
Forum on HIV/AIDS Issues

*“Testimony from individuals and groups with knowledge about
HIV/AIDS issues affecting the residents of New Jersey”*

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Trenton, New Jersey

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HIV/AIDS FORUM SPONSORS:

Assemblywoman Bonnie Watson Coleman
Assemblywoman Loretta Weinberg
Assemblywoman Mary T. Previtte



ALSO PRESENT:

Meredith L. Schalick
Assembly Majority Office

***Hearing Recorded and Transcribed by
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ASSEMBLYWOMAN BONNIE WATSON COLEMAN: Good evening. We'd like to get started.

I'd like to first introduce you to my colleagues, who are here with me: Assemblywoman Loretta Weinberg and Assemblywoman Mary Previte. I am Assemblywoman Bonnie Watson Coleman from the 15th District.

We represent an interesting lot here tonight. We represent the Appropriations Committee; the Health and Human Services Committee; and Family, Women and Children's Services. So we hope that what you have here are three sets of listening ears -- along with the Department of Health and Senior Services -- that could, potentially, result in some reorientation, some readjustment, some prioritization, certainly, some sharing of information, and, hopefully, informed decisions made from that.

Anyone who wishes to testify this evening, we really do need you to fill out one of these (indicating sign-in sheets) and give it to our staff person here, Meredith Schalick. We are going to ask, with the exception of one person -- I'm going to define that a little bit more -- we're going to ask that you give us a copy of your testimony and take no more than three minutes, or so, to summarize your testimony for us. We will then review the testimony, and hopefully, you will hear something from us in the near future with regard to what we've learned, here, this evening.

We are really pleased to see you on this Monday evening. We believe that this is a really important undertaking here. That while we are definitely making strides in medicines and opportunities for people who have HIV/AIDS infection to live longer, live better quality of life, there are certainly, still, tremendous challenges before us, not the least of which is the fact that

there is a disproportionate growth and impact of this disease in the communities of color, particularly African-American and Latino communities, and particularly among women. And then there is a serious threat to our children -- the African-American community who represent a disproportionate representation of AIDS victims.

So we come here this evening hoping to give you an opportunity to discuss whatever it is that is important to you -- be it youth or adults or housing or transportation or access to protocols or whatever it is -- so that we might, as members of the Legislature, be more fully informed and equipped with information -- that we would be able to impact policy decisions that will, obviously, do better things, do better things as it relates to this community of need.

I'd like to start this evening with the Assistant Commissioner from the Department of Health and Senior Services, with a particular emphasis on HIV/AIDS, Mr. Larry Ganges. Since I believe that it is vitally important for the information that he is going to share with us, I have asked-- I'm going to indulge him. And, if he needs more than three minutes, as a Committee, we have decided that we will be able to grant that.

So, I thank you, and, Commissioner, I ask you to come forward and testify.

If your red light is on -- you push your button, your red light is on, that means that the microphone is on. (referring to PA microphone)

ASSEMBLYWOMAN WEINBERG: As opposed to a green light in every other facet of life.

ASSEMBLYWOMAN WATSON COLEMAN: In every other facet, right.

ASSEMBLYWOMAN PREVITE: Is this being recorded?

ASSEMBLYWOMAN WATSON COLEMAN: Yes.

ASST. COMMISSIONER LAWRENCE E. GANGES:
Thank you, Assemblywoman. Good evening.

ASSEMBLYWOMAN WATSON COLEMAN: Good evening.

ASSISTANT COMMISSIONER GANGES: Just over 20 years ago, we began hearing about this strange new virus that was, primarily, infecting young, gay men in various areas across America. The ripples of infection cascaded throughout segments of our population, and this unknown virus took center stage as people quickly became very sick and, tragically, died. Yes, HIV was born. And as it evolved into a major public health phenomenon, it struggled to become a part of the daily agenda of most Americans, despite this devastation.

