puerto Rico, Juarez, Mexico, Los

Angeles, and Boston. But I'm going to talk to you about the Los Angeles project.

I would first like to share with you an article that I read about six months ago in the Los Angeles Times, and it was a very long and interesting article about AIDS and homelessness in Los Angeles. I would just like to quote just this one small section in the article.

This was about a man who was HIV-infected. I say I'm going to go down to the clinic, but I wind up getting high, he said. Last time my check came, I got me a room, then I got me a little strawberry--a strawberry is a slang term for sex worker in Los Angeles--and then I got me some cocaine. The time for his doctor's appointment came and went, he said, while he and the prostitute had sexual intercourse without a condom and without her knowing that he had tested positive for HIV.

I became very concerned about the man, because I know in Los Angeles you have to wait three and four months to get medical attention. But I was very angry concerning the women, because that was the only mention about a woman in that entire article.

When I brought the article to the WARN staff and I shared with them, because we are working on the streets in the downtown area, and we're working in the hotels, and they shared, gee, who could she be?

And this woman could have been 13 to 50. She was probably black or Latino. She may be on crack or other drugs, and we may have tried to get her into a drug program. But Los Angeles, with eight million people, one of the largest counties in this country, has 34 public detox beds.

So if a woman is on crack and she wants to be detoxed and we can reach her when she's tired--because sometimes the women say they hit the curb, they want help. And we will try to get her help, and there are no beds available.

In Los Angeles, the drug treatment programs are supposed to be treatment on demand. If a woman is HIV-positive, it doesn't matter. If you can't get a bed, you can't get a bed. So it could be a woman who we have tried to get into a program, and that was impossible.

She may be a woman who is undocumented. She could not get work for the day, and needed food or money or a place to stay because she was hungry. Her children could have been waiting in the hotel lobby because she didn't have child care.

I could go on and on with some of the women that we are seeing and some of the reasons why they are on the streets, why they don't have a place to stay, and AIDS is probably the tenth thing on the list of needs.

The women we are seeing are extremely diverse, culturally, economically, and spiritually. They have a wide range of sexual engender roles and are in family configurations.

WARN has provided AIDS education to over 5,000 women, and we feel that we have made a difference with a very small staff and limited resources. The things that we feel that have worked is that we have hired women from the communities. We have approximately in all of Los Angeles about 15 women doing outreach to women. The rest are primarily men, and who are reaching men who are injection drug users. We have very few programs that are reaching women who are at high risk that don't fall into a certain risk category.

By hiring women from the community, women who understand the drug culture, women who speak their language, women who are recovering from drugs and alcohol, women who may be former sex workers, and women who are seen as positive role models.

Some of the things that we definitely need in Los Angeles, and which when I'm on the East Coast I see more printed material, more advertisement at bus stops, et cetera. In Los Angeles, you see very little of that, and you see a number of posters with women who are pregnant to get help to protect their child, but there's very little information of where they can get medical services, what are some of the symptoms and signs, where they can go to be tested if they want. There's just a lack of information in Los Angeles regarding women.

We've also found that we've had to have a staff that has to be very aggressive in getting referrals for women, to getting them into drug treatment programs that are very limited for women and their children.

We have to have funds for food and shelter. We have, in our Federal, county, and State funding, not one of those projects will allow us to buy food. Now, this is a small thing, to buy food for the women. If a woman is hungry, we have to feed her first. So many times, out of the staff salaries, they will pay for food and then talk with the women regarding HIV. But you have to deal with first things first.

We also need funds for bus vouchers to get women to medical services. With so many women that we have to see, it's very difficult many times to provide transportation. But in order for a woman to get that, we have to take her.

We need to have safety for battered women. Many of the women are battered, and we need to have more shelters where women can go if they want to. And as has been mentioned, we need child care. We also need referrals for job training and jobs.

And I think one of the most critical issues that we feel for the women we're seeing is treatment on demand. If we are serious about this virus, we must include all of the above. Women need to know about all of their options so they can make well-informed choices.

We see incredible strengths among the women. It all seems so hopeless, but we see incredible strengths. And when women are given options, changes can be made. Thank you.

DR. ROGERS: Thank you very much, Ms. Slaughter. Elegant, elegant testimony.

One observation, before I--I was just thinking as all of you were talking this morning, as a country we're not taking very good care of women, but fortunately women are trying to take quite good care of women. Blessings on you. Marine says, we always have.

Questions from Commissioners? Yes, Scott?

QUESTIONS AND ANSWERS

MR. ALLEN: I have a couple of questions, one for Ms. Moreno. You talk about the needs of the women from a large geographical area. I'm assuming there's a different between the urban and rural areas--

MS. MORENO: Yes, there is.

MR. ALLEN: --the psychological needs and so forth. In the valley itself, do you find a lot of the migrant issues of those that are in transition, as the crops go--

MS. MORENO: Yes. What I have found--I have had maybe like two couples that were referred out of Curran County, which is the Bakersfield area. And in my trying to follow up--because part of our study is that we follow up every three to six months--by the time I go back to follow up in three months, they have already moved and we've lost them to follow up.

MR. ALLEN: Do you find that--what type of social support is there for, say, the rural woman--is it telephone, networking with other HIV-infected women helpful, or is there any of that? Do you find culturally Latino women less receptive to that, or family structure--

MS. MORENO: Yes, especially your farm working women, who are here undocumented or in the process of getting documented. They're not going to talk about their HIV status or the possibility that their partner is, because again of the fear of being possibly deported, and/or that what little resources they have--a lot of them already live with extended family members, and they are deathly afraid that other members of the family will find out, and they will be kicked out, and then they will end up homeless.

MR. ALLEN: So what the scenario you're painting here is of absolute isolation.

MS. MORENO: Definitely.

MR. ALLEN: And there's not a sense of breaking through that, of would you like to talk to another woman that's in the same situation?

MS. MORENO: Yes. As a matter of fact, that's one of the programs--one of the activities, I guess, that you can say that myself and the other women up north as well--because throughout the State, there's seven of us who are doing this type of work.

We have developed what we call a buddy system. We have been able to hook up couple who fit into a similar situation with each other, and they have become a support system for each other.

For example, in the San Fernando Valley, which is much closer to Los Angeles, I have a couple who is commuting to San Diego, and the couple from San Diego is coming to San Fernando Valley to sort of hang out with each other and be part of a support system, and that's the way it's working.

Again, if they don't have a telephone, they can't call. Long distance is costing money. But they're very eager to talk to somebody else who might be like them, yes, and that's exactly how they say it, because they feel so different. They feel that they're separate now, and I really work hard in trying to let them know that they're not.

DR. ROGERS: Ms. Diaz?

MS. DIAZ: A question for you, Alva. I've heard you in presentations previous to this one talk about the range of education and social spectrum of your cohort that you're following. I would really like for you to comment on that a little more.

MS. MORENO: Yes. The women, I mean, are just from all walks of life. I have women who are Ph.D.s, two women who have only got three years of education or none at all--all walks of life. Again, I could mention that I've got women that are living in some of the most beautiful mansions in the Laguna Hills Beach area to the women who are living in what we call South Central Los Angeles or the Jungle of L.A. in the housing projects.

Again, as I mentioned earlier, the emotions are the same, all the feelings of fears. The only difference is that some are able much better to cope with it because of their financial reasoning.

And I have to admit that all these women, all along the same spectrum, are so grateful that they have somebody to talk to that they all treat me the same. There's no difference.

MS. DIAZ: Now, this is a more difficult question, regarding the bisexual issue. Fifty-one percent, did you say?

MS. MORENO: About 51 percent.

MS. DIAZ: About 51 percent. Could you just comment on any differences in the populations, because you have Anglos and Hispanic and black and other?

MS. MORENO: Yes. I would venture to say that the Anglo male is more open about his bisexuality versus the Latino or the African American.

MS. DIAZ: What about their partner?

MS. MORENO: The American, or the Anglo woman is, too. She may suspect, and she's more open to talk about it with me, where the Latino or the African-American female will talk and just say, well, there's a possibility, but I'm not sure. I mean, we have children. He's always been very masculine. I don't know that there is.

There's a lot of denial. I mean, it's like they know. They know that he has probably participated in male-to-male sex, but they're just not going to talk about it. So that--they're holding it inside is definitely causing some stress.

Where the Anglo female will say, well, you know she's got--she's reading. Once she finds out she's HIV-positive, these women are definitely reading up, following all the articles. I mean, they're way ahead of stuff, more so than I am. They're actually educating me when I go into their homes. They're always saying, did you hear about this, did you hear about that, I read this, I read that. I can't keep up with them.

Because they have that ability to be able to read and research themselves, they have more information, and they're more in tune with possibly what is going on. But the communication of that behavior is definitely not being talked through these couples at all, or many of them.

DR. ROGERS: Thank you. Mr. Dalton?

MR. DALTON: Well, much as my fellow Commissioners want me to summarize all the testimony, I have one question for one person.

Ms. Mohamed, among the factors that you've focused on with respect to adolescence that makes it difficult to communicate with them about HIV, you mentioned the sense of invulnerability. But as you said that, I was just realizing that you're from New York City. I'm from a place 72 miles away.

In our part of the country, adolescents, in fact, are becoming increasingly aware that they may die from a bullet. That is, that the myth of invulnerability or what in a sense maybe used to be the reality of invulnerability at that age is quite clearly gone.

And I was curious whether that affects the way that you can talk to people about HIV, or does it make it even harder because it's farther down on their list of concerns?

MS. MOHAMED: Well, I think it's what was said here, that it is just one of many things that young people are confronting. And in fact, your whole comment about the bullet, that I've heard young people say, why do I have to worry about AIDS? Chances are, I'm going to get shot before AIDS ever gets me. So that it is very difficult.

I think the other thing important to realize about adolescents is that even though they may be putting out one thing, there's often something else going on inside. So even though that adolescent may be talking through a great deal of bravado about yes, I know I can get bumped off, there still is that place inside of them where they don't really believe that that is going to happen to me.

So I think both of those things are going on with the young people, that there's so many things for them to already deal with. This just becomes another one.

DR. ROGERS: Ms. Slaughter, you mentioned your 34 detox beds for eight million people.

[Laughter.]

DR. ROGERS: A nice, generous kind of supply. My question, because you mentioned only detox and detox beds, are you able to put those people who ask for treatment on methadone?

MS. SLAUGHTER: Yes.

DR. ROGERS: Can you move them--how available is methadone treatment for those that you can't get into detox beds?

MS. SLAUGHTER: We have been able to get women on methadone. But that's the woman who wants it, because we really talk to women about her options, and some of the women want to get off drugs. They want to get off all drugs, and so they want to go into a program and not to get on methadone. So we talk to her about everything, and then she has to make the choice.

DR. ROGERS: Can you persuade them it's a halfway house in terms of methadone first, or--

MS. SLAUGHTER: We just look at options--

DR. ROGERS: Fine.

MS. SLAUGHTER: --and she has to make the choice.

DR. ROGERS: Very good. Other questions from the Commissioners? Thank you all very much. Much appreciated.

We're now going to talk a little bit about prevention strategies, and I would ask Ms. Beaulieu from Minneapolis and Ms. Dixon and Ms. Jacques--is that right--and Carmen Paris to first come up, and then we're going to have the others come up afterwards.

I would comment while you're getting assembled here, I realized to my distress that we have one hour of time and we have six of you we're going to hear from, so that does not give any of you a great deal of air time, but if you'll play it like those who've preceded you, speak from your heart and tell us what you want us to know and then let us interact with you, that works very well.

Ms. Beaulieu, welcome.

STATEMENT OF MS. LORI BEAULIEU

MS. BEAULIEU: Good morning. My name is Lori Beaulieu, and I am an Ojibway and Midwaukitan (?) Sioux from Minnesota, and I'm the training coordinator and a health educator for the National Native American AIDS Prevention Center.

It is with great honor and respect that I come to you today to share briefly what I have observed and learned in my work about American Indian and Alaska Native women and HIV AIDS.

I've been asked to speak to HIV prevention strategies for American Indian and Alaska Native women. However, before we can explore strategies, it is necessary to consider some of the general facts about Native women.

Despite the recent surge of public interest, Native Americans have been and for the most part remain an invisible population. With each label that is placed alongside Native, woman, lesbian, HIV-infected, the respect and recognition that is the birthright of each human being is too often denied.

Because we are an obscure and exotic people to others, Aboriginal Americans have, in the age of HIV, been labeled a hard-to-reach population. To soften the words, we are also referred to as a special population. Hard-to-reach--the term in and of itself creates barriers between critical, life-saving information and service and our people.

Hard-to-reach? For whom? We are, in fact, not hard to reach. We are right here. You live and work and play amongst us. We are everywhere, in cities, in rural and reservation areas, in government, in the arts, in business, and in the field of HIV AIDS. One need only to turn and look and ask what is needed with an open mind and heart.

Clearly, American Indian and Alaska Native women participate in behaviors that place us at risk for HIV infection. Rates of teen pregnancy are high in Native communities across the country. In some States, gonorrhea and syphilis rates have been found to be two or more times greater than that of non-Natives.

It is a commonly held belief that alcohol is the drug of choice for Natives who use chemicals. Research and observation tell us that this is not the case, and we have communities both urban and reservation where intravenous drug use is a significant problem.

You are well aware of AIDS-related statistics, so I will only make note that 15 percent of reported cases of AIDS among American Indians and Alaska Native women--15 percent of reported AIDS cases among American Indians and Alaska Natives are among women. In comparison, five percent of cases in the white non-Hispanic population are found to be women.

Principles of HIV education and service delivery for Native women are the same as for women of any other racial or ethnic minority. It is the context of where, when, and how those things are delivered that is different.

Because in many material respects we start out at a disadvantage, the needs and experiences of native women in relation to HIV and AIDS are magnified when compared to women of mainstream society.

Widespread poverty, poor health status, inadequate access to health care, lack of educational opportunities, disproportionate out-of-home placement of children into non-Native homes, and the pervasiveness of substance abuse and dependency in our communities are but a few of life's realities for Native women, realities that place survival needs well before those of self care, and realities that compound the myriad of psychosocial issues and physical manifestations of HIV infection.

There are as many HIV prevention strategies as there are individuals to develop and implement them and constituents to receive them. In consideration of our limited time, I will share three elements that are critical to HIV-related activities for Native women.

These principles are the outcome of discussion with Native people working in HIV and AIDS, Native people who are working very hard with an abundance of non-material resources--creativity, compassion, and commitment, but with an unrelenting dearth of funds.

HIV prevention activities must pay attention and respond to the needs of individual Native women. All programs should create room for the one-to-one client encounter. Because HIV does not exist in isolation, channels of support must be established. Personnel must recognize the connection between health and inescapable daily reality, and extensive referral networks must be instituted.

Our activities must create a system of long-term support for behavior change. In essence, we must affect social change. Research has shown that health education alone has a time-limited influence on behavior. If Native women know about HIV but do not see and feel the support for behavior modification around them, change will not be sustained on a community-wide scale, and in effect, our efforts to stop the transmission of HIV will have failed.

What do we need to develop and implement HIV-related programs for Native women? Resources. Specifically, funds are sorely needed in order to adequately address HIV in our communities. Funds are needed to ensure that personnel have access to information sources that keep them abreast of current HIV and AIDS material, and provide the opportunity to become a part of a larger HIV network.

It has only been three to four years that American Indians and Alaska Natives have been acknowledged as a population at risk for HIV infection. Our communities need funds in order to continue relatively new programs, and in many cases to initiate prevention programs.

Simultaneously, we must begin the process of developing and implementing direct service programs for Native women with HIV infection. Funds are required to support these direct services so that Native women and their families may experience and maintain a quality of life that is supported physically, mentally, and spiritually.

We are a strong and proficient population. With appropriate and adequate resources, we will implement HIV prevention and service programs for Native women that celebrate the diversity of our communities, programs that incorporate the value of our traditions, and programs that protect and support our continuation as a people and sound nations. Thank you.

DR. ROGERS: Ms. Beaulieu, thank you very much. Very nice. Ms. Dixon?

STATEMENT OF MS. DAZON DIXON

MS. DIXON: Good morning. I'm very happy to be here. I was asked to serve, or to testify for the Commission before, and felt real reactionary about it when I got that invitation, because it came about two days before the meeting was to happen. And it just felt to me in the conversation with the person who was trying to organize speakers for a particular panel was that this was one of those last-minute things that got thrown in and with respect to trying to get people to participate that I just didn't feel comfortable, like we had been thought of in advance.

In terms of we, I mean women, and the issue of women and AIDS. So I'm really glad to be here and that this is a focus for today. Thank you.

DR. ROGERS: Are you less angry at us this time?

MS. DIXON: Oh, definitely--not angry at all.

[Laughter.]

MS. DIXON: I've been doing this work now with women and AIDS with respect to education for almost six years. It started out real simplistic, in terms of, we're going to develop these safer-sex parties and do informal work and put it down the line somewhat like Tupperware, so that people could invite their own friends in sort of an informal environment.

And we did that for a long time, thinking that we were making a difference, because people seemed to enjoy the parties. Women seemed to appreciate the fact that they had a space to come and talk about their own sexuality, and to come up with their own idea of what prevention of AIDS was all about.

But years down, I realized that what we were doing was that one-stop drop education stuff that isn't working. So we have modified those to incorporate a practice or a process that we call self help support development, so that not only do women get the education, get the information around HIV and AIDS, but also get the continuing ongoing support to change.

There's a bit of a difference to come into a group and say here's AIDS, here's how you get it, here's how you prevent it, here are the tools you use, go forth and be safe, and hope that you've made a difference.

But if you come back to that same group that you've been meeting with, and not doing follow-up, but doing support work--what kind of changes have you made, what's been good, what's been bad, talk about how we can support you to support yourself, and the differences that you can make, are you making them, and those that you can't make, talk about them.

And what we're finding is that in a lot of the instances, we may not get women to decide in the next week-and-a-half that they are going to instantly start negotiating safer sex with their partners, or that they're going to start budgeting themselves to go out and buy condoms, or that they're going to start reading research on new female technologies, or technologies around female barrier methods.

But we have women who may have been living in abusive situations for years that have decided that they're worth something, to get out of those relationships. Or that they've been living in public housing and that it's a real repressive environment for them, so they are doing something different. And as far as we're concerned, if that's the first step they can take, then that's the first step in the right direction.

What we do in addition to just the HIV information and education sharing is that we automatically incorporate HIV into everything else that's going on. We don't come in with our own agenda and talk about AIDS and HIV.

We come in wanting to know what's on the agenda for everyone who's in the group, not just what we identify as women at risk, but even the facilitators who are doing the work. They are also women at risk, and have a space and have a place to voice what's going on for them.

So I encourage that in any programs that become developed in the future, not just for women but for anyone, that the support mechanism be included in any aspect of that education, and that AIDS not be isolated from all the other issues in terms of doing prevention education.

There is the particular situation with which we're working on, looking at the difference between one-to-one and group counseling, and how that, in terms of prevention work--or the efficacy of those two types of intervention, and comparing the two.

And it's real hard to compare, because it really depends on where an individual is. For a lot of the women, particularly who live in public housing, their information about themselves is stuff that they have to disclose all the time. Somebody's always in their business.

Everybody next door knows what's going on, and the last thing they want to have do is come into a group and talk about what they want to do in terms of prevention, or what they need to do. So one-to-one is very good for them, very important. That's what they ask us for.

For women who, let's say may be in the middle-class sector or living in their own homes or working every day and spending a lot of time trying to run their lives instead of having a lot of social contact, then having that group impact is extremely important.

Providing a safe space where they can talk with other people about what it's like just to be black and female, or what it's like just to be a woman living in 1991, and then relating to how HIV impacts all of that is real important in a group setting.

And laying out how we reach the women, and this is both what we identify as women at risk and the other invisible group that doesn't get a lot of prevention information is the women who are already infected with HIV, and that it seems for a lot of the education programs, we leave--once somebody's infected with HIV, we leave them out of the scope of preventing HIV, unless they're dealt with in terms of preventing transmission to their unborn children, they don't get that same information about preventing the spread or the transmission.

So we work very closely with women who are already infected with HIV on what their issues are and incorporating the further transmission, prevention aspect.

We stopped using the terms cultural sensitivity because I think everybody's now sensitive to the fact that there are cultural differences. We're using competency, and the fact that just because you recognize cultural differences doesn't mean that you have developed programs that can effectively speak to the cultural differences.

So we have trained women from every aspect of a heterogeneous group of women so that they can all become opinion leaders and relate. It doesn't matter whether they're houseworking women or whether they're women who live in public housing. Everybody from the different community takes the information and the training they learn back into their communities.

Empowerment issues, we work very strongly on those, simply because no one's going to feel the power to change anything if they have not felt the worthiness or the self-love and self-esteem to make those changes.

The other thing that I would encourage, because condoms are not the only solution for women--there's not enough research going on around how other barrier methods of birth control are being incorporated into HIV-prevention education.

And that for a lot of women, they may not think to use condoms, but it's not a problem for them to use the "Today" sponge, or it's not a problem for them to use the cervical cap or diaphragm. And how is this preventive? Is it somewhat of a placebo measure, or is it an actual measure of prevention that they don't have the access, whether it be mental, emotional, physical, or economical access, to the use of condoms?

The last thing that I would want to say is when we take a look at women, whether they're already infected with HIV or presently at great risk, that if we don't recognize the differences between what happened in the early-on phases and process of AIDS in our communities and what's happening now, we won't understand that in terms of looking at how the different communities were struck, if we focus on the white male population, the gay white male population, we can look at that as people who are at the top of the wall, already in a place of privilege, already.

You know, some of the women in my group say, we're talking about people who had to move from the penthouse to the first floor. I'm moving from the street to the curb. So we call them the bricks at the bottom of the wall, these women. And they call themselves that, because they understand that if that gets chipped away, the wall crumbles. In the early stages, when the wall started chipping away, it just made a shorter wall.

DR. ROGERS: Thank you so much, Ms. Dixon.

I have another observation to make. Women are remarkably able to stay within their time limit and say very powerful things. It's simply not true for men, as you've noticed here.

[Laughter.]

DR. ROGERS: Ms. Jacques, it's a pleasure to see you again.

STATEMENT OF MS. COLETTE JACQUES

MS. JACQUES: Good morning. It is indeed a pleasure to be here to share with you some of what I believe is essential for prevention strategy, especially for Caribbean women, especially for Haitians.

Just before I go further, I would like to take the time to thank the National Commission on AIDS staff, who really worked to bring all of us here. And we do appreciate being able to participate in this important day.

Dear commissioners, my name again is Colette Jacques. And to be more specific, I would say Marie Colette Jacques, because if I was the daughter of a voodoo priest maybe today, the sect would be mad because I left Marie out, because it's part of some of the Caribbean culture.

I will go through this very fast, and I will make sure that I give you a written report so you won't miss anything.

DR. ROGERS: Fine.

MS. JACQUES: I can appreciate that we need to get out of here on time.

DR. ROGERS: We don't need to get out of here, we just need to have our Commissioners talk to you. Otherwise, they go away very unsatisfied.

MS. JACQUES: That's right, okay. Anyway, the reason I want to express to you the issue of the Caribbean is because I feel that maybe nobody has spoken enough about this issue. It's probably the reason why this group has been left out. If I'm wrong, just correct me.

I am a nurse, and I am the founder of the Support Organization for AIDS Prevention. I do prevention for the

Caribbean community in Los Angeles, and for Haitians in New York, Miami, and Connecticut.

The most important thing for me is that I am very proud to be a Haitian, and then I have many negatives that face me because I'm a woman, I'm a black woman, a Caribbean woman, and also a Haitian woman. So I say these things just to show you how many steps I have to take when I have to reach certain goals in life.

Why do I speak about prevention strategy for Caribbean women? It's important because if we do not know about the specific culture and specific beliefs of certain groups, how can we talk to them about their sexual activity and even dare to ask them to change that?

So I will further to let you know, first of all, do you know there are 26 islands in the Caribbean, and among those 26, only three of them speak Spanish? We have Cuba, Santo Domingo, and Puerto Rico. And among those 26 islands, only Puerto Rico has free access to the United States. So 25 of those islands have great immigration problems.

Do you also know that close to ten million islanders are living here in the U.S., and do you know that 40 percent of them do not have access to medical care, because they face legal issues in the U.S.?

Do you also know that only 10 percent of Caribbean individuals do not visit their home frequently? Do you also know that Caribbean men drink every day? Do you also know that 90 percent of Caribbean men smoke? Do you also know that 20 percent of Caribbean women drink every day? And do you know that 15 percent of Caribbean women smoke?

Do you know that Caribbeans are forced to have sex, even if they are not up to it? Do you know that Caribbean women sometimes get punishment, they get whipped by their husbands, and then they have to make love even though they are not in that mood?

Do you know that sometimes, even if they are not happy, they have to stay home just to satisfy their children? Do you know they sometimes have to hide even if they are separated for fear of hurting the children's feelings? Do you know that Caribbean teenagers practice anal sex for birth control purposes?

Do you also know that Caribbean women have given birth to many children and never once did they know the shape of their partner's private part? In other words, they don't really see what it is; they just do it because they are asked to do it.

Do you also know that it's okay for Caribbean women to accept sometimes someone else's mistress next door because of financial situation? Do you also know that Caribbean women sometimes are accused of having wild sexual practices because they suggest to their partner to wear condoms? Do you know that Caribbean women practice homosexuality just to satisfy their partner's fantasy, not because they want to?

Do you know that Caribbean individuals believe in voodoo? Do you know that Caribbean individuals believe in zombies? Do you know that 90 percent of Caribbeans love politics? Do you know that Caribbean children know also about zombies, and do you know that Caribbeans are very superstitious?

So much for that. I just wanted to share with you, because my purpose here is not to tell you what I do, but to share with you about the group that I serve.

I know that you know that a great number of AIDS-reported cases in women has been steadily increasing in the U.S. For example, from 1989 to 1990, 11 percent diagnosed cases had increased to 34 percent. And now in 1991, AIDS is one of the five leading causes of death among women. For example, in Texas, women and heterosexual AIDS cases increased by 24 percent to 38 percent, respectively, between 1988 to 1989.

I do have a lot of things that I wrote here, but I'm trying to read very fast, so--

DR. ROGERS: You're doing very nicely, and we will read them if you give them to us.

MS. JACQUES: Why do we need to know all these things that I have shared with you? It is very simple. You use data to tell us where to direct our attention. Then by not giving us proper data, attention is taken away from Caribbeans, especially Caribbean women.

It will appear bizarre that the first cases of AIDS were among Caribbean women, especially Haitian, but yet very little attention is given to educate these people until today. Look around you. Do you have any Haitian representing you on this board here? Why not?

It's not important, but the fact is, together we are partners in this fight. I need to point out these things to you not because I don't like you, but simply to show you the facts of life.

If we are looking at a disease, we must carefully study it, and yet protect everyone to provide a good environment for everyone.

I'm going to skip all these pages here, because obviously you know about all these things already because you have so many competent persons that already reported, and they don't need to be repeated twice, but I will definitely give them to you in my report.

What can be done? In looking at how much already has been spent, quickly, we can see that the American department of public health spends over $40 billion on personal health services yearly, and in addition, the thousands of local public health clinics in the country are the front line for provision of needed intervention services.

Are these clinics accessible and acceptable to the target population, especially do they really serve Caribbean people? Most clinical organizations operate on tradition. They do things because they have always done it that way. If your service is valuable to your customer, why do you frequently decide quality of care is what you think it is, not what your patient thinks it is?

Suppose you want to treat your patient with dignity--how can you do that when you do not know the difference in cultural diversity that exists? When you have a patient admitted, do you ask him whether or not he is black, or you just write he/she is black because of the color of his skin?

If you notice an accent, do you care? Do you ask whether or not he is French, Dutch, English, Hispanic? This little information is not obtained sometimes, but could save the government a lot of money. How can you treat someone with dignity if you cannot offer them something that they could appreciate?

If you offer rice and beans to a Caribbean person, do you think maybe when you come back later would you find that plate empty, or would you find that plate full? Would you note that that person had lack of appetite if only you knew that a little rice and beans will help him eat, and maybe he will gain some strength?

Did sometimes your patient pretend to understand by knocking his head, just because he doesn't understand what you say, or is it because you think he's depressed or you think that he's scared?

How many times we do chart wrong information because of our own ignorance and because of lack of love for the patient that we serve. How many times have we failed to obtain information which costs government lots of money?

Caribbean individuals come to the clinic or hospital only when they have to. They have been mistreated, misdiagnosed, they have died because of lack of knowledge from those who are servicing them.

A friend of mine was pregnant. She was Haitian. She went to the doctor--she didn't understand English. The doctor asked her, are you pregnant, because she was suffering from abdominal pain. She didn't understand what the word "pregnant" means. She said--and the doctor believed that--she said no, but she was trying to say that she didn't understand, and the doctor proceeded to have a biopsy, and she lost that only baby.

Education is the key to prevention. Do you know that Haitian dance compa, Puerto Ricans dance salsa, Jamaicans dance reggae, Martiniquans dance zuke, Asians eat avocado with bread, Mexicans eat avocado with burritos, Jamaicans eat curry with chicken. Do you know that Dominicans eat frog, but when I say Dominican, automatically, you think I'm talking of Santo Domingo, but I'm talking about people from the Island of Dominica.

Do you know that Caribbean women are often diagnosed very late because they did not seek medical care until they are very sick? Do you know that the increasing number of women with AIDS, a great number of Caribbeans go back home to die silently?

Do you know that if you live in the Caribbean, so little attention is really given to you? I have many friends, many people that I have known who are HIV positive and go back home silently. They would not say they have AIDS. They would say, "I have tuberculosis." They would say anything else. I knew a young man who ran until he died.

This is the kind of thing that we are facing, and if we are in this fight together, everyone should be educated. Caribbean individuals are people too. Please, bring them in together with you and help me and my colleagues educate them, and together we can make this world a better world.

Thank you.

DR. ROGERS: Ms. Jacques, thank you very much. You have given us an elegant cultural lesson.

Ms. Paris?

STATEMENT OF MS. CARMEN PARIS

MS. PARIS: Buenos dias. Good morning. I would like to first thank all of you Commission members, the people that actually refer--I'd like to thank you all for making it possible for me to be here, and for me to be able to share this information with you.

I have notes, and I have to read them, I have to follow them, because it's a cultural thing. And if I forget my notes and I start talking, the Commission members will start jumping on the table in no time.

DR. ROGERS: I discovered that in Puerto Rico.

MS. PARIS: Okay. First of all, in talking about prevention strategies, I need to say that I need to talk a little bit about what the picture is in Philadelphia, and I have to tell you a little bit about Puerto Rican Latinos in that city.

Forty-eight percent of Puerto Rican males and females live in poverty. Sixty percent of Puerto Rican children, compared to 37 percent of other Latinos, live in poverty. We are residentially segregated, where the housing stock is severely deteriorated and substandard, when there is any house at all.

Unemployment rates are very high. Infant and adult mortality rates, drop-out rates, and alcohol consumption per capita are the highest for Latinos in the city. And an estimated 20,000 Puerto Ricans have been involved at some level with drug use.

There are approximately 180,000 Puerto Rican Latinos, and I say a lot Puerto Ricans, because 80 percent are from Puerto Rico. This data gives you a picture of what the socio-economic status of these people are in the City of Philadelphia.

And now added to all these problems and many others that I have not mentioned, we have AIDS. There is no doubt in our minds that we have a serious problem on our hands, and with the government cuts in our social and human services budget, and the AIDS budget was just recently cut by approximately 40 percent, the situation can only be expected to get worse.

It has been proven that those health centers with bilingual/bicultural staff in the Puerto Rican Latino neighborhoods are the ones where our community goes to, but it's not easy to get access to the services, because even though there might be a doctor available, there might not be any medication at all to provide the patients with, as has been the case with insulin.

In Philadelphia, even though we comprise 3.8 percent of the total population, we are 6.7 percent of the total of AIDS cases, and it clearly signifies a disproportion of AIDS per total population. Of all the pediatric cases, and they all have been reported in minority communities, nine out of the total of 36 have been identified as Puerto Rican babies.

In Philadelphia, we have been able to develop a program, Program Esmerelda, where we target the Puerto Rican Latino community, and we have educators, outreach workers, and counselors who are not only bilingual/bicultural, but are also residents of the community.

We also work with the women inside on the work release program from the prisons. Some months into our effort, we learned that the best way to truly reach them was by doing door-to-door canvassing, a task that by its very nature is costing tens of--although it's going to take us longer to reach the number of people that we're expected to reach, because you know how it is: The city gives you a little bit of money, and then they want a lot of numbers, and you need to provide them in order to keep up with your funding for next year.

It's going to take us longer to do it. We believe that this is the only way that we're going to be able to reach any people at all.

Our women, all the women that we work with that are getting infected at this point share one thing, and it's that they are very poor. Unlike what Ms. Moreno was saying earlier that she has women from different backgrounds, not so the women that I'm working with. They're all very poor. And they also have a very poor health history and do not understand the proportions of this terrible epidemic.

But the sarcasm about the situation is that they're not the only ones, because in the Latino community, in the barrio in North Philadelphia, we do not have one OB-GYN who is Latino and who cares to service the women that I work for every day, which leads us to the problem that was referred to earlier this morning about the definition of AIDS and the necessity that we have in the barrio to have this definition revised, so that at least doctors can start getting information about how things are changing and they can be pointed out to what they need to start learning and looking into.

It's extremely difficult for a woman to make the time or simply get to a doctor's office. We know that there are many reasons for this, socio-economic reasons, but it's incredibly frustrating for us that after we have gotten that woman in to see a doctor, that the doctor can just turn around and say, well, I can't find what is wrong with her, or I simply don't know how to treat what she's got.

And it's basically because the information is not out there, and from what I hear this morning and from the doctors that spoke earlier, you know, this is just getting worse. And I am scared to death, because I see now that nothing is in the process of getting done.

In my community where I come from, AIDS is a family issue, and we certainly have a hell of a problem on our hands, because we are now seeing that women are the ones that are getting infected, and I don't know where these women get the strength from. I truly admire them, because they still are the ones who are keeping the families together.

In North Philadelphia, 43 percent of Latino families are headed by single women. And we're not talking about only one or two children. For the most, these women have four, five, and six children.

I have a serious problem when it comes to the definition of things, and it's not only because Spanish is my first language, but I hear people who speak English that I don't know what they're speaking about. I have a problem when we talk about prevention, because where I come from, prevention is nonexistent; it isn't in my dictionary.

I do early intervention, because when they come to me, there's nothing to prevent; everything is already there. So when CDC starts putting out these people for early prevention and early intervention and early this and early that, I mean, when is "early", when the people who are coming to me have so many diseases and so many problems?

Our women have been oppressed for so many years. Workers from different ethnic groups can't understand, you know, how we can save money and still go back to the homeland, to Puerto Rico. The problem is, that's where our support is, and even though there might not be monies for many things, there's got to be some money left to go back to the homeland, because that's where our mothers can talk about what's going on in the families, and that's where they can set up for the future of our children once they have passed away.

I just want to talk very briefly about, just for a few minutes about what we have done at the program. The first thing that we did was we screamed very loud, and we made a lot of noise. I got kicked out of city council a couple of times until they finally gave me money to start the program. The reason for that was because I was telling them that they were not responding to the epidemic, but then once I started pointing out that they were doing that because they were racist, then they gave me a contract, and not only that, but this year I was the only one that got an increase of $5,000. My God, you know, I don't know what to do with all that money.

Anyway, we have hired educators, but the most important part about the program is, the part-time workers that we have--a couple of foundations have been able to give us a little bit of money, and we have hired part-time educators. There are six of these women that we have. They range from the ages of 16 to fifty-something--she didn't want to tell me how old she is--to fifty-something, and they come from different backgrounds. They're homemakers, one of them is in a work-release program, one of them is HIV-positive. They have been able to put together a program where we go--as the sister was talking about--going into the homes and giving these home parties.

They have been so effective, because for the most, they live in the same block, or they've been there, or their families have been there, and we do what they call house parties, but we don't talk about only sex, and we don't talk about AIDS only.

We talk about, oh my God, what is that pink slip--is that the gas bill? Do you have a problem? What can we do to help you to pay the gas bill? And then the next thing you know, they're calling back because they did go to the social service agency, they got the money for the gas bill, and now they have a little bit more time, and they're less stressed out. And now they can watch the video, because the first time we presented it, they really didn't look at it.

So it's a combination of doing many things at once. But again, it's a real problem because with Ryan White monies and all these things that are coming down the pike, it's so important to get tested.