We forget that before there was AZT, protease inhibitors, and other legions of life-sustaining medications, AIDS patients had little offered to them except hope. But hope gave birth to motivation, movement, and then action, and, on various levels, a concerted response of funding and subsequent programming occurred. This was coupled by spurts of media coverage, which gave the HIV issue a viable platform to convey its message.

New Jersey was particularly impacted by HIV, largely due to high transmission rates driven by the sharing of contaminated needles by injecting drug users. In the late 1980s and the early 1990s, blinded studies in selected drug treatment centers reported sera-prevalence rates of over 60 percent

among injecting drug users. Through collaborative and strategic planning, funding partnerships, and programmatic cooperation, a comprehensive network of HIV service delivery emerged and continues to evolve to address the changing demands of the epidemic.

To date, the State Division of AIDS Prevention and Control provides the following: A network of over 300 health-care settings where HIV counseling and testing is provided free of charge. This network tests over 65,000 New Jerseyans each year. We also have a network of 12 geographically accessible early intervention programs where state-of-the-art, primary medical care is provided to an estimated 12,000 HIV-infected individuals yearly. We have the AIDS Drug Distribution Program, or ADDP, which provides life-sustaining medications to over 5,000 HIV infected individuals, annually, at no charge.

We provide rental and housing assistance to over 650 HIV individuals. We have a network of over 50 HIV prevention programs that provide education, risk reduction, and prevention case management, and referral and linkages to services. We have a network of intensive outreach programs to identify and bring into care those who are either infected with, or at risk for, HIV. We have an insurance continuation program that provides insurance payments for eligible HIV infected individuals. We also have a variety of support and ancillary services through funding relationships with AIDS service organizations and a network of community-based organizations. In our prisons, we have a network of comprehensive services in 12 of the largest correctional facilities throughout the state.

With all these services, I can tell you, here, today that there is good news. Things have gotten better. The overall death rate is down for everybody. Being HIV is no longer the death sentence it was in the 1980s. People do live longer and maintain a higher quality of life. The disease is much more manageable now. Perinatal infection has been reduced to less than 5 percent. Prevention works. This good news, however, is tempered by some very disturbing and chronic realities.

While the death rate has dropped for all population groups, including African-Americans, the death rate for African-Americans is still higher than it ever was for their white counterparts. While African-Americans comprise 13 percent of the State population, they make up 52 percent of all people living with HIV/AIDS. They make up 64 percent of all women living with HIV and AIDS. And very disturbingly, they make up 73 percent of all children living with HIV/AIDS. New Jersey, also, has the highest proportion of women living with HIV and AIDS, by the end of 1999, and again, the majority of which are African-American. While one out of every 850 white New Jerseyans is living with HIV and AIDS, the rate for African-Americans is one out of every 66. The rate for Latinos is one out of every 184.

There remains almost a passive acceptance to HIV as people, especially our young people, still engage in risky behaviors and people tend to get tested later in their infections. Access to and consistent participation and care remains a major challenge. We still need to identify individuals earlier in their infection. We must, absolutely, prevent new infections. We need to assure that infected individuals utilize services that are nearby and free and

available to them. So you may ask the question: Given all those challenges, Larry, what are we doing about it?

Well, I think one of the things that we really need to do is -- I believe, as public health professionals, we've been, to a certain degree, looking at the selling, if you will, of HIV a little incorrectly. I think, as public health professionals, we assume that everybody knows and feels and believes everything we know, feel, and believe. That is not true. So we are looking at and currently implementing a revised social marketing campaign, and that is really selling HIV as a product the way somebody would sell shoes on a television commercial. We are looking at trying to get individuals to buy into buying a concept, and the product is HIV awareness, HIV education, the need for HIV prevention, to get tested for HIV, and if you are infected, to access and remain in care.

One of the primary methods that we're using is what we call a community mobilization project, designed, specifically, to deal with the African-American situation, and we call that project, Project IMPACT. IMPACT is an acronym which stands for Intensive Mobilization to Promote AIDS Awareness through Community-based Technologies. We are implementing Project IMPACT in 10 high sera-prevalent cities -- Trenton being one of those. We are implementing Project IMPACT in the city of Trenton right now. We've already accomplished that in Atlantic City. We will soon be moving to Camden, the Newark/East Orange/Irvington area, and then on to Paterson, Jersey City, Elizabeth, and several other cities.