Let me tell you something. The women in North Philadelphia just don't want to get tested. They do not want to get tested. I mean, they don't want it. There is but so much you can do, because then when they come back to you is when they need the so-called early intervention plus.

So it's very difficult. And the way we've done it is we go in there with an educator and a phlebotomist, we spend sometimes three hours a night in those homes. We give them the AIDS 101, we give them the pre-test counseling, and those that can identify themselves as people that have been involved in activities that might put them at risk for HIV get tested all in one night.

But it takes our workers sometimes three to four hours in these homes, and it is very difficult. That's one of the biggest concerns that I have with testing and what we call early intervention.

I just want to thank you again for listening to my concerns. I just want to share one thing with you. And that is that I have a real concern, because I feel sometimes that we keep on, how do you call that, preaching to the converted?

DR. ROGERS: Preaching to the converted.

MS. PARIS: Yes. And I just pray to God that the messages that we are giving to you can be taken to a place where something can be done for the women that I work for.

Thank you.

DR. ROGERS: Thank you, Ms. Paris. We will do our very best.

Dr. Ehrhardt?

STATEMENT OF DR. ANKE A. EHRHARDT

DR. EHRHARDT: I would also like to thank you that you have centered these days on women's issues, and I would like to in addition thank you that you have accommodated me in this prevention panel, because I know it would have been more appropriate if I had been on the research panel, but this allows me to fly in from New York and to fly back out. So you have both my colleague Dr. Stein and myself together and in tandem.

I am speaking to you as a researcher and principal investigator of a large interdisciplinary center on HIV infection in New York City. Both my colleague Zena Stein and I have particularly focused our attention and our research on women for the last three years or so.

My own research has been in studies of sex and gender long before the AIDS epidemic hit the society. And as you know, we have an epidemic that is largely transmitted through sexual behavior. We also have proclaimed that education and prevention is our most powerful tool and most effective vaccine--in fact, the only one which is available to us--to curb further spread of HIV infection.

And yet we have not based our messages and our prevention strategies on careful information, on the determinants of sexual behavior of women at different ages, in different circumstances, and among different groups of the population.

As is well known, we have an appalling lack of knowledge on sexual behavior among Americans, and rather than correcting the deficiency, we have rushed into giving messages on sexual behavior that are unrealistic and simple-minded for women.

I'm sure the messages are well-known to all of you, and the list is short, when it should be detailed and carefully adjusted to different groups of women in different circumstances. We tell women to be abstinent, to have sex only within a long-term monogamous relationship, to reduce the number of their partners, to take sexual and drug use histories of men, and to use condoms.

While we certainly need more information, we do have already enough sexual behavior data that we know that these messages hardly are relevant for large groups of the population.

Indeed, the current prevention messages to women bear very little resemblance to the realities of many women's lives, as you have heard from several of my sisters here. Therefore, not surprisingly, our prevention efforts have not been very successful, and the number of women with HIV is rising in this country and elsewhere.

For instance, we need to target our prevention to women's needs of wanting pregnancy or not wanting pregnancy, and we need to focus on protecting against both sexually transmitted diseases and HIV infection.

At the present time, for instance, the program needs to include the reality that most adolescent girls do not want pregnancy and that most of them are sexually active, and we need special prevention strategies for them. Women in long-term relationships require a different kind of message than people who are in new relationships.

It may be the most unrealistic and in many ways damaging that we have given the message to women to use condoms. Condom use is not a method that women can control. It is a male-controlled contraceptive barrier method.

To tell women to use condoms reflects a lack of knowledge about the anatomical, gender role, and power differences between men and women. It is a message that has been adapted from the early mandates of the epidemic that mainly dealt with gay men.

To rely solely on condoms and to expect women to control condom use ignores important gender differences and power relations between men and women which are alive and well in the United States, and often much more so elsewhere in the world. Those power differences play themselves out in sexual encounters, in words, pictures, and sounds all around us in our society.

We have not only ignored the fact that women do not control condom use, we also in addition have rushed into prevention efforts aimed at empowering women to insist on condom use without taking into account that they may risk, women who try that, severe repercussions such as violence and other serious threats to their economic and social support.

Our own research at the HIV Center, based on focus groups with inner-city women, suggests that negotiation around condom use during sexual encounters is extremely difficult for many women. Women need and want methods that are independent of sexual negotiation.

As we should have learned from the contraception history, pregnancies became only more effectively controlled once we had the pill, IUDs, and the diaphragm--all methods under women's control.

Another group sorely neglected are women who have sex with other women. They have been almost totally ignored from research, clinical care, and prevention efforts. This policy is based on the naive assumption that sexual behavior is dictated by labels of sexual identity.

Our own studies, as that of other colleagues, have shown that many lesbian women have also sex with men, and that they may even frequently have partners who are bisexual. The rationale for excluding this group of women is that transmission from woman to woman is rare. As we are doing no research on this issue, we will hardly find out how rare it really is.

This brings me to another important point, namely that we have neglected to develop and to distribute important new and sophisticated visual and auditory educational material that might become norm-setting and that will lend itself to model safer sex scenarios, indeed that could be used to much more effectively encourage condom use in heterosexual men.

We need to focus on research required for effective prevention. As you already know, women also--and I'm sure you've heard that this morning--have been grossly neglected in terms of basic research on disease progression and clinical care. I feel strongly that only if there will be a mandate for research on women will we make substantial progress.

We need prevention strategies and research that start from women, placing women at the center of the analysis. Unless we do this, we cannot design prevention strategies that are acceptable for women, that women can use in their particular living and cultural circumstances. In other words, if we do not start with women as women, we will fail.

I would like to conclude by making a few specific recommendations. One, we are starting late to make women a priority, and catch-up is urgently needed. We need a standing committee or task force on women and AIDS in order to make more rapid progress.

Two, key positions at every level should include appropriate women.

Three, special attention and funds are required to serve the needs and to develop prevention and care for poor women in the inner cities, since they are currently bearing the major brunt of the epidemic.

Four, women's health studies are presently being announced by the NIH. It is essential that those studies include research on reproductive function, STDs and HIV, rather than, as has been announced, a total emphasis on cardiac disease, cancer, and osteoporosis. Thank you very much.

DR. ROGERS: Thank you very much, Dr. Ehrhardt. I hope you'll share your written material with us too. That's very important.

Dr. Stein, welcome again. I hope you'll give us a little time to ask questions of all of you. You need a microphone.

STATEMENT OF DR. ZENA STEIN

DR. STEIN: My name is Zena Stein. I'm from Columbia University and HIV Center, and I'm professionally an epidemiologist. I've been working in this field several years.

DR. ROGERS: You're not only officially an epidemiologist, you are an epidemiologist.

DR. STEIN: I want to follow on Dr. Ehrhardt's comments, and I, too, will do this by placing women in the center of the stage and urging preventive approaches from their perspective.

I'm focusing here deliberately on methods women might use to reduce the risk to them of contracting HIV infection by the sexual route. We argue here for the wider dissemination of those methods that do exist, and for research into further development.

It is a sad commentary and an accusation on this ten-year anniversary of the epidemic that there is at this time no virucidal method that has been explicitly developed for use by the woman in her sexual encounters and tested for that purpose. Ten years. I will here review current experience and urge advances on this front as a matter of urgency.

Contraceptive technology has for many years included spermicidal preparations incorporated into creams, gels, foams, foaming tablets, melting suppositories, or films--this is a film--which a woman applies shortly before a sexual encounter. She applies it, and often, in many cases, they are very acceptable, and the man doesn't know they've used them.

Typically, these are sold over the counter at prices comparable to condoms. Some are very simple to apply and unobtrusive, and all that I'm going to discuss today dissolve after use. I'm omitting the ones that need to be thrown away, like the sponge.

Generally, there have been no adverse effects, no adverse health effects, from the use of this category of contraceptives. There is absolutely no suggestion that the use could increase the risk of HIV. There are couples who find one or other foam to be irritant, in which case it is advisable to switch to another preparation.

The most widely-used spermicidal substance in the U.S. is called non-oxynol-9, or NO9. Some years back, the suspicion was raised of NO9 endangering the fetus, but that relationship was not confirmed by several studies, including one from my own group.

Now, at family planning clinics, they know all about spermicides, and they tend not to push them. They tend not to push the use of these preparations because if they're used on their own, they're reasonably unreliable as contraceptives.

You have to think a bit about this. Different considerations must be paramount when weighing the usefulness against infections. Thus, spermicides have been tested for reducing transmission of a number of sexually transmitted diseases. Certainly in the laboratory, they do kill a range of micro-organisms, gonococci, gonorrhea, chlamydia, trichomomas and syphilis, and the HIV virus, demonstrated many times.

In the field, and this has recently been summarized by WHO expert committee, there is good evidence of their reducing transmission against several sexually-transmitted diseases. And when you use NO9 in the laboratory in conjunction with condoms, that increases the apparent protection against HIV afforded by the condom.

So techniques to prevent HIV infection may derive from experience in family planning, but the purposes are now clearly different. Thus, we might urge the use of NO9 because of its virucidal properties, for instance, at the same time appreciating that its use is compatible with conception and pregnancy.

Relevant to this purpose, we note that NO9 may be used at lower concentrations if the objective is to provide a virucide rather than a spermicide, and there is some evidence from the laboratory that regarding the way in which transmission of HIV occurs, it is the cells, lymphocyte or macrophages, in the seminal fluid which are responsible for transmission, rather than the sperm, which lack the relevant receptors.

It is not far-fetched to consider a virucide that is not a contraceptive, which would leave open the possibility of a woman being protected against infection and still permitting fertility for the woman. This is seldom, if ever, discussed. I wonder if your commission has much on that?

In sum, we see a role for the use by women of selected virucidal preparations. We see that role now. There is presumptive evidence that they would provide a degree of protection if used alone, and enhance the protection afforded by the condom if used in combination.

It is already established in the field that they would at least reduce the incidence of other sexually-transmitted diseases, which many people regard as favoring transmission of HIV.

A wider range of virucidal preparations is badly needed. Their development should be encouraged, and their progress through the FDA greatly speeded up. Their acceptance and efficacy should be evaluated. Research into the laboratory and clinical aspects of locally-used virucides is an utterly neglected area of research, urgently in need of creative and coordinated development.

And I have my recommendations, three. One, I would say now women should be advised of the likely benefits of the use of over-the-counter soluble spermicides. I cannot understand why this isn't highlighted in our message about the condom. I would say, while the condom should continue to be the main message of protection to women as to men, condoms are not an option for many women. Spermicides used alone or in combination with condoms will reduce the risk.

Secondly, specific efforts should be made to test the acceptability of a wide range of spermicidal preparations. New products should be tried, as indicated in the testing phase. The FDA should expedite their passage and distribution.

Lastly, a coordinated, interdisciplinary research program in the laboratory and in the field is needed to forward the development of virucidal methods, modeled after existing spermicides, but now would give women control over their own protection. These virucidal methods should include an approach that spares the sperm from destruction as far as possible. A woman should be able to protect herself from infection while retaining the opportunity to consider conception if she so desires.

DR. ROGERS: Dr. Stein, thank you very much. Very, very provocative.

I now am pleased to say we can go overtime, because all I do is cut out of Commissioner's lunch, not the time of our next participants.

Mr. Dalton?

MR. DALTON: Just one comment to fellow Commissioners, and then one question for the last two panelists. I'm quite aware that as we have sort of outlined in the final report, we have a section on prevention. But I must say, I've also never understood the word, and you captured for me that reality.

At least three of the first four panelists talked about the importance of providing ongoing, not single-shot, and not simply prevention, but support of various sorts, including AIDS and HIV. And I just hope we get the message, and that it is reflected in what we do.

My question has to do with this question of virucides and spermicides, because there is at least the worry out there among some women that non-oxynol-9 is itself dangerous to women, that it is associated with genital warts, which in turn are associated with cervical cancer.

I don't know whether that's true or not, but at least I would like to ask you to respond to that. I've heard it from a number of African American women in particular.

And Dr. Ehrhardt, number one, it's nice to see you again. But number two, could you respond to the question about research done on other barrier methods besides condoms?

DR. STEIN: On the question of warts, I've never heard that, and I've gone around and asked and read and thought for a long time before coming up with that clear statement that there are no adverse effects so far shown, certainly nothing like warts, for the use of these spermicides. They've been used all over the world for years and years. I also consulted this recent WHO report by real authorities on sexually-transmitted disease. The use of a spermicide is not dangerous to a woman's health.

DR. ROGERS: Dr. Ehrhardt?

DR. EHRHARDT: We have, unfortunately, a great lack, also for other STDs, of research on other barrier methods. We really urgently need to look at the diaphragm, at other methods, at the pill, what it does to STDs. There are some studies out there, but we just need to make it a concerted effort.

DR. ROGERS: Mr. Goldman?

MR. GOLDMAN: Thank you. I have two questions, if I may. The first question is directed at--

DR. ROGERS: Don, I think you may have turned your microphone off.

MR. GOLDMAN: I have two questions, if I may. The first is directed at Dr. Ehrhardt and Dr. Stein. How do you ethically design a study that would test the efficacy of those kinds of methods.

In particular I'm thinking about the recent report, for example, of the family in a State that chose to attempt to have children by having various applications done to the sperm of the HIV-infected husband. That unfortunately didn't work, and the woman became infected as a result, even though there were many who thought that might be a viable method, and how you can ethically design a study under such circumstances where there's some doubt as to whether or not they might work?

DR. STEIN: Well, being an epidemiologist, this is one experience I do have. We can design such a study. Briefly, you go to your group of women with whom you're working and you mention to them that you're doing a study, and to a random group of women, you say, are you getting your man, are you trying to use a condom, and they say yes, and you say go ahead and use the condom and keep in touch with me every few months.

And for another group of women, you say, are you using a condom? Well, I'm trying. You say, go ahead and go on using the condom, and use this as well. Basically, that's the design. You follow both groups.

There are variants on that design, but basically you try and keep both groups using a condom, and the use may be high or low depending on their cultural and social situation, but to one group you've urged as well, use the virucide.

This is the type of design that's been tried in Zaire, and it's--what I'm really saying to you is there are ways you can design the problem if you face the problem. There's one.

DR. EHRHARDT: Just to add. Since we know from many women, as other people have seen, while they attempt condom use, it's not going on. So if you do that kind of design, if you say, try to use a condom, use a condom and a spermicide, if none of that then works, you hope that the person at least will use the virucide or the spermicide, because right now, what is typically happening is that nothing is being used.

MR. GOLDMAN: My second question was really a question of, it seems to me, and Lori, thank you for giving us such a wonderful guide and help on our trip to Minnesota, South Dakota, and your Ojibwa community up there. It's something that you can be proud of. The way that they have responded to AIDS and HIV infection is a model for any community.

In listening to all of you, coming from different communities and areas, I hear a certain consistency in terms of what are the necessary ingredients of an appropriate care and prevention strategy, and I'd like to see whether or not that is consistent with you.

The first thing is that it has to be done in an atmosphere which is not punitive and which is accepting and in which the people involved and the community involved, both in terms of the general community as well as the specific cultural community that the person is dealing with, is not punitive in nature or is perceived as such.

The second thing is that the prevention and education messages have to be done in a culturally competent way, and probably the most effective mechanism for doing so is a peer-to-peer kind of setting, and that peers both from an age, sex, cultural, value perspective are those that are likely to be the ones that have the most effective response.

And lastly, that whatever kind of system you do set up, that it has to be repetitive, consistent, follow-up, and provide support.

And that those are the essential ingredients that we're talking about, that regardless of whatever the cultural differences may be from community to community are the ingredients that, in fact, or seem to be from what I'm listening to what you're saying, are consistent from community to community, from country to country, from city to city, from rural area to urban area, and from ethnic group to ethnic group.

And I'm just wondering whether or not you agree or disagree, or whether or not you think that there's more that should be added to that list that I've omitted?

MS. DIXON: First of all, I'd say I agree. And I can see that in terms of looking at it comparatively to other social programs or education prevention programs that work on behavior change, nobody leaves addiction without support and alternatives. Nobody leaves abusive relationship without support and alternatives.

It is the very same thing in terms of dealing with personal behavior changes around sexual behavior risk for all diseases, not just HIV. As I didn't mention earlier--that's why I got to finish on time--

[Laughter.]

MS. DIXON: --is something like in my State--

DR. ROGERS: I haven't changed the counter-punch.

[Laughter.]

MS. DIXON: In Georgia, we have a 300 percent increase of syphilis in less than two years, and I would say that's probably because we're focusing now on AIDS and have left STD out of the conversation.

But that is all a part of the same, that we can't expect people to simply change something that has been ingrained in them for life just by providing education. Smokers know it's dangerous to smoke.

DR. EHRHARDT: I just may add, yes, I think the ingredients are correct, but I would not stop at the peer-to-peer level, because of course that will take us too long.

While that may be the most effective in conducting and carrying out prevention, we need to get to institutional changes and to cultural changes in terms of normative changes, because clearly what goes on on television and in print and wherever shapes our behavior, and we need to get to these three different levels in order to make major impact and changes fast enough.

DR. ROGERS: Ms. Ahrens?

MS. BEAULIEU: Can I just add something to this?

DR. ROGERS: Yes, of course.

MS. BEAULIEU: I would agree with what you've just said, and I think that it's real important in addition to the repetitiveness that in trying to affect a social change or a cultural change that you involve the people that you're working with in your planning efforts or whatever, so that you know what you're doing is right, and so that there's a sense of ownership in what you're doing.

DR. ROGERS: Ms. Ahrens, Ms. Diaz, and then Mr. Allen.

MS. AHRENS: I'm struggling with an issue, and I know you can help me with it. If it goes to any one of you, and as long as there's no disagreement in the panel, then we can leave it with the first response.

But there are two questions here. One is a prelude to the second. And it may sound like a really dumb question, but it is certainly, I think, not simplistic.

Do the women that you know, the women that you deal with, want to know whether their partners are HIV positive?

MS. PARIS: Well, I'd like to talk about that, because I did miss to mention the fact that 70 percent of the women that I work with have gotten infected through heterosexual contact, so, you know, just like Ms. Moreno was talking about before, they don't consider themselves at risk at any point about how they refer, and how they relate to their partners and the fact that they're infected.

Many of them still don't believe that it's through their husbands that they got infected, and it's very, very difficult to make them understand that if they had not any blood transfusion or had not been involved in drug abuse, I mean, where else did the virus come from?

And it's because of--we are very protective of our men, and even though we might say, well, they probably got infected through blood transfusion, knowing perfectly well that they have been in different addictions for many, many years, and the things that they go from one addiction to another addiction. From heroin, they go into cocaine and so on, and it's very difficult for them to keep up with that.

DR. ROGERS: Ms. Paris, come back to her question. Do they want to know the HIV status of their partners?

MS. PARIS: No.

DR. ROGERS: No. Others disagree or agree?

MS. JACQUES: I disagree.

DR. ROGERS: You disagree.

MS. JACQUES: Right.

DR. ROGERS: That's a smart thing to do, because that gives you a chance to talk.

[Laughter.]

MS. JACQUES: Because some of the Haitian women would call and would ask, send them--how can they detect if their husband is HIV, and they are well aware that among Haitians, Haitians are really promiscuous, and a lot of them are worried, and they'd like to know.

DR. ROGERS: They'd like to know.

MS. JACQUES: Their concern is that they want to know, how could they get involved in helping him wearing condoms, and without being accused of them being conducting some kind of wild activity.

DR. ROGERS: They'd like to know, but probably don't want to ask him themselves.

MS. JACQUES: Right.

DR. ROGERS: Diane, you had another question?

MS. AHRENS: The second question is the controversial one. Since there's not unanimity on the panel, perhaps there will not be unanimity with the second question. But what is your view on contact tracing as a method of prevention among women?

MS. JACQUES: Addressing to me?

MS. AHRENS: Anyone who wants to tackle that.

MS. JACQUES: We're so far behind in really this prevention type of thing, and I don't know if--I don't know. I can't really answer how it's going to affect that community specifically.

DR. ROGERS: Ms. Dixon, you look like you want to say something.

MS. DIXON: Yes. I would first say that if--I would only support contact tracing if all the stigma related to HIV were removed, because that--it's not informing someone--just like along the lines of syphilis and gonorrhea, it's not just informing someone of what a partner has that comes into play when AIDS is the case, because it's the same thing in terms of how I was going to answer your first question, is that I think women want to know, but they don't want to ask because they don't want to believe it.

There's a difference in wanting to know and wanting to accept it, and people won't want to know, simply because by knowing they'll have to believe that that's what is going on.

And that's the same thing with contract tracing, is that by informing someone--particularly if it is the husband or the male partner or the partner of a woman who is informed, then the women oftentimes is going to have to suffer and not the person who has told. That is the main reason why I would not support or advocate contact tracing.

DR. ROGERS: Do any of you disagree?

MS. JACQUES: I still would not support it, because also of the violence that also the men may bring on a woman. Like for instance, I have a Haitian man come to my office who says, you know, I love my wife, but I'm turned off. But I have this girlfriend. Whenever I'm mad with her, I have to go to that girlfriend. But again, that girlfriend is married, and I'm worried that she may be doing the same thing.

See, it's--and he'd be mad at her, but yet he can do it, so it's a complicated situation.

DR. ROGERS: Ms. Diaz?

MS. DIAZ: I wanted to thank all the panelists, because I've learned so much from you, particularly some whom I have worked with in the past, but particularly Dr. Stein and Dr. Ehrhardt, whom I didn't now before.

I know you may find this strange. I have been working in HIV education in the Latino community for ten years. And many times, in dealing with small women's groups or even large groups, the question came up, could I encourage contraceptive, spermicidal contraceptive use even if we didn't know what it did to the HIV virus, simply because the women thought if it kills sperm, it just might help.

And for ten years, I've been telling those groups, go ahead and do it if there's nothing else available. And today you've validated something that I've always wondered in the back of my mind, was I doing right or wrong.

But the one thing that concerns me is that in the educational campaigns of this country, particularly the ones that are government-funded, I have never heard an emphasis on the use of non-oxynol-9 as a strong component of any education campaign that stresses condoms.

And I'm thinking, what do you think are the social policy and political realities of that, and how can we get what you have said here--I was so moved by what you said--and here I'm telling you, I didn't think of that. Women in groups around this country have said, even if it didn't work, I just feel like it might lend some protection.

And today you've just really clarified something for me in the terms of prevention education that made it very real, and I want to thank you.

DR. ROGERS: Dr. Stein, let me just build on that, because then I'm anxious to hear your answer to my question. If you designed the virucidal that you mentioned that exempted the sperm, do you think the Catholic Church might buy on to that?

DR. STEIN: Well, as a matter of fact, you were at the same meeting as I.

DR. ROGERS: Yes.

DR. STEIN: You remember the Italian-New York meeting, that was attended by a couple of priests who came and took a long story from me afterwards about the possibility, so I think there's a strong interest.

Now, I didn't say that we had such a virucide yet. I believe that it's possible. I believe it's much more possible--if you want to quote me on this, I believe if we concentrated, we'd get there sooner and then we can get on to the vaccine. That's what I think, but we have put practically no funds into developing it.

And I answer your question by, historically, I think in this country we started with men, and we thought of the condom. And we have simply not moved off there. No one has done a controlled trial of the condom. You know that. No one has done a controlled trial.

At the point at which we started recommending the condom, exactly the same evidence was present for preventing sexually transmitted diseases to women as the condom with the use of the diaphragm and spermicide--exactly the same status of research for that field.

And we haven't moved. And why haven't we moved? My answer is, we haven't put women at the center of the problem. Your women were right. They said, what about us?

DR. ROGERS: Thank you. Let me see, Scott Allen, and then Larry Kessler.

MR. ALLEN: I have a question for Ms. Paris. The question I have, and it really is for all the panelists, but you mentioned it about humping through hoops for the funding issue and putting in all the extra time so you can keep that funding going.

The question I have is that you have been a part of the education process for a while. I know some of you said '86 and so forth. Do you see a change in the emphasis in prevention, and in the funding issues, now that we're moving more into the care aspect, and is it harder to get your monies, is it harder to document and find that stability, and is it also--another concern that I've always had is, do you find that you are part of the up-front formulation of the evaluation of the whatever prevention monies you're getting? In other words, my concern is that you're given an evaluation to do that may not be appropriate for the group that you're dealing with.

Do you see that changing? Do you see that dynamic evolving into something that's maturing, or including you more in that kind of stability? There's several different questions all in there.

MS. PARIS: First of all, as far as is it getting harder to get the monies for education and prevention, the answer is yes, because what the city's telling me is that Carmen, you need to rephrase everything and change the word education and prevention for early intervention, which is in reality what you've been doing for all these years.

It's harder. It gets harder to get city money in Philadelphia, and what they do is they say that it's--you know, they blame it on Centers for Disease Control and how they want their monies channelled.

And then by the same token, they want more people to get tested, but you don't get tested by looking in the sky and praying for them. You know, you need to get that early intervention that you don't want to fund. So it's a catch-22. It's very difficult.

As far as being part of the evaluation process of those programs, I started six years ago as the only Latino person hired by the city to do education and prevention. So I was at the beginning when things were kind of getting settled, so I had the opportunity to put out some of the things that I thought were crucial for the Latino community in the very beginning, in the very first planning stages.

But all that is just sitting on the shelf right now, because what the Federal government wants to see, the city's doing. And because the priority is not for education, because--I don't know if it's the idea that they think everybody's already educated and they need to go beyond that, but it's not the case for us.

MR. ALLEN: So you find it slipping away?

MS. PARIS: Yes, it is.

MR. ALLEN: Thank you.

DR. ROGERS: Last question, Mr. Kessler?

MS. DIXON: But the one point I would add to that is that the funding itself is inadequate in terms of time reference. Most grants last a year. It takes two to three months just to start up a program, and we're talking about making lifetime changes in people in six months.

MR. ALLEN: And the strategy is a one-time shot education rather than a continuing--

MS. DIXON: And it doesn't work. If we're not funded for a minimum of three years, then how can we even evaluate the success of behavior change?

MR. ALLEN: Okay.

MR. KESSLER: Ms. Paris, this question is related to the funding issue, and I want to make sure I heard what I thought you said. Did you say the City of Philadelphia cut their AIDS line item by 40 percent?

DR. ROGERS: That's what she said.

MR. KESSLER: Okay, so what happened to your Ryan White monies?

MS. PARIS: Okay. That had been the year before, they cut it by 40 percent. Then this year, what happened was the mayor came up and said, well, we're going to have a severe decrease again in the funding, and that's when we went to city hall two weeks ago and we picketed and we made all this noise, because that will mean that we were not going to get Ryan White's money.

At this point, we don't know what's going to happen with those fundings, because the city has adopted a policy where they don't care whether they lose Federal money if needs--that they need to cut the funding within.

We have no support from the State. The State of Pennsylvania did not support AIDS services and funding.

MR. KESSLER: Well, I really urge you to hold firm on that, because the law is clear, and in those States that have tried to cut the funds that have made that a public fight, in terms of the Ryan White regulations, they've won, because the public thinks it's very strange to say no to several million dollars over a couple hundred thousand dollar cut. Because it doesn't require matching money, but it does require level funding from the previous year, so--

DR. ROGERS: So hang in there.

MR. KESSLER: --keep hanging in there and fighting, because it would be a disgrace for Philadelphia to lose an additional several million dollars over short-sidedness.

DR. ROGERS: We thank you all very much. It's been a very compelling morning, and it proves to you that my Commissioners would rather listen to you than eat, so thank you all so much.

We will reconvene promptly at 1:30.

[Whereupon, at 12:52 p.m., the proceedings recessed, to reconvene at 1:50 p.m. this same day.]

DR. ROGERS: I'm sorry we're starting late, but we're now privileged to have the Chairman of our Commission with us, who's worth at least five other Commissioners. So we are going to start, because I'm vividly aware of the fact that some of those who are about to participate have to catch a limousine to Washington, where they're going to do it again.

Judith, I think we will start with you. We're going to reverse the order, and we're going to ask Judith Cohen and Denise Rouse to speak first, but we hope we will get you all in and have opportunity for questions before you leave. I know you have to leave at about 2:45, so if the rest of your panelists will oblige, we'll try and get you out there.

June would like to make one comment.

DR. OSBORN: I'm sure David has done a gracious job of offering my apologies, but I want to add to them. I am very sorry that I wasn't able to be here before, and I have been told that it was a wonderfully rich morning of testimony, and I'm delighted to be here now. Thanks very much for putting up with the vagaries of trying to move around the country.

DR. ROGERS: Dr. Cohen?

STATEMENT OF MS. JUDITH COHEN

MS. COHEN: I will waste no time. I'm Judith Cohen from San Francisco. I am the Director of a program called AWARE, which stands for Women's AIDS Research and Education.

We've been lucky enough to be in business with rather variable funding since 1984, and in response to questions about funding, I should say it is an ongoing struggle, as long as you want to look at women who are other than prostitutes are pregnant.

There have been Federal agencies that are willing to give us money to look at prostitutes, but not at other women, and this is true for international meetings and funding interests and presentations, and I'm really glad that the Committee is seeing a rather broader picture, because that's not where the problem is.

I am also responding to a concern for being able to talk to women with full-blown AIDS. I'm sorry to say that in terms of our experience with now 2,000 women participants, of whom fortunately only four-and-a-half percent are infected.

There are not too many women with full-blown AIDS. Their survival is significantly shorter than with men, and when we begin to build a natural history cohort and look back before 1988 in the City of San Francisco, there were no women alive who had been diagnosed before 1988.

I'm going to just touch very lightly on three major points. One is the issue of getting research funding, and I'm very concerned about the separation of research funding that is medical and research funding that is social, because I think particularly as this epidemic looks at women as a focus, those are not separable issues.

If women do not get into diagnostic or treatment or research protocols because of social circumstances, then we will not have complete and adequate medical information on them, and I think that's much more of a related issue and a set of barriers for women than it has been for some other groups that we have information on.

So I'm terribly concerned that the funding that becomes available for research takes those social considerations into account.

I'm also concerned about the notion of routine testing. We certainly get phone calls from many women who discovered that they were sero-positive on the basis of routine testing.

And when we ask them what that means, it means that as part of prenatal care or some other public primary care, they were given a whole battery of things to sign with a lot of small print and no explanation, and among the list of tests was, in fact, an HIV test, and that was their only pre-counseling, and they are in shock, and have had really no information that they were even being tested.

And if they question it, even at a very basic level, the assumption is that they will not get that prenatal care if they don't submit to the entire protocol, whatever it is. So for them, it is not a voluntary choice, if they wish to participate in those services.

I think there is another very critical difference in getting people into care and getting people into cooperating with what we do know and what we can provide, and that is that when people find out they're infected that way, this being shoved off the cliff metaphor, which I think is a terrific one--

DR. ROGERS: With no safety net.

MS. COHEN: --with no safety net--they do not react with anger the way many people who have support and knowledge and expectation react. They react with guilt. What did I do to deserve this, what have I done to my children, because they often hear that way, and because in this culture, being women means that you take responsibility for everybody and everything, and you say what's the matter with me instead of the system owes me some help and some resources. And that's not a very good place to start seeking help and seeking information.

So we need support and communication that starts from where that is, and that's relevant and that's understandable to them as women, because they are not invigorated, they are not angry, they are not moving forward when they get this information.

For women who do use drugs, I think it's important to point out that most of the programs we have in this country are for heroin users and for me. And for most women, heroin is not their drug. It's too expensive, and it's a men's culture drug. They use a lot of other drugs, they certainly use crack cocaine, and there are just no programs to speak of that are directed to that pattern of drug use.

The few that do exist almost always require women to choose between keeping their families together or obtaining treatment. If you have to give up your kids to get into a treatment program, what kind of a choice are we giving them that's real for them? And that's common, as I say, in the few programs that really do address the issues of women.

There are, at least in our area, very limited emergency alternatives for women. Many people referred this morning to people becoming medical emergencies when they share information about their HIV status or when they ask a partner to use a condom.

And for battered women, there are few enough resources in this country. For battered women who are drug users or battered women who have been sex workers, most of those battered women's shelters will not admit them. They can't get in even if there's a slot, and that's a major barrier for many women who are at risk in this epidemic.

I think for women who don't use drugs, the situation is worse. Our experience suggests that they truly are hidden, that they feel stigmatized, that they might talk to us on the phone at length, that there are no support groups for them, and when they go to support groups for gay men, their agendas are just very different.

They're concerned about making arrangements for their families. They're concerned about finding housing. They're concerned about becoming poor, if they aren't already. They have lost insurance benefits when their spouse dies. All of these are family issues for them, and those support groups deal with other issues.

They're valuable in so far as they go, but they don't help women deal with those issues at the top of their list of ten things that they need to work on.

In our area, there is a very famous private support group system that provides alternative housing and homes for people who are not sick enough to be hospitalized and so on, and with considerable publicity last year, they announced that they were implementing their program for women. That consists of one apartment, okay?

And that's the only program that has alternative housing for women who have AIDS or who are too ill, but not ill enough to be hospitalized. That one woman can take her family to that one apartment. It's hardly adequate.

By and large, I think women who have limited education and limited resources are not used to using the medical care system. Their primary care is in public clinics with long lines and mysterious rules. Their primary care comes, too often, through the emergency room. They don't recognize what alternatives are open to them, and there certainly is no communication or advocacy system as there is for some other groups to get them in.

If you're a drug user, you can get information if you're in a treatment program. If you're a gay man, there are tremendous resources for you. If you're a woman who is neither of those, there's no path, there's no word, there's no place to turn and get coordinated information on what little there is.

So we really need to improve our communication services for women who are facing this disease. And that communication system has to recognize that AIDS is a family disease for women, and the net result is "me last", rather than "me first".

And if you have to deal with a spouse who's in one institution and take your child across town on the bus because your child is ill to another institution and you have symptoms and you're worn out, you don't get around to dealing with whatever your own problems are.

And too many women end up being admitted to the emergency room and dying within a month of diagnosis. In San Francisco, nearly a third of the women diagnosed with AIDS have died within a month of diagnosis, and a fair proportion of those are post-mortem diagnoses. They come to the emergency room, they don't make it out, basically.

In terms of their survival, if they survive that experience, access to treatment and protocols is not something they know anything about. It's not something that they ordinarily would have access to. There's a tremendous amount of publicity in the gay community in San Francisco. Not much of it reaches the women that we talk to.

There's an elegant new matching computer system now that's been publicized as available. You get your T-4 cells and other measures of immune function tested regularly. You fill out very elegant and sophisticated forms that report your systems and the medications that you're taking and what your current T-4 cell levels are, and you pay for the service. And every quarter, you go through this process again.

None of the women that I know who are dealing with HIV infection and symptomatic have a prayer of using a system like that. They don't know--they certainly have no money to get their T-4 cells done. They have no help in filling out these complicated forms, and that is the matching system that has first grab at any new experimental developing kinds of slots that are available. Technology is wonderful, but not if you have no access to it.

The net result, at least in San Francisco, and we've been working with the San Francisco Health Department Surveillance Office on this analysis, is that while survival for women has been significantly shorter than for men throughout the epidemic, with the advent of treatment like

AZT, that survival gap has increased, not decreased. Men are surviving longer. Women are not. Thank you.

DR. ROGERS: Thank you very much, Dr. Cohen. Very powerful testimony. Ms. Rouse?

STATEMENT OF MS. S. DENISE ROUSE

MS. ROUSE: Good afternoon. I'm Denise Rouse, with the D.C. Women's Council on AIDS. And I need to tell you further that I am a U.S. Public Health Service Commission Officer on loan from PHS to a community health center in the District. Because of the graciousness of the director of that health center, I'm allowed to spend a part of my time with the D.C. Women's Council on AIDS.

Because of the richness of the testimony that's been given so far, I'm just going to cut to the chase and give you my recommendations.

DR. ROGERS: When you say, cut to the chase?

MS. ROUSE: Yes?

DR. ROGERS: What's that mean?

MS. ROUSE: It means I'm going to not give you--let me move forward, because I know you only have five minutes.

[Laughter.]

MS. ROUSE: The first recommendation is that I'd like to see--and I'll speak in terms of I--I'm not even going to make any allusion to being objective and not having some biases here. I've been in the trenches too long, and so I'm just going to speak from what I experience and the things that I think need to happen.

I'd like to see the creation of universal access to comprehensive routine primary health and social services. These services need to be delivered via case management system. And by access, I mean financial access, access by location. As we talk about this epidemic and as we look at service delivery mechanisms, frequently we forget about rural communities and the needs of rural communities.