We need to increase our intensive outreach. As much as we'd like to admit, even though we have all these great services out there -- and they are

free -- people sometimes do not come to them. So we have mobilized health vans throughout the state. We have five. We are adding three more, so that we can go where people are.

More comprehensive planning: If you know anything about HIV, everybody is a planner and everybody wants to be in charge of a planning group. We are trying to streamline that process so it's much more comprehensive and less divided, if you will, because we have a prevention field, an intervention field, a counseling and testing field, so forth, and so on. How about a HIV services plan, period, one document?

We need to increase the availability of community-level services, such as drop-in centers, as well as expanded drug treatment capacity. We have several programs where we provide drug treatment free of charge to get individuals to come in and then provide specific HIV counseling and testing and intervention and risk-reduction services for that population.

We also have an open formulary in our AIDS drug distribution program. Whereas before we only had 30 drugs, we have over 200 now. And again, 5,000 individuals benefit from that program. We're also continuing to track and monitor the epidemic and provide information that is used to enhance our programming efforts.

And lastly, we are utilizing new HIV testing technologies to facilitate the identification of new infections and to transition those individuals to care. If you were looking at the papers recently, you know that the Federal government recently approved, through what they call CLIA, a rapid HIV test technology. We are looking at that technology and plan to use it in a number of our sites. Whereas, you would have to wait anywhere from one to two

weeks to get your test results, at most this provides test results in 20 to 60 minutes.

Thank you.

ASSEMBLYWOMAN WATSON COLEMAN: Wow.

Thank you very much.

Any questions or comments?

ASSEMBLYWOMAN WEINBERG: Yes. I do have a couple of questions and one comment.

First of all, you're being--

ASSEMBLYWOMAN WATSON COLEMAN: That we reply just to IMPACT. (laughter)

ASSEMBLYWOMAN WEINBERG: Good.

ASSISTANT COMMISSIONER GANGES: That's a great advertisement.

ASSEMBLYWOMAN WATSON COLEMAN: That's part of your information campaign in the African-American community.

ASSEMBLYWOMAN PREVITE: Oh, that's wonderful.

ASSEMBLYWOMAN WATSON COLEMAN: Yes.

ASSISTANT COMMISSIONER GANGES: Yes. Completely unsolicited.

ASSEMBLYWOMAN WATSON COLEMAN: Thank you.

ASSEMBLYWOMAN WEINBERG: Let me just -- a moment -- and say that the idea of this AIDS hearing was put forth by our colleague, here, Assemblywoman Bonnie Watson Coleman, who, as you know, chairs the

Appropriations Committee. I'm glad that she, kind of, nagged us into this to make sure that we got this on the schedule, in an appropriate time schedule.

I have one question to ask you. You said perinatal infection has been reduced to less than 5 percent. Five percent of what?

ASSISTANT COMMISSIONER GANGES: Well, it's 5 percent of the total number of women that provide birth. It was 24 percent about six to seven years ago. We have a policy in the State of New Jersey that's, basically, called mandatory counseling and voluntary testing. So, when a pregnant woman is engaged by the physician, he or she has to provide counseling to the individual, and that's been very beneficial in reducing that rate from 24 percent, or maybe even 26 percent, down to 5 percent of the--

ASSEMBLYWOMAN WEINBERG: But it's 5 percent of all births?

ASSISTANT COMMISSIONER GANGES: Yes.

ASSEMBLYWOMAN WEINBERG: It's still a pretty high percentage, but--

ASSISTANT COMMISSIONER GANGES: It's still pretty high.

ASSEMBLYWOMAN WEINBERG: --lower than--

Okay. Another comment, perhaps, but I think the idea that things have gotten better, in some way, has been also a negative, because people-- There seems to be some general feeling, now, particularly among the younger population that are always, kind of, living on the edge, anyway, that AIDS is something that is manageable. You take a couple of pills and you'll be fine. I think that is something that we have to address, that it is not so manageable that one takes two aspirin in the morning and then manages the illness. I

think that there is a growing misconception, because of the lack of information, that we've done so well with this disease that one no longer needs to fear it. I think that is another public relations campaign that really needs to be undertaken.