I'd also like to talk about, in terms of access, cultural access. Homophobia is a major barrier to care for people of color and particularly for women. And it takes too long to work a person through their homophobia in order to get them into the gay men's clinic for health care. We've wasted six months, maybe a year, of that person's life getting them to work through their homophobia. What we need to be working them through is how to use the system.

I asked the question, early intervention for what? That's the new buzzword--early intervention. What does that mean? It means testing people, with or without their consent--and very frequently for women, without their consent, as you heard over and over again.

It does not translate in our experience to access to care for women. What it translates into is a drop of that person, or getting rid of that person by the person who tested them. Frequently they'll test them, and then they'll give them an offhand referral to an STD clinic, a gay men's clinic, or a public hospital.

That is not early intervention. Post-test counseling is dismal, and physicians are giving people death sentences. They're not giving people a reason to stay in life. They're not giving people a reason to struggle. They're not giving people a reason to try to get into a clinical trial or to try to take medication or to try to take care of themselves. So again, early intervention for what?

We need to expand and improve the medical education around AIDS services. As I said before, the post-test counseling that's happening is inadequate. We need to teach physicians how to keep hope alive, and we also need to teach physicians how to make referrals.

Clinical trials are not the answer to the health care needs or long-term survival of women with HIV and AIDS. The current focus on gaining access to clinical trials is a diversion from the discussion that needs to happen about the more fundamental issues of what is the American health care industry--not system, but industry--why is that system not providing adequate health services to people of color and to women? Why is it that that system is failing?

All clinical trials ought to be required to assure that each patient be enrolled in a case management system of care, and that each clinical trial needs to further be required to operate in tandem with the primary physician of that patient.

We have had case after case where people have--where physicians have referred their clients into clinical trials. The clinical trial never discusses the patient with the primary physician. Patients are given medications that are contraindicated, and the primary physician had that information and could have given that information to the people conducting the clinical trial.

Earlier, Lorelei said that her mother had cancer, her brother had lupus, and I'd just like to add to that that my best friend's husband died on Christmas Day from colon cancer, my brother is dying right now from a terminal kidney disease, one of my best friends lost her baby this year, and I'm saying that to say that when we're looking at trying to provide an answer to the AIDS epidemic, that a single focus or a primary, sharply-directed focus at fixing the system to make it work for AIDS isn't going to work.

What we really need to be looking at is fixing the whole system. The AIDS is merely, as it's being manifested within the system, is just another in a long line, a long series of health problems that people of color and women are already experiencing, and an AIDS diagnosis doesn't change that. It doesn't take away your hypertension, it doesn't take away your diabetes, it doesn't take away the fact that your children may have been born prematurely.

I'd also like to recommend that we're not going to be able to make a dent in this epidemic unless we're able to provide treatment upon demand for substance abusers, that it's totally inadequate and it's shameful that the richest country in the world only has services to provide substance abuse treatment to ten percent of the people who are substance abusers.

We're always as a society talking about the children, what we owe the children. And we see in the media this incredible debate going on right now about the rights of the children versus the rights of the mother. But when we're talking about the rights of the children, no one ever focuses on the rights of the child to have their parents back.

The rights of the child whose parent was an IV drug user who now has HIV or AIDS and is going to die relatively soon, that no intervention with that parent, no support to that parent, to help that parent become sober and competent, that what we're doing, in effect, is taking away the last opportunity of that child to have a parent and to have a model that's going to help in their later growth and development.

We heard earlier--I've forgotten the name of the woman who spoke, who talked about her 15-year-old son who loves her, and how when she was 15, she didn't love her child, and we have numerous cases of women who have said again and again, thank you for having helped me get clean and sober so that I could have this last productive time with my child, so that I know the last memories of my child are not going to be me drugged out and doped out, but that it will be a memory of me as a loving, whole parent, and it'll be a sober memory.

DR. ROGERS: That was Ms. Suiter who said that.

MS. ROUSE: Thank you. We have in our history of delivery of health services in this country a number of programs that have worked. We have community health centers, we've got migrant community health centers, we've got our family planning programs, we have a history of programs and interventions that made a difference in the past in the delivery of care to women and people of color.

And unfortunately, we've gone through this process of eliminating those programs because they didn't produce profit. And I'd like to recommend that we go back and take a look at those programs and reinstitute those programs.

I'd also like to suggest that we not create new AIDS service organizations for women. That instead of reinventing the wheel, let's look at existing programs that already provide services to women and expand those services so they can provide the appropriate HIV-related services.

One of the things that we would not like to see, and that is the development of health department or public hospital style HIV clinics for women, where women come in one day a week to get all of their "HIV-related treatment". That is a disservice to women, when treatment services are provided in that manner.

We've struggled long and hard to try to get health departments to move away from the delivery of services on a clinic basis, where you come in on Wednesday for one service, and you bring your baby in on Thursday or the following Tuesday for another service.

We also need heterosexually-focused primary prevention. We need male-focused prevention that addresses male responsibility, and we need programs that teach children survival and life-coping skills. And I bring that up because in the women that we have encountered who have HIV and AIDS, the majority of those women are the survivors of child sexual abuse and child physical abuse.

And we know that those sets of abuses seriously undermine those persons' ability to function and cope in society and to protect themselves. It creates a certain kind of vulnerability that makes them much more readily vulnerable to HIV and AIDS, and that when we're talking about comprehensive services and comprehensive prevention, interventions along the line of child sexual abuse and child physical abuse are very critical.

I'd also like to recommend to the Council that with the tremendous amount of influence that you wield, that one of the things that I would like for you to consider is the possibility of the Commission recommending to the private foundations to take another look at what seems to be the present move away from HIV-funding, away from HIV-prevention funding.

Now is not the time. We have not gone far enough in primary prevention for us to begin to back off of that now. And it looks as if that the private foundations are moving away from that.

The amount of monies that have been allocated for HIV services are clearly not enough. We cannot take money away from gay men's services in order to provide services for women. It's not going to work. It won't work politically, and all it does is create squabbling and infighting among the people out there trying to do the work.

I'm from the District of Columbia, and I serve on the Ryan White Planning Council. And one of the things that's very clear, you know, that in the gay men's community, that they're feeling very, very threatened by the introduction of women's concerns and people of color's concerns, and that's a very destructive mix. It's an incredibly destructive mix.

Prevention versus--

DR. ROGERS: Ms. Rouse, I would ask you to finish up fairly shortly so that we can ask you some questions.

MS. ROUSE: Sure. Prevention versus treatment--it's again the same issue, is that it looks as if there's going to be a shift of funding away from prevention and towards treatment, and also it looks as if there's going to be a shift in funding away from primary prevention for the so-called early intervention. And I think that needs to be revisited as well. In short, we simply need more money.

I think that the issue of contact tracing is the wrong question. I think that the question that we need to be asking is, how can we create systems that will enable people to inform their partners themselves.

Another issue that needs to be dealt with is the notification of patients when their medical providers are found to be HIV-positive or to have died of AIDS. One of our clients is a woman whose physician died a year ago of AIDS during the same week that she was actually diagnosed.

She found out from the newspaper that her physician had died of AIDS. He was her OB-GYN and delivered two of her children. She had been married for nine months in a monogamous relationship, as far as she can tell, and she has no other risk factors for getting AIDS.

So in her mind, she's convinced that the physician caused her to have this infection. Whether that's true or not, I don't know.

However, one of the issues that comes up for her is why didn't the hospital contact her? Why didn't the hospital let her know so that she could have gotten tested earlier and begun to do something about it? When she asked the hospital what were they going to do about it, were they going to let other women know who were his clients, their response was no, we're not going to do anything about it.

I'd also like to recommend that we protect the reproductive rights of women with HIV, and I think that's all I need to say about that, because that was very well dealt with earlier.

One of the groups that has not been dealt with, and that's incarcerated women. Some of the work that we do is with women who are in the D.C. jail and the minimum security prison at Lorton, and one of the things that comes through very clear for us is that those women have clear information that they're at risk.

They know what puts them at risk. They know that their behavior puts them at risk. But they don't have a clue as to what to do about that, how do they change that risk. And they very, very much want people to come in and to work with them and to provide services for them.

Also, that population in D.C., 16 percent of the population's HIV-positive, and the medical services that those women get is worse than the services that people get on the outside, so you can recognize that that's abysmal.

I'll conclude by saying that there is no shortage of resources to deal with this problem. What we have is a shortage of will. And somehow or another, as a society, as a people, we need to put in place the resources that we need to deal with this.

I was speaking with the director of the Soweto AIDS Project just recently, and she was describing what she had gone through to create her project and to get the resources, and the hair on the back of my neck stood up. And the reason that it stood up is that she was describing my experience in Washington, D.C. Thank you.

DR. ROGERS: Thank you very much, Ms. Rouse. Ms. Allen, let's hear from you.

STATEMENT OF MS. LYDIA ALLEN

MS. ALLEN: Well, our category was service needs, and my background is I'm a nurse who does education and support with parents in a pediatric AIDS project, primarily women.

Before we can talk about service needs and quality of service for women, there has to be access to the services. And I know this was already touched on this morning, but I just want to talk a little bit about the fact that in Texas--I'm in Dallas--we get outlying areas.

Just recently, this was brought home to me in a very real and dynamic way, that in a tiny town outside of Dallas where we were seeking services for a woman and her child, there were only five doctors in that town, and none of those five were willing to care for that woman or her child, which necessitated her to take a two-and-a-half hour bus drive into the city in order to seek medical treatment for she and her child.

The same is true for a woman who wants to get a tubal ligation, if she's not in the urban area, then she often has to travel long distances in order to achieve that, sometimes crossing State lines in order to achieve it. And the same is true for abortions for women who seek those services.

So one of my recommendations to this Commission is that you use your influence and your power on an educational campaign to sensitize physicians, to sensitize medical schools, and to get physicians involved on a compassionate basis and decrease their fear. Sometimes we forget that physicians are people too, and they carry all the same baggage that the rest of us do.

As Dr. Cohen already mentioned, drug treatment for women is very inaccessible, especially for women with very young children. In Dallas, Texas, we have three programs that will accept women when there are beds available. Only one of those accepts women and their children together, and those children have to be over the age of three.

So a woman that has a baby either, as Dr. Cohen said, has to give up that child for a period of time for drug treatment or not go into drug treatment, and it's a very, very difficult decision for a woman to make.

In many communities, there are not alternatives for those children. We are very fortunate in Dallas that we do have an alternative situation for children to reside, but it's still an unacceptable situation for a mother to have to leave a small child for three, six months.

What I find that women need more than anything else, there's been a lot of talk about one-stop shopping. And it's a wonderful idea on paper, but I'm not sure that it works in the real world, because what happens in one-stop shopping is that a woman never gets an opportunity to focus on her own needs, as opposed to her child's needs or her husband's needs.

The demands are so great on any person with HIV just to coordinate all the different services. I want to read you just a list of the different scheduled appointments that one woman had to face in one week's time. This is a woman whose husband was infected, and both of her children were infected.

In one week's time, she had a doctor's appointment for her child's HIV doctor, a dentist appointment, an ear, eye, and developmental appointment with a developmental specialist, speech therapy for another child, a trip to NIH, a trip into the hospital for a blood transfusion for a child, an IVGG treatment, a social worker appointment, a WIC appointment, a Medicaid appointment, a Social Security appointment, and an AFDC appointment. That was in the space of one week. You need a personal secretary just to coordinate and calendar all of that.

And so one of the recommendations I would make for any program that is helping women is the case management idea, but also a lot of extra support services, making services really accessible for women. And I'm talking about the auxiliary services, not just walking into the doctor's office, but making sure that that woman doesn't have--or that patient doesn't have--to wait two hours for a pharmacy requisition to be filled, or to wait another hour-and-a-half for an x-ray.

So support services are very important in making health care accessible and getting people through systems so that they're not so exhausted that they can't come back again.

The other emphasis that I would make, for women who are already infected, there's been a lot of talk about prevention. But again, there's very little education campaigns, public media campaigns, telling women how to take care of themselves, encouraging women to get pap smears every six months. Very few women who have HIV know that they should be having a pap smear every six months.

And getting women to value the time that they have left and the time they have available to themselves and their children. There needs to be educational campaigns media-wide to emphasize that for women.

And my final recommendation is that all support programs have an ongoing component for women of support and education. Of course, that's what I do, so that's what I think is important. But I see that over a period of time in working with families, in working with women, that that can be a very high motivation for them to continue to get their own health care and continue to seek their own wellness.

Thank you for your attention.

DR. ROGERS: Thank you very much, Ms. Allen. Ms. Hutchinson?

STATEMENT OF MS. YVONNE HUTCHINSON

MS. HUTCHINSON: I'm Yvonne Hutchinson from San Diego, California. I'm here under two umbrellas, actually. I was asked to present before the Commission for the National Black Nurses' Association.

And after hearing everything that I've heard, I've not only been educated myself--because I do not work directly within the AIDS community. I am in a community where there is a large AIDS population. I work for Planned Parenthood, so I am part of what I think is the early intervention.

Initially when I went to Planned Parenthood about eight years ago, I was seeing the majority of my clients were people from 13 to 25 who were there for well-women treatment, nothing else. Over the past few years, I have seen an increase of that. I'm seeing a lot of women over 25 not just there for family planning or for their annual paps, but because they have problems.

Those problems have come about because of a lot of things, our economy, the cuts in services, doctors refusing to take Medicaid, Medical, husbands losing jobs, or whatever. So I am seeing a lot of women who need early intervention.

And I think the problem I'm having right now is that I don't have any place to send women to who have problems. Everybody here has talked about what we need to do for AIDS. I see--I think the young woman next to me mentioned that we need to look at the whole system, everything, the whole health care system has, I feel, failed the people.

The people who make the rules for health services usually do not have to worry about where they're going to sleep or eat or what they're going to eat. There are choices about what they want to do, so they don't have to concern themselves with that.

They only have to pick up the phone and call their physician and say, I'll be in, and they go there and get services, because they have the money to pay. It's the people who don't have, the people who live in the crowded areas and places that are really poverty stricken, not enough this, not enough heat, not enough cool in the summertime. All of these things need to be addressed.

I think in the community that I work in, which is low- to middle-income, predominately Hispanic, not so much black--I don't have many black clients--but Laotians, Cambodians. That's a community that also has been forgotten as far as health care services are concerned, and also understanding their cultural diversity.

And they are getting into the mainstream of everything and they are becoming HIV-positive and getting sexually transmitted diseases like everybody else, so that is another culture that needs to be looked at, needs to be addressed.

There was something that came up earlier about the spermicides, as far as being protective against possibilities of HIV. I have to say one thing about our planning personally. We have two clinicians there, and both of us kind of work from the same perspective, and we do encourage our young people not only to take birth control pills but to use condoms and spermicides, and the reason is because they do protect against STDs, the non-oxynol-9, and it's not harmful to their body unless they're allergic to non-oxynol-9, and some women are--very few. So that's just a point of clarification.

As far as education for the services, I think several people have already touched on the fact that physicians need to be educated. They need to be educated, I think, before they ever leave school so that they know that they're not prima donnas, that they don't know it all, and that they do need to know how to communicate with people.

Sociology, I don't know if it's a part of their curriculum, but certainly should be. I think if they were required to go into some of the areas where these people that they treat live, they would be a little more sensitive about how--not only the treatment, but how they address their issues, and they'd be more sensitive to that person's needs.

I'd like to say one of the things--

DR. ROGERS: Ms. Hutchinson, could I just interject? I'm not--you've got plenty of time, but I'm vividly aware of the fact that both Dr. Cohen and Ms. Rouse have to leave to catch a plane because they're going to influence Congress like they've influenced us.

So I think I will just interrupt your testimony just for a moment just to ask if the Commissioners would like to direct some questions to Dr. Cohen or Ms. Rouse so that we can let them catch their plane.

Mr. Allen?

MR. ALLEN: I have one for all of you about volunteers and about burn-out and turnover of personnel, especially with women and other women as a resource. Do you have a difficulty with that? That seems like a crucial need, as Ms. Allen was talking about ancillary services and so forth.

MS. COHEN: There are a lot of women who care about these issues and who have served long and hard. I don't see burn-out, because they're used to working long hours and not being paid. But it would be better to have money.

MS. ROUSE: I have a different experience, in that yes, there are a lot of women involved, and we experience incredible amounts of burn-out. Our project would not exist if it were not for volunteers, but there just simply aren't enough of us.

Volunteers in low-income communities where people are just struggling to live, to survive, to keep the roof over their head and the food on the table, it's a hard thing to ask for people to turn around and start volunteering to take care of someone else.

We need money so that we can hire staff. We need people who can be paid to go out in communities and do this work.

MR. ALLEN: So the follow-up on that would be possibly, would you recommend that we look at utilizing family members as some type of reimbursement--the family structure's very important--

MS. ROUSE: Yes, family structure is very important. But rather than moving to a situation where we have to pay people to take care of their own folks--

MR. ALLEN: Yes.

MS. ROUSE: --I think that what would make more sense is if we were to provide the support services to those families, so that they've got the education about how to take care of them, how to give compassionate care--

MR. ALLEN: Yes.

MS. ROUSE: --family members do want to take care of their family members, but they experience as much of the trauma and stigma as the person with HIV. So we've got to work at how to get rid of the stigma, how to give family members permission, okay?

Right now, families don't really have permission to take care of their family--their persons. So giving them permission, giving them the social services supports that they need, and also giving them the educational supports that they need so that they can take care of their family members.

So what we need to do is enable families, not pay them.

DR. ROGERS: Mr. Dalton, and then we're going to let you ladies whisk for the bus.

MR. DALTON: Okay. My questions actually are for Ms. Rouse. You, I think for the first time today, made reference to the need for male focus programs aimed at male responsibility.

I'm a little surprised it was not until the afternoon that someone suggested that, given all the conversation this morning about ways in which women can take control of protecting themselves. But I wanted to give you a chance to give a quick sense of what that might look like.

And then secondly, toward the end of your testimony, you said that we should focus on the question of notification of patients when their physicians are diagnosed with HIV. I don't think I heard you say quite what that focus should look like.

You reported on the experience of a particular patient, and you described very well her perceptions and feelings in the matter. But I guess I want to ask you to wear your public health hat rather than your patient advocate hat and tell us how we ought to look at that issue.

MS. ROUSE: My public health hat doesn't have an answer, which is why I chose to simply give you the experience of the person who just went through this about a month ago. Earlier, people talked about, do women want to know about whether their partner's positive or not, and some people said yes and some people said no.

My experience is that most people want to know.

Women also want to know whether their providers are going to give them the virus, or whether that's even possible. There is such an incredible amount of disbelief in the system, disbelief in the information that gets put out by the government about whether a person can get a virus from a provider, and then that situation with the dentist didn't help any.

So I, as a public health professional, I don't really know yet. But I do know that the women themselves want to know.

In terms of no responsibility, people focus on women because women are easy to focus on, and because women have traditionally been the targets of most public health campaigns. Men have been hard to get into the health care delivery system for a variety of reasons, and rarely do you see major public health campaigns--with the exception of heart disease and smoking--focused towards men.

Women cannot prevent HIV by themselves. For women, HIV infection is essentially a heterosexual phenomenon, which means that we have to be in concourse and discussion with, and in partnership with, men. And the men have been left out of the picture.

And so what I would like to see are programs, requests for proposals, requests for funding from the government and from the private sector which specifically target men's organizations, men's groups which have men learning how to work with other men to teach them the kind of male responsibility in terms of not protecting their women, but protecting themselves.

Let me just add one other little piece to that.

DR. ROGERS: Ms. Rouse, don't. You work while you're ahead.

[Laughter.]

DR. ROGERS: You two go catch your bus so that you can tell Mr. Weiss exactly what you've told us. You may have the last word, Dr. Cohen.

MS. COHEN: Perhaps you can ask Dr. Wofsy to present this, because it really is her idea, when she has time later this afternoon. She has a marvelous idea about basically getting condom advertising for the Marlboro man. That's the level we need to start on.

DR. ROGERS: Very good. Thank you both very much. Good luck in Washington.

Ms. Hutchinson, please continue.

MS. HUTCHINSON: Thank you. I was concentrating a little bit on education, and I spoke of what the doctors needed. Also, I think that education for women, again I'm looking at young women and young men, it needs to start quite young, a young age.

I see a lot of patients right now who still do not believe that they need to use condoms or spermicides for any kind of protection, let alone AIDS.

The subject of warts and cervical cancer and dysplasias was mentioned earlier. I see quite a bit of that. Women are dumfounded when they find out that they have warts, yet they've had several partners and don't know where it came from.

We're talking about 1991, when most people should be literate and able to read. I don't know where we're missing the boat.

So there needs to be some concentrated effort into educating, either from the school system, which you know we're fighting. Most people don't want sex education--they're calling it sex education, but I think it's education period, not necessarily sex education--in schools, so that these young people come into relationships aware of what can happen, aware that they need to use measure so that they are not contacted, they're not transferring STDs and/or AIDS amongst them and their friends.

Also, I would like to tell you what the National Black Nurses' Association just did this past year. We have what we call regional conferences, and we had training for the trainers. It's kind of like, what someone just said, we're just like preaching to the choir. Well, I've heard a lot, I've been to a lot of HIV classes, sessions--this is good.

What we're doing now, we train people to go into their prospective communities, their churches, their other organizations, groups, community groups, to try to teach preventive precautions against AIDS, against HIV-positiveness.

And these organizations like the National Black Nurses do need support from the community. They need funding from some of these places so that they can take the time. As she said, volunteers--there just aren't enough volunteers. You need to be able to pay people so they will--and it's too bad that you do, because I volunteer half my life, I think--you have to pay people to make them commit and stay committed.

Someone may put in an hour or two, but we need more than that. We need ongoing training. We need ongoing education. We need ongoing sessions. We need somebody always talking about how to and how not to get infected with HIV.

One of the things that was just--

DR. ROGERS: Ms. Hutchinson, I wish you would just close with what you would like this Commission to do to be helpful.

MS. HUTCHINSON: I'll tell you what I'd like for this Commission to do, as an individual and also as a Commission. I do not understand how we can send hundreds of thousands of troops in a matter of days to the Gulf, but yet we can only have 34 beds in L.A. for detox.

I don't understand how we can pay five past Presidents' Secret Service funds for no telling how many years, but yet we cannot give enough money for education and research for something that's killing this generation very quickly.

And what I would like for you to do, to be a vehicle to the politicians who sit above this board to open up a means of financing and funding health services, not just

AIDS, so that people's lives can be more quality.

DR. ROGERS: Thank you very much. Very fine.

Questions from Commissioners? Yes, Ms. Diaz?

QUESTIONS AND ANSWERS

MS. DIAZ: I have a question for Ms. Allen. You talked about the importance of a case management system in facilitating the kinds of supportive services that you represent here today. In the cases of women who have children and are impacted by this epidemic, you heard the testimony this morning.

Would you suggest those case management systems be built around the needs of the child or the mother or the entire family, or is it just to humongous to deal with an entire family context, in terms of the fact that some of those services are community-based provided, others are hospital-based provided, and others are ambulatory clinics that provide the case management?

MS. ALLEN: I would say it has to be family focused, and that seems to work very well in communities that already have a system, a network kind of system of those community-based organizations. Unfortunately, there are many places in the country that do not have any kind of networking going on, and so it's very disjointed services.

But where there is community cooperation, that system for one case manager per family has worked very well, and it works well in Dallas. Unfortunately, there are sometimes more than one--

DR. ROGERS: Even in Dallas?

MS. ALLEN: Even in Dallas. It often takes more than one case manager. Even though there's one case manager per family, what I do is a lot of case management, so that family's case manager sometimes calls me, sometimes calls the health care providers for the adult, that kind of thing. So there may be more than one case manager, although there's only one designated per family.

MS. DIAZ: So even though the needs of the child and the mother and father need to be served within separate networks of services, one case manager, in your feeling, can pull that?

MS. ALLEN: That way they have the whole family spectrum together, and they know that--they know that this mother has 15 different appointments, because they're helping coordinate those services.

MS. DIAZ: Thank you.

DR. ROGERS: Mr. Dalton?

MR. DALTON: I have one request for Ms. Allen, and then one question. The request has to do with that wonderful description of a week in the life of one woman, and your conclusion was that there's a need for a lot more support services. I just would hope that you would sort of spell out what those support services might look like.

You gave us one or two examples, but I think it's not the kind of thing that people normally think about who get embedded in this business, and so afterward or something, if you can just drop a line just giving a sense of what it would take to enable anybody to live through that week. That would be helpful.

DR. ROGERS: And give us that menu, too. I think that would be a nice horrible example for us to use.

MR. DALTON: Yes, repeat the--.

The question has to do with your observation or conclusion that one-stop shopping may not work in practice, because even then the result is for women, "me last", to use Dr. Cohen's phrase. I gather that's also the result without one-stop shopping, and so what can be done to keep a woman who's part of a family with more than one person HIV positive from being last?

MS. ALLEN: Well, I think the first part of your request was the answer, which is support services. If we make health care accessible for women, if we make it easy for them to walk in, be seen, get their drugs at that same time, not have to wait for another hour-and-a-half for x-rays, then they're going to come back, and that helps them to survive, to get through all of those different things.

And by the way, the example I gave, that woman certainly did not keep all those appointments. She had them, but it's undoable.

[Laughter.]

DR. ROGERS: Thank God.

MS. ALLEN: The other thing that's undoable for women, and keeping in mind all those appointments that I listed, is clinical trials. One thing that all people with HIV need is hope, and research clinical trials, as they are now constructed, are undoable for women.

A woman who has that many other responsibilities cannot leave for three days to go to NIH, either for herself or for her child. Also, the wages lost during the--even though NIH will pay for airfare to and from clinical trials and will pay for housing while they're there, there's no reimbursement for wages lost from that woman's employment while she's gone. So that's a very serious problem.

And those two things, I think if those were addressed for women, it would greatly reduce their burdens. If they had support services that helped them get through the systems quicker and faster, and then they had some hope through the research trials.

DR. ROGERS: Mr. Allen?

MR. ALLEN: Perhaps this should have been done in the psychosocial issues, but since I know you've dealt with that rather extensively--someone earlier, I forgot who, said that it's not immediate anger, it's guilt of the woman when testing HIV positive, and what has she done to her child and so forth.

I was surprised by that, but it also triggered something in me of how the psychological systems of counseling and so forth is a service need. Where is that for the women, and also the grief, the perpetual grief of perhaps having a child or personal grief of the individual herself having to deal with their own mortality, in the midst of accessing.

I mean, is there a time when it just becomes too much, or where do you find the structures of the support in that kind of context?

MS. ALLEN: Well, we have a women's support group in Dallas that all women who come through our particular system are referred to. Not all of them choose to access that, because of confidentiality and denial and lots of other reasons that I'm sure you're all familiar with.

But largely the support comes from other mothers, and hooking those mothers together and the women together in the program.

DR. ROGERS: Dr. Osborn?

DR. OSBORN: I just wanted to say to Ms. Hutchinson that I hope we didn't seem like we didn't hear your main message. Sometimes we've said in other contexts that the only--in a very important sense, the only thing new about our charge is the virus of AIDS, and that the needs that we keep hearing about and seeing are very universal.

I was afraid, particularly when we had to interrupt you, that you might not think we heard you, but we do, and your message is wonderfully well put, and we do appreciate it very much, and Ms. Allen as well.

MS. HUTCHINSON: Dr. Osborn, may I include one thing I really would like to mention that was touched on briefly by someone else about incarcerated women? I have two friends that work in the prison system.

I think there needs to be a real serious look taken, a real serious look at the prisoners who are released and have sex while incarcerated, willingly or not, they're usually heterosexual people who come back out into a heterosexual environment.

And as you know, you read all the statistics, it's a largely black and Hispanic population that's incarcerated, and those men do indeed bring that back into the heterosexual community if they do so engage.

And I think that something needs to be looked at in that perspective, whether they need education or maybe women need to be made aware of the possibility or something. I'm not sure what needs to be done, but I think it's a place that certainly needs to be looked at.

DR. OSBORN: Well, we agree with you about the importance of looking at the prison environment for people with HIV. We have just recently released a report, having spent some time looking at that issue, and it doesn't look so much as if the prisons are the site in which HIV is transferred as the prisons as a lost opportunity to achieve the kind of education that you're talking about so that people going out of the prisons could be better equipped to be positive influences within their community.

But we agree with you very much about the importance of that venue as a place to be improving things in this epidemic instead of letting them continue to get worse. Thank you.

DR. ROGERS: Ms. Hutchinson, Ms. Allen, thank you very much. We will reconvene at precisely three o'clock. Precisely at three o'clock. Commissioners, hear me.

[Laughter.]

[Short break.]

DR. ROGERS: Ladies, we are honored to have you here. This session is to focus a bit on research, and we have Mary Lucey from ACT UP who's substituting, but I think is going to tell us what Nima was going to say. We have Janice Jirau, welcome, from Washington, and we have Constance Wofsy, who's Professor of Medicine at the University of California at San Francisco. We're delighted to have all of you.

Ms. Lucey, I think you're starting out.

STATEMENT OF MS. MARY LUCEY

MS. LUCEY: Okay. I'm from ACT UP/LA. I'm testifying for Nima out of Seattle. Unfortunately, she's at the hospital with a friend of hers that's dying from AIDS.

There's a few things I'd like to add to this, too. I'd like to give a report on research in lesbians and AIDS, but unfortunately there is no research on lesbians and AIDS that we know of.

I also would like to give a report on the efficacy on dental dams, but there is none of that either. A dental dam is an old dental instrument that our government has given us women to protect ourselves, and the only place you can really obtain a dental dam is in a dental supply store.

I'm going to read what Nima was going to read to you today. ACT UP has long recognized the appalling lack of attention and resources devoted to women with HIV infection.

It is for this reason that we committed ourselves to the production of the Women's Research and Treatment Agenda. Even though it is a work in progress, the information about women with HIV presented within this agenda still presents far more direction for research, education, and treatment than what has come out of our government agencies in the past ten years.

We have researched and written sections on the following topics: clinical manifestations of HIV in women, alternative therapies, drug detoxification, prison issues, the ACTGs, the FDA, AZT issues, and the Center for Disease Control's policies and their impact on women.

Each Commissioner has been provided with a copy of this.

DR. ROGERS: Ms. Lucey?

MS. LUCEY: Yes?

DR. ROGERS: A suggestion. You can slow down a little bit. I may be terrifying, but I won't cut you off that fast.

MS. LUCEY: Okay.

[Laughter.]

DR. ROGERS: Take your time so you can read it clearly.

MS. LUCEY: Okay. Collaboratively produced document, and we urge you to consider its contents vital in the struggle against HIV and AIDS. Our goal is to prompt more and better research on women with HIV.

Women are the most misdiagnosed, under-diagnosed, and undeserved population in the AIDS pandemic.

DR. ROGERS: I think you mean underserved, not undeserved.

MS. LUCEY: Underserved, excuse me. You know, I'm really nervous, because I--

DR. ROGERS: You're doing fine--relax.

MS. LUCEY: --I didn't plan on testifying today, I really didn't.

DR. ROGERS: Relax. You're doing fine.

MS. LUCEY: Life expectancy for a woman from day of diagnosis currently ranges between 15 weeks and six months. The average life expectancy for an African-American woman in New York City is approximately 15 days after diagnosis. In San Francisco, average survival time for women after diagnosis is less than eight weeks.

Women have been both technically and functionally excluded from AIDS clinical research. Many AIDS clinical trial group, ACTG, trials requires a CDC-defined AIDS diagnosis as entry criteria.

CDC definitions limit research, options, and access to services. Not one woman-specific opportunistic infection is listed by the CDC as an AIDS-defining illness. Because many of the opportunistic infections common in women are not considered AIDS-defining illnesses by the CDC, women with HIV are routinely barred from potentially life-saving trials.

Until the CDC changes the definition of AIDS to include gynecological infections, there is no reason to believe that NIAID will sponsor clinical trials to study HIV-related gynecological infections.

Because many of the clinical manifestations of HIV in women, such as pelvic inflammatory disease, menstrual irregularities, and vaginal candidiasis go unrecognized as HIV-related, pap smears and pelvic exams are not part of standard research protocols. This further inhibits efforts to fully understand the nature of HIV in women's bodies.

There are also explicit exclusionary criteria which keep women out of trials. Almost all protocols specify high liver enzymes as criteria for exclusion. This effectively excludes women with a history of substance abuse, who make up a large number of women with HIV.

Women with AIDS are denied their reproductive rights as a matter of course. All trials require that women participants practice an adequate method of birth control, regardless of their self-defined sexuality. The FDA argues that pregnant women are too high a risk, due to the possibility that experimental drugs might cause fetal damage.

The Federal government and private drug companies are unwilling to assume the liability involved. Ironically, there is no liability implied in the premature deaths of women due to their exclusion from clinical trials and their lack of access to basic health care services.

Although most protocols exclude women who are pregnant and/or breast feeding, a few trials focused on pregnant women currently exist. However, these trials prioritize the health of the fetus over the health of the woman, focusing entirely on the issue of vertical transmission and failing to address the women's health needs.

One trial is ACTG's protocol 076, an unsafe trial based on faulty data which does not research treatments for medical conditions facing women with HIV, but rather attempts to discern whether AZT prevents vertical transmission of HIV from mother to fetus.

This trial intends to enroll 748 pregnant women, the largest number of women to ever participate in an ACTG trial. WHy isn't the ACTG seeking out equally large numbers of women for trials of other anti-retrovirals and prophylactic therapies?

ACTG trial 076 is a clear indication of how the system fails to respond to the specific research and treatment needs of women with HIV. Currently, AZT is the only drug being tested in HIV-positive pregnant women. This is appalling, when one considers the many adverse side effects of AZT, particularly in women.

All people with HIV should be able to gain access to treatments, regardless of their pregnancy or childbearing status. Women with HIV should be provided with the full information about risk and benefits of a treatment, and then be granted the autonomy and self-determination to make her own choices about treatment, unconstrained by paternalistic agendas which limit her choices because of pregnancy or child-bearing potential.

In closing, we urge all of you to examine carefully the information about women with HIV collected by the ACT UP Women's Network. This information must be used to expose the lack of direction and information regarding women and AIDS currently plaguing the CDC, the FDA, NIAID, and the ACTGs.

ACT UP chapters nationally are actively conducting an endorsement drive to demand that CDC expand its definition of AIDS and revamp its problem-ridden classification system. Community-based organizations and individuals concerned about the AIDS pandemic are encouraged to add their endorsement.

Our goal is to collect a thousand endorsements to present to the CDC. Already, there are several hundred endorsers from around the country. Currently, endorsers include policy makers, community-based organizations, and health care workers.

Ultimately, we hope that today's hearing will encourage changes in the path of research and treatments for women with HIV infection. If there is anything to be learned from today's testimony, it is that women living with HIV and AIDS and community-based advocates are our best resources in fighting HIV and AIDS in women.

Government and scientific institutions, if sincere in their efforts to combat AIDS, must systematically include the input of a broad spectrum of women living with HIV and community-based women's health care advocates. Thank you.

DR. ROGERS: Thank you very much. Well done. Ms. Jirau?

STATEMENT OF MS. JANICE JIRAU

MS. JIRAU: Hi. I'd like to thank the Commission for this opportunity. I'd like to add, I'm very nervous today--I don't know why--so I wrote down--

DR. ROGERS: We're nervous too, so you're among friends.

MS. JIRAU: I wrote down some thoughts that I have, and I based these thoughts on the fact that I'm HIV-positive. I nursed a sick husband who died of AIDS in 1989. I have experienced, by growing up in poverty, a lot of the things that poverty breeds, and I have a real issue with research and the psychological conditions of women being understood.

So, I've tried to explain that in this little brief that I wrote, so bear with me.

We now know that the nature of AIDS, of the AIDS epidemic, and special research and services required to address the issues surrounding this virus as it relates to women and families present a special challenge to researchers, service, and health care providers.

The challenge for 1991 is to fully disclose and address the issues of women and families affected by HIV and examine the impact of the role of women in society, the family, et cetera, on their ability to cope with the virus and related stresses.

We can no longer ignore the additional stresses placed on women as they carry out the traditional responsibilities that come with having to be heads of households in a socially and economically disadvantaged environment.

In a male-dominated society, many women have become prey to men who are sexist, abusive, and inconsiderate. As second-class citizens, we have struggled with the impact of emotional, physical, sexual, and intellectual abuse. Sadly, many of us have been brainwashed into believing that this is a normal procedure, and our only role is to serve and preserve society, our families, our children, our spouses, et cetera, in spite of our own unacknowledged pain, disappointment, lack of support, and low self-esteem.