ASSISTANT COMMISSIONER GANGES: I agree with you, Assemblywoman. I think, by conveying the message that it's a chronic manageable disease -- I agree with you completely -- we've taken the fear out of it. You don't have to be a wizard to take a look at these stats to understand that we are, really, still in trouble. I'd rather have people scared than complacent.

ASSEMBLYWOMAN WATSON COLEMAN: Thank you.
Assemblywoman.

ASSEMBLYWOMAN PREVITE: My only question is: The figure on perinatal deaths, is that 5 percent of all births of mothers who have AIDS?

ASSISTANT COMMISSIONER GANGES: Yes. Yes.

ASSEMBLYWOMAN PREVITE: Not of the 5 percent of all births.

ASSISTANT COMMISSIONER GANGES: Not of total births. Right. Not of total births, yes.

ASSEMBLYWOMAN WATSON COLEMAN: I just have two quick questions. Number one is that -- some information that I read that there still is a disproportionate impact in AIDS in the Latino community, not to the same degree that it is in our community, and I'm wondering if any of the, sort of, programs that you have in the major cities is translated into language and in message that resonates with the Latino community.

ASSISTANT COMMISSIONER GANGES: Everything is translated into Spanish, from our informed consent forms that patients have to read and understand when they go into one of our counseling and testing programs. We also have a similar social marketing campaign for the Latino community that we are doing in the northern part of the state, and that's going to come down to the central, as well as for the southern part of the state.

ASSEMBLYWOMAN WATSON COLEMAN: And then the other question I have is that a good proportion of our HIV/AIDS infection is related to the use of drugs, intravenous drugs. I'm wondering what, if anything, is the Department doing as it relates to either. We have several different kinds of legislation available. One is, I believe, recently introduced that would just allow you to get a syringe without a prescription. There are some other, sort of, programs that have been, legislatively, introduced that would provide programs on a very limited basis, access to clean needles. To what extent is this being considered in the Department? Is this part of your, sort of, campaign, your methodology, your response to the disease and its impact on the communities?

ASSISTANT COMMISSIONER GANGES: Well, as you said, it's a very prominent problem. Fifty-three percent of the transmission that's caused by HIV in this state is due to injection drug use and IDU's sharing contaminated needles. So, clearly, anything that would interrupt that process, this Department is clearly in favor of. So there are several initiatives that are being discussed that would, in fact, interrupt that process. We are, certainly, available to work with whatever those initiatives will be, to pursue them and see them to their fruition.

ASSEMBLYWOMAN WATSON COLEMAN: Thank you very much.

ASSEMBLYWOMAN WEINBERG: Assemblywoman, you just made me think of something else. The Governor has supported a needle-exchange program, if it were hospital-based. I think that's actually something that the Health Department could help us with by coming up with a program that we might be able to enact legislatively, that is a hospital-based needle-exchange program, but still answers the problems of getting this into the communities.

ASSISTANT COMMISSIONER GANGES: Yes, it would. It would answer that question and respond to a great need.

ASSEMBLYWOMAN WATSON COLEMAN: Actually, I have one last question for you. In a recent public forum on HIV/AIDS in our community, there was discussion-- No, it was your conference, actually, down in Atlantic City. What was raised was that there are certain behaviors that are not being addressed and there's, sort of, an education forum -- same sex relationships, not as it relates to men, but as it relates to women. I'm wondering, what if, any, of your campaigns now have seen fit to address, sort of, a heightened education awareness campaign as it relates to those relationships and the impact of unprotected sex among women.

ASSISTANT COMMISSIONER GANGES: Excuse me, we clearly need to do that better. One of the things that we are attempting to do is to take a full look at the entire gamut of behavior, in terms of what is going on here. We, clearly, will address that. As a matter of fact, before this hearing got started, a friend of mine in the audience said something to me about the types

of things that this Department needs to address, and we will move forward in terms of doing that.