Too often, we are denied services or cannot find services that adequately address the real needs in our lives because of gender issues, economic issues, politics, racism, sexism, and because we do not yet have a single strong voice of advocacy.

We are so preoccupied with meeting the needs of others that there is never enough attention focused on our own needs. Many of us are poor, and must improvise and compromise ourselves or simply do without much needed support, basic services, love and attention, and all of the simple things in life which help people develop whole and wholesome attitudes about themselves.

We have never been educated about our own vulnerability to abuse and misuse by others. In reality, our strength has been for others and not ourselves. We need to know that the pain, the lack of self-worth, the lack of self-love, and the lack of self-esteem many of us experience is very real, and it's okay to share these feelings in an effort to understand more fully ourselves and the impact of such emotions on our decisions and coping skills.

The psychological impact of HIV and women goes far beyond the medical manifestations of this virus. Researchers, service providers, and health care providers have to examine the whole woman and her entire struggle. Everything in her life is relative, and how she responds to the insurmountable stresses has a tremendous impact on her ability to tackle HIV and live to tell about it.

Outreach is a vital tool that must be reinforced cooperatively through research and community health care and services. I am too terrified to consider the number of women who will die and suffer needlessly because no one reached them in time or cared enough to provide the types of real services needed to empower them to reduce stress, claim a healthy attitude about themselves, and create wholeness and well-being so that she can have hope in spite of HIV.

Women, in spite of the circumstances in their lives, have the inherent ability to make it better for others. Now we must teach them to make it better for themselves. We must provide the tools and a mechanism for women in this struggle.

Women must know that they are not alone and are not expected to be superwomen, superwives, supermoms, and superdaughters. Women need to be freed up to seek the help they need for themselves without feeling that they are letting others down.

If the outreach is done in an effective way, we will find universally that the percentage of women already infected will be staggering.

I believe that outreach to women has to be just that. Service providers can no longer wait for them to show up half dead in hospital emergency rooms. Researchers can no longer wait for women to show up in their studies. There must be much more initiative and innovation and collaboration on the part of researchers and service providers to earnestly attempt to reach women in their circumstances and meet their needs.

Dr. Young spoke earlier about stepping off the cliff. These women will need to have in place a one-stop, one-shop system, which I know that everybody doesn't agree with, but we have to have something. We have to put our heads together and come up with some kind of system where the woman will not be forced to go through additional stresses in order to get the services she needs.

Because we all have a responsibility to meet this challenge, it is imperative that we diminish as much as possible the negative impact of politics, gender issues, racism, sexism, social and economic conditions, and overall greed on the plight of women and HIV.

Some of the research issues that I feel would be very important is--I know that we have a lot of studies done on transmission of HIV, but there are a lot of women who carry an enormous amount of guilt and are brow-beaten down within themselves because they feel that they are dirty.

They feel that they have contracted this virus. They feel that they can no longer have love relationships, that they can no longer--that their life is over. And I think as a woman, it's important for me to be able to say to myself that that part of my life is not over, that I can still have a healthy relationship with somebody.

And as long as society has it set up where if a woman gets syphilis or gonorrhea or something that makes her a bad girl, as long as we have the victim-villain sign hanging over a woman's head, a lot of women are going to go into depression, they're going to commit suicide, they are going to give up. They are not even going to try. And that's what's really happening today.

I think also the community-based collaboration between researchers and community-based organizations needs a lot of work. We need to do a lot of work in that area, because the women that are coming through, number one for the outreach piece, we need to work together to reach the women before they die or before they become too ill to benefit from the services that we have.

And also when a woman comes through a study, she's coming into that study hoping that you can relieve some of that additional stress by giving her hope that this is going to work for her. She has multiple diagnoses. She has a lot of stress going on inside of her, and that needs to be addressed. You cannot just have her in the study. You need to help her, too.

So I think the collaboration part between the community-based organizations and researchers is a very important part that we need to address in 1991.

The AIDS definition, the CDC, you've heard a lot about that today. I would like to add to all of the things that you've heard about that is the chronic fatigue and depression is real. It is not just coming from the virus. The virus complicates the chronic fatigue and depression that's already existing because of the psychological condition of women. And I think it is a real issue and it needs to be considered.

The creation or expansion of women and family-specific programs that are--I think that a lot of women--our best resource is women, and women who have lived through these conditions can certainly help. There needs to be jobs created for women like myself, who bring this aspect into what it is really going on there.

I don't know if I'm saying this right, but we bring a lot of experience that is much needed. And we need not--we don't need to have to worry about our own HIV, the conditions of the sisters around us, how to make life better for everybody else, and then how to find out how I'm going to pay my rent next month. So, it's a whole lot of issues going on there that need to be addressed.

Yeast infections in women--I believe that we are susceptible by nature to yeast infections, and because that is a primary part of this virus, that that means that we do have different conditions from men. We are susceptible to having a whole lot of other problems that are defined in CDC definitions, the gynecological, but the yeast infections, there need to be some special studies on that, I think.

Greater dissemination of information about research and services to women, I again go back to the outreach piece. There are a lot of women in the community don't have basic information, and certainly when the research--when the programs come up, a lot of them will not hear about it. They won't get access to that information until it's all over or until the studies are all filled up. So we do need to have a way of disseminating information into the community into where the women are.

There are--I guess this is taking this research to another stage, but I'm going to talk about it a little bit. In-home--

DR. ROGERS: Ms. Jirau, you're doing elegantly, but I would ask you to complete fairly soon, so we can ask you some questions.

MS. JIRAU: I'm on the way, I'm on the way.

DR. ROGERS: You're doing fine.

MS. JIRAU: Okay. Families--it is important that a woman have a strong family support system, and unless we can bring down the stigma by teaching families about HIV, a lot of women are going to be left out in the cold with this virus and their sick children and/or sick husbands. And I'll conclude. Thank you.

DR. ROGERS: Thank you very much. Very eloquent.

MS. JIRAU: Thanks.

DR. ROGERS: Dr. Mays, we're delighted you came in. I saw you puffing and blowing as you came through--

[Laughter.]

STATEMENT OF MS. VICKIE MAYS

MS. MAYS: It's like the Hertz commercial, of running from the plane. That's what it felt like.

It's my pleasure to be here, and I really thank the

Commission for having these hearings, particularly in terms of focusing on women and HIV disease.

What I'm going to try and keep my remarks addressed to is actually the issue of the research agenda, in terms of women and HIV disease.

I am an Associate Professor of the faculty at UCLA, and I've been working as a researcher on a multi-ethnic study of young adults which began back in 1986, tracking their behavior, some of their risk behaviors and some of the changes.

And also, I've been providing education, intervention, and prevention services to women, and finally I've also been a woman who has had to be a caregiver, and who, because of all the needs in my community, am very clear that I will continue and will have to be a caregiver again in the future.

Probably one of the hardest parts of all those different roles that I occupy, one of the hardest parts of those roles is really when I'm in the community, the lack of culturally sensitive, gender-specific data to drive our education, prevention, and treatment effort.

It is not unusual to often work with groups and find out that some of the initiatives that they have responded to have kind of tied their hands in terms of the kind of work which they're required to do.

One of the things that I think is also a very important issue to talk about, in terms of the women's HIV research agenda, is that in discussing that agenda, we cannot--and I've heard this several times, but we cannot in this day and age start with the phrase, in these times of shrinking resources.

We cannot, for instance, fund only one or two of the WAC studies, the women's area cohort studies, for these will not be adequate to really address questions of natural history, disease progression, sexual practices, or the cultural context of HIV-related risk for all women.

As of the diversity among the women, in effect it cannot be easily subsumed under this notion of a community, the way that we have talked about community before. We have to realize this in terms of our research efforts.

It would be a mistake to assume that the cultural beliefs and ethnic traditions about things like help seeking, sexual behavior, methods of contraceptives, definitions of health and illness, or even past exposures to infections, which we often believe are co-factors, will necessarily be the same, for instance, for a Hispanic woman in New York, in Miami, or Los Angeles.

Now while for the purposes of our data such as surveillance, or in terms of a classification, we see all these women as being Hispanic. We see them sometimes being in inner cities.

What happens is that there are some very basic differences in their notion of what is acceptable in terms of levels of illness which may require medical attention, for instance, to a much more complex issue, such as who they turn to for help and information. We may find very vast differences here.

So some of the strategies that we currently are funding, which are the multi-method strategies, and which we are trying to bring together very diverse communities, may be problematic when we try and generalize that to entire populations.

DR. OSBORN: Vickie, why don't you stop for a minute. It's a tornado warning, okay? We're okay, I just wanted to--

[Simultaneous discussion.]

MS. MAYS: Rather than talking about these diverse groups of women, we may find that the Hispanic woman in New York, that her source of support and information may actually be in Puerto Rico, while the woman in Los Angeles may travel to Mexico for help. Or she may find herself going to swap-meets in our area that often offer medicines from Mexico that are recommended by her family.

In spite of whatever systems of care and prevention efforts we put in place, they will be under, if not not utilized by the women most impacted by this epidemic if they fail to take into account the culturally specific patterns of extended family that serve as sources of information, as probably some of the most real agents of behavior change, and that function as a systems of support in crises.

In a study I conducted with some of my colleagues from the University of Michigan using the national panel income dynamics data, we find that who a person turns to in an emergency differs among whites, blacks, and Hispanics.

For instance, Hispanics have fewer different sources to turn to for emergency help. So that tells us that over time what will happen in the need of respite care, the need of making sure that we have paid sources and not rely on volunteers. Blacks, for instance, were as likely to turn to in-laws as they were to turn to parents, and they were more likely than whites and Hispanics to turn to aunts and uncles.

Yet I challenge you to tell me in terms of all the hearing, how many of our own prevention efforts have really targeted an outreach to these particular members in our community?

Instead, our efforts and all our research is driven by a notion of community that really focuses on sexual and drug use partners, a reality that will work less effectively with the women who are being most impacted upon in the coming decade.

Community efforts are often hampered by the State, county, and Federal initiatives which are targeting women either by their risk as a function of their partners or as groups, similar in sexual or drug use behavior, such as--and these tend--

DR. OSBORN: I'm going to interrupt you again, Vickie. Apparently, there's a fire alarm rather than a tornado warning. It's on the 12th floor, and it has been suggested that we go outside until the fire department arrives. I think that would be wise.

I think it's unpleasant to keep interrupting you, but I think it's better than to be worried. So let's just do that until we get clear here.

[Short break.]

DR. ROGERS: Please continue.

MS. MAYS: Okay. I think what I'll do, because I realize that we are in the interest of time, is go to some of the recommendations. What I would like to say is that several of the recommendations made by Ms. Jirau, I strongly support, and will therefore even cut down the number that I'm going to talk about.

I would like to ask the Committee in its recommendations to Congress to consider the following. First, that we encourage all relevant biomedical studies to incorporate psychosocial and contextual assessments in their activities. It is not going to be an easy job, but I think that there has to be a marriage between the biomedical and the psychosocial researchers.

Secondly, I would ask this Committee to consider establishing either a standing committee within your own group or task force or whatever you want to call it on women and HIV disease. I suggest that as a model which you can encourage other institutes, such as the National Institute of

Medicine and other Federal agencies who are currently addressing the HIV disease issues to also do.

I would suggest that in terms of the issue of women and HIV disease that it also be put as a very prominent issue in the report to Congress, because I think as we move into the next decade, I would hate to see it buried under all people being at risk, but instead to try and be very clear that some people will be more at risk because of the context in which they live, and less in terms of just the disease itself.

I'll end there. Thank you.

DR. ROGERS: Thank you very much, Dr. Mays.

Dr. Wofsy, we have not forgotten you.

DR. WOFSY: I don't feel the least bit forgotten.

DR. ROGERS: Welcome.

STATEMENT OF DR. WOFSY

DR. WOFSY: I'm Dr. Connie Wofsy. I'm Professor of Clinical Medicine at UC San Francisco, an infectious disease specialist and by my own description, an AIDS old-timer, since I was involved with the first patient at our hospital and have been working with HIV ever since.

I want to start out by making a point that is important to me, and that is that women and HIV disease is not a women's issue. Men with HIV disease have benefitted from the care, teaching, research, education, support, and all those other systems and services from both men and women, and the same thing is absolutely essential for women with HIV disease.

I can't think of a single speaker this morning who I would want to eliminate from the roster, so it's with hesitation that I make the next observation, but I think it would have been even more ideal if some of the men involved in research issues on HIV disease had been here to present their findings as well.

And while I agree about having focus groups on women, as was just mentioned, I think it's important that as that happens that women not be moved off into an all-women's phenomenon.

You may have noticed that I have a book with me. You may have thought, my goodness, she's coming before the Presidential AIDS Commission and she intends to read. But I wanted to read a passage from this book entitled Fried Green Tomatoes at the Whistlestop Cafe, which I enjoyed very much, in which a middle-aged woman gets into a dispute over a parking space with some teenagers, and the teenagers call her a name that's a derogatory term for her genitalia.

And she says--there's a paragraph that says, Evelyn wondered why always sexual names, and why when men want to degrade other men do they call them P-U-S--a few more letters--as if that were the worst thing in the world. What have we done to be thought of that way?

People don't call blacks names any more, at least not to their faces. And then it goes on to discuss Italians, and no more kikes, japs, chinks, et cetera. The key sentence is this one. Everybody had a group to protest and stick up for them, but women were still being called names by men. Why? Where was our group?

And the point I want to make is that in the issue of advocacy, we are now, I think, going through a very, very important and powerful year of being pushed, prodded, pulled, sometimes yelled at, sometimes slipped little notes of encouragement, from advocacy groups of the women themselves. But I want to get at the issue of who are the advocates from within the establishment.

One of the criticisms of research related to women has been that there's so much focus on pediatrics and on maternal-fetal transmission, but that the woman herself seems to be invisible. But let's examine that the children have pediatricians, a well-established group of men and women, to advocate on their behalf, and that maternal-child health issues of neo-natal transmission have OB-GYNs.

But in fact, women's health is not an area that is a particularly sub-specialty of medicine, and in fact most of the women investigators--and I realize that as someone in the biomedical area, I'm focusing more at this point on medicine itself--draw on other specialties, such as infectious diseases.

So the woman really doesn't have a key advocate. That's an important, and I use the example if I'm advocating for women investigators, as we've heard others advocating for others with whom they work on a daily basis--there are two individuals in my unit at the assistant professor level, both outstanding, humane, articulate, concerned, and kind assistant professors, a man and a woman.

They are both very creative and productive, and publish widely in peer review journals. When meetings arise, she will always have the yellow pad and will be asked to have paper borrowed. He will have the tacit permission to speak out. This is a very warm person, who doesn't take this aggressively. She will wait until there's a pause.

They share a secretary. He has volunteered to supervise the secretary. There are many things that influence the rise of women in biomedical research.

The focus of this discussion is research. I agree with the statements that have been made by virtually all of the speakers before me about the need for social behavioral and biomedical focused research.

In the biomedical area, virtually every woman who is infected will at some point ask the question, will I did, when, and will it be different than others, what drugs can I take and how is that influenced by pregnancy, can I get the therapies that have been read about in newsletters--although it takes some time to find out about those newsletters--can I now get pregnant and what is the risk, what about disability, and are research studies available to me, so that those issues will have to be addressed by concrete research methods.

I want to move to the issues, I think, or the recommendations that I see as having major priorities, and some of them will reflect what others have said.

One, I do agree with most of the things that have been said today. One, there need to be attention and focus on incentives for women in biomedical, epidemiologic, and social research to carry out the research efforts as well as including their male peers.

Two, a prospective natural history study is the number one priority in women, but it's confounded by a couple of issues that may not initially be visible. The multicenter AIDS cohort study of men took place at a time when there weren't interventions, and where there wasn't competition for these individuals as research subjects.

In fact, another point is that we have become kind of inured to the ease with which we have access to the first group of individuals infected with HIV, and we have taken them as the norm, so that gay men who were already involved in research studies in other areas, like hepatitis vaccine, came willingly to research.

In fact, one barely had to recruit at all. They came knocking on the door. And we've come to accept that more or less as a standard of how research is in HIV. And in fact, having to find innovative ways to recruit research subjects is much more akin to our need to find innovative recruitment methods in certain other diseases.

In such a cohort, it will be necessary to get the cooperation of government agencies to nest studies within this prospective epidemiologic study, and there will be considerable competition for funding.

A third point is that research must be linked with clinical care, but not all clinical care will necessarily be linked with research. Attempting to have freestanding research institutions has, from what I have heard in various testimonies and discussion groups as well as many comments made this morning, been very difficult.

Next, enrollment criteria will be standardized as much as possible. That's a focus--to standardize enrollment criteria, and to liberalize to the greatest degree enrollment for women, focusing on the woman herself.

To provide access to research and willingness to take part in research as part of the research method, women-specific studies are absolutely essential. Competition for studies is very real, and as Martin Delaney pointed out, that it's not the maleness--I'm quoting from a previous talk where I heard him convey his ideas--it's not the maleness, but who's doing the studies.

Often it's males with large numbers of male patients, and gay white men often "know how to do it". So there may be an enrollment because the person has the first track in. So studies that specifically focus on women are absolutely essential and appropriate, including not just OIs and yeast infection; but anti-virals.

I'm concerned about a potential split between the AIDS clinical trial group and the CPCRA, in sort of a town gown, one university-based and one community-based. And increasing competition for women as all are required to include them as part of their studies, including those by the pharmaceutical industry.

Gynecologic-related research, I think, we all agree with. I won't go into that further.

The re-evaluation of the case definition, I think, is something that we must touch on. But I think that to focus on that exclusively as the means by which people can get disability is to lose the opportunity to put pressure on disability for the sake of being disabled because of various criteria, and there's an obvious mix of the two.

We must focus on opportunistic infections in research and the diseases, in looking ahead to prophylaxis for women, as was mentioned by Dr. Anastos.

Access to care, again, is an important research issue as well as a personal expectation and a right of individuals. We can actually study these issues.

Thank you.

DR. ROGERS: Thank you very much, Dr. Wofsy.

Questions? Mr. Goldman?

MR. GOLDMAN: Thank you.

DR. ROGERS: He knew I was ignoring him the last time, so he wanted to get the first question.