ASSEMBLYWOMAN WATSON COLEMAN: Thank you. Thank you very much, Commissioner.

ASSISTANT COMMISSIONER GANGES: Thank you.

ASSEMBLYWOMAN WATSON COLEMAN: Ms. Susan Wilson, Network for Family Life Education, Rutgers University.

If anyone walked in after the announcement, if you wish to testify before the Committee, please get one of these forms, fill it out, and hand it in to Miss Schalick. Thank you.

It's good to see you.

S U S A N N. W I L S O N: Nice to see you, too.

ASSEMBLYWOMAN WATSON COLEMAN: Thanks for coming.

If your light is red -- if you pushed the button and your light is red, you're on.

MS. WILSON: Okay, good.

Thank you very much, Assemblywomen Bonnie Watson Coleman, Loretta Weinberg, and Mary Previte, for hearing my testimony.

I have worked in the field of sexuality education, Family Life Education, HIV/AIDS education for about 20 years. I'm here today because I am very concerned about primary prevention of HIV in the public schools.

I was very glad to see that you really wanted to hear about education and prevention among young people. New Jersey, for almost a decade, has really been considered a leader in providing young people with

honest, medically accurate, balanced education about HIV and AIDS. When I say balanced, I mean information and skills so they can make good decisions about being abstinent, but also providing them with backup information, about condoms -- certainly about the healthy, beneficial aspect of using condoms.

So everything was going along very well until the passage, last year, of Assembly Bill No. 792, Senate Bill No. 868, which is called the HIV/AIDS Prevention Act. The Legislature passed that bill, and Acting Governor DiFrancesco signed it into law. It is Public Law 2001, c. 303, it “requires public school sex education and AIDS education programs to stress abstinence,” but it makes no reference to including information about the medically accurate, healthy benefits of using condoms to guard against the transmission of sexually transmitted infection and HIV. The law says it’s perfectly all right to tell young people about the negative aspects of using condoms, but it is silent upon providing our youth with positive, medically accurate information about condoms.

I believe that withholding truth from young people turns public health information on its head and endangers their lives. The law, which seemingly is innocuous, when you first looked at it, requires constant reiteration of abstinence and requires all speakers, audio-visuals, or printed materials to stress abstinence, as well. Besides telling teachers what and how to teach, the law requires the purchase of certain materials, many of which either censor information about condoms or gives inaccurate facts about them.

There is a remedy to this law that I want to just talk about briefly to you, and that is a law that was introduced by Assemblyman Reed Gusciora. It’s Assembly Bill No. 2272. He introduced it last May. This bill would

require each board of education to offer instruction in comprehensive family life education. As described in the bill, “comprehensive family life education means education on family planning and sexually transmitted disease that is medically accurate and age appropriate; promotes responsible sexual behavior and addresses both abstinence and the use of contraception.” Assembly Bill No. 2272 would repeal P.L. 2001, c. 303. I urge you to look at it and to consider its passage.

I know all three of you oppose the stress-abstinence bill, and I really want to commend you for that. But I think I really sense that there are school districts all over this state that are going to feel that they have to comply with this law and are going to really endanger young people. I’m particularly concerned about young people in urban areas, who I think need all the information they can get, not just some of the information.

I realize that this is -- would pose a major battle to get involved with this subject again, but from what I sense is going on in the districts, I really worry for our young people. I think all of you worry for them, too. So I ask that you give some consideration about trying to repeal what I think is, really, a very dangerous piece of legislation and would really hurt young people when it is implemented.

Thank you.

ASSEMBLYWOMAN WATSON COLEMAN: Thank you very much.

Any questions or comments? (no response)

Thank you very much.

Dr. Terry Zealand, AIDS Resource Foundation for Children.

Thank you, Doctor. Welcome.

TERRANCE P. ZEALAND, Ed.D.: Thank you.

My name is Terrance Zealand. I am Executive Director of the AIDS Resource Foundation for Children, Incorporated. Fifteen years ago, my wife and I opened the first home for children with AIDS in the country in Elizabeth, New Jersey. We now operate three homes for children who have AIDS or who are medically fragile: St. Clare's in Elizabeth, Jersey City, and Neptune. We have cared for over 600 babies in our three homes. Our agency has also renovated 40 scattered-site housing units in Newark, Irvington, and East Orange for families with AIDS.

I am currently the Acting Chairman of the Governor's Advisory Council on AIDS, and I have served on that council since its inception under former Governor James Florio. I served as the Chair of the Ryan White Planning Council in Newark for two years. I am a member of the National AIDS Committee for the Child Welfare League of America. I have served on two legislative committees that authored the Standby Guardianship Act and also the Kinship Care Act in New Jersey. I have a lot to say regarding AIDS and what should be done in New Jersey to stop the spread of the virus and improve care and treatment.

Most of what I want this forum to hear today is written in the Governor's Advisory Council on AIDS transition report 2002-2003. I have given you a draft of this report. It is yet to be published. There is a graph that is not drawn properly, and there are some typographical errors that is holding up final publication. But I thought it important that the members of this forum have a copy and review it.

Some of the highlights in this report are the availability of syringes. Syringe exchange programs is recommended by the majority of the council. Also, we would like to echo the words of Suzie Wilson that we should have condom availability and knowledge in the high schools.

We also need to have-- The report talks about the need to allow adolescents to be tested without parental consent for HIV. The report also talks about kinship care. Governor DiFrancesco signed into law the Kinship Care Act, and authorized -- I'm not sure of the exact dollar figure -- anywhere from \$16 million to \$20 million last year. As to date, only 59 kin are caring for children under this act. I'm not sure why it's taken a year before we implement this most important piece of legislation.

The second issue I'd like to make you aware of: In New Jersey, there are approximately 19,000 children and adolescents who have already lost their parents to HIV. This is a very serious number, something that has to be looked at by the Legislature. What happens to a kid whose mom dies from HIV? They drop out of school, become pregnant, end up in the criminal justice system, end up in gangs, addicted to drugs, and, indeed, at risk for HIV themselves. So I'm asking the Legislature, please, to pay attention to this most vulnerable population. We know what happens in New Jersey if a child falls through the cracks of our social service system. This cannot happen to more and more of the children who feel the impact of AIDS, although they may not be infected themselves.

My particular agency has just initiated a program. In Newark, we purchased a firehouse. It's going to be an after-school program for affected kids. Affected meaning orphaned or moms have HIV. We are currently being

overwhelmed with numbers. We have to limit the membership into the firehouse just because of the number of kids that are seeking such a program. We also need funding for this program.

I understand that the Commissioner, Larry Ganges, is in the audience here. He has been very supportive of this work, as well as many new initiatives, and I look forward to working with him in respect to the development of the firehouse.

The reason New Jersey has so many orphans is because we have so many women who are infected. Thirty-two percent of those that are infected in New Jersey are women. Thirty-two percent that are infected in New Jersey are women, women of child-bearing age. Therefore, AIDS in New Jersey is a families disease. So I wish you would please focus on it during this legislative year and during your budgetary hearings.

The first thing the report mentions, and the most important, is that we need continued support of program services for the care and treatment of HIV. So I really wish that this remains high in the Governor's budget.

Thank you very much for your time.

ASSEMBLYWOMAN WATSON COLEMAN: Thank you very much, Doctor.

Assemblywoman.

ASSEMBLYWOMAN PREVITE: Dr. Zealand.

DR. ZEALAND: Yes.

ASSEMBLYWOMAN PREVITE: We've just become very concerned -- and I know the Assembly has just passed legislation last week that dealt with what happens to a child whose parents are incarcerated, and how

does the court, or how does DYFS, find out about this? Could you explain to me what the process would be if a mother dies of AIDS -- is there any strategy, right now, when some tragedy like this happens, where somehow or other the State becomes involved to make sure that this child has a network of safety?