QUESTIONS AND ANSWERS

MR. GOLDMAN: First, I just have a general comment that relates not only to the testimony of this witness, but to the testimony of the earlier witnesses as well. I would urge my colleagues on the Commission to look at the briefing book that was put together by the National Hemophilia Foundation.

There is a section in there, and there is a whole program that's been set up for a women's outreach network of persons affected by hemophilia, and that would include spouses, uninfected spouses of affected individuals, infected spouses of infected individuals, and infected widows of people who have died as well as mothers of children, and all working together in a network providing some of the kind of peer-to-peer self-support and education, both on a local, regional, and national basis, as well as information sharing in terms of research issues as well.

That information is in that briefing book and a rather, pretty good description of it.

I have a question. If I recall correctly, there has been a new women's office set up within the NIH, and my question to you is, is that a good idea--is that good, bad, is it likely to have any impact on any of the issues that you're discussing here, and if that person who--I don't even know if somebody's been named to--has there been an appointee to that--

DR. WOFSY: Yes.

DR. ROGERS: Not yet.

MR. GOLDMAN: There's an acting, but not a permanent. Does anybody know what the NIH position would be on some of the issues that you're discussing here?

DR. WOFSY: I can respond to that. There will be a core committee, which will be one of ten core committees through the ACTG as part of NIAID. It has been set up and voted on by the executive committee. A chair has been named-

-I am the chair--about a week ago, and there is--the committee has not been formed, a core has not met, so a response to all of these questions is not possible per se.

However, the ACTG--the individuals in the ACTG, the executive committee, feels very strongly about the issues of women's research issues, and many of the issues that have been brought up.

I think it is very good. It is a step forward, and I'm enthusiastic about setting up the core committee. What are the reservations? The reservation is the one I started out with, that it is very easy to say, now we have a solution to all of the problems. This one committee now can be sure all of these needs are addressed and met, and obviously no one committee can do that.

But I look at the positive. I think it's very, very important the chair will sit on the executive committee. A very important goal is to make associations with the other committees within the ACTG, to look at women in studies that have already been done, to look at issues of enrollment, and I think as a real priority is to ensure or increase gynecologic-related research. There are very few gynecologists on the ACTG, and focusing on this area, I think, will be a big,

big plus.

MS. JIRAU: I would like to also add that I have been nominated to be on the subcommittee, I think connected with this--with what you're talking about--and I've been invited to attend a meeting to give input on research. And I was very impressed that they listened to me and they encouraged me, by the amount of interest that they had in fixing things. So I think it's a very good step.

MS. BYRNES: Can I just make a clarification?

DR. ROGERS: Ms. Byrnes?

MS. BYRNES: I don't think that's the same committee as you asked--and I just want to make sure. That was what I wanted to ask. That would be a committee of the ACTG within the NIAID?

DR. WOFSY: Yes. Of the ACTG within the NIAID. Oh, I'm glad you clarified if I misheard.

MS. BYRNES: I think Mr. Goldman was asking about the new office of research that is NIH-wide for women?

MR. GOLDMAN: It's NIH-wide.

DR. WOFSY: You will then disregard the previous--

[Laughter.]

DR. ROGERS: We'll take that as a good plug.

MS. MAYS: I'd like to make a couple comments about it, because I think that it does have some positives in the sense that it is really bringing into prominence the issue of women's health.

But I think that what my concern is is that, one, the amount of power that is invested in that particular office to be able to enforce, for instance, things as simple as the issue of the scholarly reasons for the lack of inclusion of women in some of the studies.

I think that also the focus within that group is really on a more biomedical orientation, and what we're asking for is a much more inter-disciplinary focus, particularly for women in terms of the social and cultural issues that will affect their use of services, their access to services, et cetera.

So I think it will, over time, need to be shored up a little bit on the psychosocial end. But I think it's a positive to have it.

MS. LUCEY: Excuse me. I'd like to go back to the definition a little bit. It concerns me, because I am HIV-positive.

When I was tested, it was a nightmare for me. I was six months pregnant, and I didn't fall into the definition, and they didn't treat me properly. I have severe gynecological problems all the time. My doctors don't know how to treat me, because they go by the definition.

We've been collecting signatures. Mr. Larry Kessler has signed on, so has his agency. I'm wondering why, as individuals, you know pretty much we agree that the definition does not include women, period. We all know what's right, and we all know what's wrong.

I'm just curious as to, as individuals, why you haven't signed on? And it's just not ACT UP, because I appreciate you invited us here today and everything, but you know, I mean, we're usually not invited to places, okay?

We're just not the only ones that are doing this signature thing. Other agencies are too. I was down at an STD conference down in San Diego. Dr. Noble did a presentation there. Not once did the word woman come out of that man's mouth. Not once.

We confronted him. He agreed that yes, women should be included in clinical trials. They should not be excluded from clinical trials. But he wouldn't go into the definition.

As individuals, you realize what the problem is. I'm very curious on why, because we're dying. We're not getting diagnosed. We're not getting treated. Our doctors say well, you've had a two-year yeast infection, but it's not considered an OI, so I don't know what to do. You know, you're just going to have to live with it. That's not an appropriate answer for me, because I'm living with the virus.

DR. ROGERS: Ms. Lucey, I know you're suffering on that one. I guess one of the responses would be, there are multiple routes to roam. We are all shooting for the same goals.

We may have different ways of approaching that goal, and I think we should all be respectful of the fact that we're all, in our wisdom or unwisdom, trying to do the right thing on this. Some will be doing it via your petition, some will be doing it via other routes.

Other questions? Yes.

MS. DIAZ: I have two brief questions for Dr. Mays. You touched on an area that I feel has not been researched by too many people I know. I know there's a little bit of work going on in a DAT in New York under Yolanda Sarano, but you mentioned that some individuals, particularly within the minority communities may be having traditional and non-traditional systems of care, particularly in L.A., I know we feel it, because of the number probably you've run into in your studies that get parallel care either in Mexico and here also.

I'd like you to comment a little bit about that, and whether you know if any research is showing how two systems of care, traditional and non-traditional, or outside of this country, non-mainstream, can be brought together and looked at in some research module.

And the other thing I wanted, which I don't think too many of the speakers have even mentioned, is any findings that you're running into in terms of lesbians of communities of color, because I know that is probably part of your cohort?

MS. MAYS: In terms of the first question, that's one of the things that we attempt to encourage the--it's one of the current projects, for instance, that are up and running, to really expand their notion of what parallel care is.

I think in terms of some of the early studies with gay men, we clearly have some ideas about some of the other drugs that have been gotten from other countries, some of the kind of home remedies that have been used, because we see those talked about quite often in the newsletters.

But we don't have that same amount of information often with our investigators about the cultural and kind of home remedies that are often used among ethnic minorities, particularly when we're talking about things like treatment of STDs with migrant workers, and maybe using kerosene, and using just a variety of different things to treat diseases, things that we will take in terms of trying to cure ourselves of what may be symptoms that are HIV-related.

There aren't a lot of studies right now that do that, because there aren't a lot of studies with large numbers of ethnic minorities in them.

In terms of your second question, I have a national data set on black lesbians, and we have a little bit of health data in it. And we're just starting now, as we also have our black gay men's data set, to look across the board at some of these issues.

What you will find is that some of the--when you categorize the data as we do with women, a large number of black lesbians have also been heterosexual. So if you look at what the cause is in terms of HIV-related disease, it often will appear under a heterosexual context.

I mean, I can only push and advocate and strongly support those calls that ask us to ask women questions about whether or not they're currently having sex with other women, whether or not they have had sex with other women, because I think that this traditional surveillance and epidemiologic orientation causes us to lose this valuable piece of information.

DR. ROGERS: Mr. Dalton?

MR. DALTON: To speak to Ms. Lucey, I in fact have signed the endorsement, not as an individual, it didn't occur to me that my name would be of much use, but on behalf of an African-American AIDS organization, which struck me as more useful. I did not simply copy the draft letter to Dr. Curran, however. I thought the letter--I did not like the language of the letter, but I wrote one of my own.

I have a question that involves no letters, so maybe I will understand it. It's a question for Drs. Mays and Wofsy, but it's really generated by the testimony of the other two witnesses.

With respect to woman-to-woman transmission, what would it take for there to be more research in that area?

Your last comment, I think, had to do with epidemiological biases, but in terms of actual research on transmission, why doesn't that happen? What has to happen to make it happen?

And the second question, just as you suggested, Dr. Wofsy, that clinical trials research should be linked to provision of primary care, what about the suggestion made by Ms. Jirau that clinical trials should also be linked to the provision of psychosocial support?

It seems to me that an argument could be made that if you want to have decent data, you want to have women or anyone else, in fact, participating in programs and taking the drug they're supposed to rather than switching around and rather than dropping in and out. You're going to get cleaner, better data if in fact you help people sort out their lives.

DR. WOFSY: Did you want me to address both of the issues, or--? Well, you started out with the issue of female-female research, and I'll make my observation. In any such research effort, one usually has to start with a cohort.

And I think that just as research into women's issues in general got off to a slow start because there was ten here, four there, six there, and the person who was taking care of each of those people didn't know each other to make an initial collaboration, the same thing may well be true of HIV-infected lesbian women.

So that getting a cohort together might constitute an initial significant problem. Most studies now are trying to take advantage of comparisons between the infected group or whatever and a control group, and finding the proper control group might be a difficulty. It may make too many cells to have infected women and non-infected women and infected women who are IV drug users compared to non-infected who are non-IV drug users--those are obstacles.

The issue, nonetheless, is extremely important, and maybe I can just turn to you for observations on the same subject, then we'll go back to the other question.

MS. MAYS: I would agree. I think that also a big issue is the tensions and the conflicts about the allocation of resources. I think if you were to go into the community and you were to say that you had a solely lesbian study, and that you had X-amount of money allocated to it, in reality I will tell you there will be some very harsh questions asked about that.

I think in general this issue of tensions has to be addressed in order for us to really be able to expand our research efforts in the directions that they need to go. I think that everyone should have reasonable access to all the research that we're setting up, and I clearly believe that lesbians should.

DR. ROGERS: I know you have--make the answer brief, please, because we've got to wrap up pretty soon.

DR. WOFSY: Okay. The question was research and all aspects, not just clinical care, but other support services. I think that research--it's important to include that to some degree, but the importance of having the other support services linked is because it ends up being multiple, then, diagrams of resources, services, and needs. And duplication isn't probably the best allocation of money.

I grant you I'm speaking in the ideal. But in the ideal, they're linked, in the ideal. And the research happens here. It overlaps with clinical care. It then feeds out to the different needs. That's the ideal--that's how I would construct the ideal.

DR. ROGERS: Thank you. Mr. Kessler--last question.

MR. KESSLER: This is for Dr. Wofsy. An earlier representor gave us a hint that you were going to tell us about your Marlboro man theory--

[Laughter.]

DR. WOFSY: Oh.

MR. KESSLER: --and I didn't want you to get out of here without sharing it.

DR. WOFSY: Yes. I have a--

DR. ROGERS: Thank you, Larry.

MR. KESSLER: Yes.

DR. WOFSY: The ad--why aren't we gearing things to men. I have a slide that I've made up in which I take a man in one of the ads for cigarettes who is eying a woman in a way that makes it very clear where they're headed, and I've put a little balloon over his head as if he's thinking and it says, thank goodness I have a Trojan.

[Laughter.]

DR. WOFSY: And the idea is that in some male stereotype of ultimate maleness, that this kind of insidious insinuation of the fact that the man might sort of automatically have in the back of his mind, as he notices the attractive woman, that maleness and condoms go together, not because there's a great big gross statement about it, but just these little subtle innuendoes. That's what she was referring to.

DR. ROGERS: Thank you all very much. It's a privilege to listen to you.

We have invited some public comments, and we have two people who have asked to speak. We have in the past, and will continue with this practice, we would ask you to confine your remarks to about three minutes, which doesn't give you very much time, but I think you've been forewarned on that.

I think we have Paul Daniels and Madrid St. Angelo. Mr. Daniels?

STATEMENT OF MR. PAUL DANIELS

MR. DANIELS: I'm Paul Daniels, and I'm from ACT UP, Los Angeles. I know you all know about us. I have a compilation here of my notes, and so I've tried to put it together into a tight three minutes.

In listening to earlier testimony, it's plain to me we have many, many battles ahead of us. There are many monsters on the path home. We must circumvent society's biased view of HIV disease.

This Commission has some power to do so, and we know national commissions also have a lot of things to say, but they don't get listened to very often, and we wish you would be listened to much more. But we have to fight. And we have to find ways to have you to be listened to.

Society at large seems to have respect for the written word and the words of a national commission. Now, how does the commission get that same respect from the President of the United States?

If we know that the percentage of HIV cases will quadruple by the end of 1992, and will continue to grow, where is there no project similar to the Manhattan Project to deal with this epidemic? Is it simply that we have a racist, sexist, and homophobic President and Congress, who believes that the HIV-impacted deserve this?

It appears the Commission has enough facts to back up the needs for major funding for AIDS programs, for education, research, and treatment. The Commission has to find a way to sell this to the President and Congress.

Now in Los Angeles, where I'm from, in Hollywood, which is the home of the entertainment industry, much of the focus is how to sell a product to the public. We've got to find a way to sell AIDS and all its gory facts to the public and elected officials and get this show on the road.

Why are women neglected so horribly? If we can document the growth of HIV in the women's community, why are the facts being ignored? Why does the CDC refuse to expand the definition of AIDS for women? Why are women considered breeders first, and the fetus is given priority over the women?

These questions, of course, have answers. I don't think the why is as important as the facts. Women are ignored in this crisis. If this huge population is ignored, what does that say about the priorities of our elected officials, and how can we change this?

ACT UP demands the CDC expand the definition of AIDS regarding women. We have given you all the necessary information in our packet, and we of course request that you please sign on to this, because your names will all have a great influence on the CDC's acceptance of this. Give this back to us if you can while we're here, or mail it to us. We would appreciate that greatly.

In San Francisco, at the sixth annual AIDS conference last May, ten documented cases of AIDS in lesbians were reported. Research is needed to document women-to-women's transmission. Dr. Ehrhardt mentioned this need also.

Also, there are no studies regarding AZT and women's hormonal cycles. Women are blasted during certain cycles, and AZT is just--runs them through the wringer, and they feel like shit almost all the time. This has got to be dealt with.

The psyche of a woman dealing with HIV disease and tons of stress is no laughing matter, and cannot be ignored any longer.

So that's all I have to say on that, except are we going to allow the women's community to die the same agonizing deaths we've seen so many gay men die? Something must be done about this now.

Now, that's my comment. Now I have a question I need to ask you. I would like to know what "Commission Business" means on tomorrow's agenda, and if this business is pertinent to the AIDS-impacted community, I feel we should be offered the opportunity to attend with you all.

DR. OSBORN: All meetings of the Commission are open.

MR. DANIELS: Oh they are? Great. Thank you very much.

[Laughter.]

DR. ROGERS: Thank you, Mr. Daniels. We're now going to hear from Madrid St. Angelo.

STATEMENT OF MR. MADRID ST. ANGELO

MR. ST. ANGELO: My name is Madrid St. Angelo, and I'm from ACT UP, Denver. I first of all wanted to thank the Commission very much for coming to Denver and for being inclusive of ACT UP in the hearings today in the testimonies.

A couple of points, one of the points being something that Paul just touched on. I think there is very little, if any at all, research being done on the way HIV infection in and of itself affects the woman's hormonal system.

I have a very good friend of mine in L.A. who was diagnosed with HIV about six years ago, and she has maintained a stable T-cell count for the last six years, and only recently has had her T-cell count go down. And her doctor wound up putting her on AZT therapy.

As a result of that, she has experienced extreme mood swings and depression and various other upsettings of her hormonal system, and I think that more research needs to be done on the way HIV infection infects the hormonal systems of women, as well as anti-virals like AZT, they way they infect the hormonal system as well.

Also, I wanted to thank Mr. Dalton for bringing up the ideas and the facts about questions pertaining to women-to-women transmission of HIV infection. And something that we've heard a great deal about today is the use of safer sex practices and condom use.

One thing that wasn't addressed was in women-to-women transmission, the use of dental dams and the way women go about protecting one another from HIV infection. I think that more research needs to be done in looking into various modes of safer sex protections for women who are involved in women-to-women sexual contact.

Finally, I just wanted to say I'm 24 years old, and as a youth who has spent just about his entire youth under this very depressing and dark cloud of AIDS, there have also been some very empowering things that I have been able to learn and discover about myself and my life.

I would like to say that in sitting here today and hearing the testimonies of several women with AIDS and various members of the medical establishment and education institutions, we've been fighting and begging for more and more education since the very beginning of this epidemic.

My hope is that--I really do wonder if there were people in power, if the President of the United States was here today hearing the testimonies of these women, how would this man feel? Would he be affected and moved, and filled with courage to go out and address this publicly in a way that demands all of us taking responsibility for our own lives?

My request to the Commission is that, I realize all of you will go back and put together your report and pass that on to Congress. My request is that each of you do take to heart very seriously all of the testimonies and recommendations made today and beyond going ahead and compiling your report, remain actively involved in challenging AIDS and hopefully one day, we will be able to address this as an epidemic that affects each and every one of us.

It's touched me greatly, I hope all of you, and I'm sure all of you have been touched in some way. And we all must, in our own way, act up and fight back. Thank you.

DR. ROGERS: Thank you, Mr. St. Angelo. I'm going to let our distinguished Chair of the Commission close this session.

DR. OSBORN: I want to thank the people who have come and spent time with us and shared your thoughts with us. I think in the very well put last statement, I can assure you that we do share the intensity, to the extent that we possibly can, of your commitment and hope that we can find ways to recognize and express the universality of the importance of these issues that we're hearing about.

I'm very, as I said earlier, very sorry that I missed the morning's session, partly because I was trying to express that on national TV. But in fact, I think that from what I know of this morning, it was an exceptionally powerful set of presentations, and one that we will try to capture in ways that we can communicate to the Congress, to the extent possible to the executive leaders of the government, and do our best to carry through.

So we appreciate the inspiration that you've given us as well as the information and the suggestions. I think with that, we will quit for today. But thank you very much.

DR. ROGERS: Thank you all.

[Whereupon, at 4:25 p.m, the proceedings were adjourned, to reconvene at 8:00 a.m. on Thursday, June 6, 1991.]