DR. ZEALAND: That's an excellent question. Absolutely not. What happens when a mother is sick and dying of AIDS and you call DYFS? The response to me and my case managers in the past has been, "Well, is the child being neglected or abused?" I said, "No, not yet, but the mother soon will die leaving three siblings." "Call us when the mother dies." There is no planning. There is no dollars. There's no Ryan White support for these children, because Ryan White dollars come down with a-- The index case of the parent has to have HIV, and if that's not there, they lose their funding.

I do a housing program, scattered-site housing, 40 units. If the parent dies, those kids have to move out, and they're in the care of grandmom. And poor grandmom is overwhelmed. I mentioned earlier the need for kinship care dollars. Sixteen million dollars in the system. There must be an overflow somewhere, because we didn't spend it. Where is the money? Can't we use it now and start getting kin, grandmothers, dollars to support these kids?

I just was asked by the *Star-Ledger* last week, "What's happening with foster care in New Jersey?" I said, "Well, foster care is in trouble, but we need kinship care as well." Kinship care is help supporting a grandmom to take care of the kids. Sibling groups. It's very difficult to place sibling groups into foster care. So we have to do planning.

I know that the Commissioner of Human Services will be very sensitive to this, once she's become more aware of it.

ASSEMBLYWOMAN PREVITE: Well, you gave us a figure that only 59 families had taken advantage of kinship care.

DR. ZEALAND: Fifty-nine, yes.

ASSEMBLYWOMAN PREVITE: Do you mean 59 families with AIDS or just--

DR. ZEALAND: No, across the board -- incarcerated, death to cancer--

ASSEMBLYWOMAN PREVITE: I cannot believe it.

DR. ZEALAND: I can't either. Well, I know it's a big system. And when you try to get a system started, it takes time. But the Legislature did pass-- It started at \$20 million. I know two court judges were hired at \$700,000 for their staff and all, but I'm not sure what the resulting figure was for kinship care in Governor McGreevey's first budget, but 59 kinship caregivers is certainly not enough with anywhere from \$16 million.

ASSEMBLYWOMAN PREVITE: Is it an education issue to get the word out that this is available?

DR. ZEALAND: I think it's a -- certainly an education-- It's a bureaucratic issue. Kinship care -- and this is a means-tested program. We're asking to pay for poor grandmothers, give them support, not the wealthy. It's not a give-away program. I'm not sure, but I hope the Governor's Advisory Council, certainly will-- I will still be on the Council, I believe, next year, and if I am, I would like to have the Council focus on this, as well.

Kinship care is a very important piece of legislation. If it's going to help these kids, it keeps the kids out of the DYFS system, and it has to be implemented.

ASSEMBLYWOMAN WATSON COLEMAN: Thank you very much, Dr. Zealand.

Any more questions? (no response)

Thank you very much.

DR. ZEALAND: Thank you very much for having this forum.

ASSEMBLYWOMAN WATSON COLEMAN: Axel Torres Marrero, Director of Public Policy, Hyacinth AIDS Foundation.

AXEL TORRES MARRERO: I was going to say good morning, until I realized it was after 5:00, so good evening. I thought I was going to speak last since I came here a little late. So everyone else will probably have to repeat some of the same points, instead of vice versa.

But I wanted to start off by saying, from the Department of Health, we've heard in terms of chronic manageable disease, and I absolutely agree with that, and the agency as well, in terms of we're so grateful and hopeful for all the advances that we have made. But I want to talk a little bit about: what does chronic manageable mean and what does it look like, as a caretaker. Chronic manageable means and looks like someone who is still struggling to stay alive. It means multiple complications. It means having to take, still, time off from work, and constantly, when having to decide whether or not to go out on disability. It means having to take an array of medications that are very difficult to take and come up with toxic side effects. So, although you may be able to live with HIV/AIDS for a couple of years, your liver might give out, or your kidneys, or you may even suffer from high blood pressure or secondary diabetes, so forth, and so on. These are individuals that are still very, very, very sick.

I also wanted to talk about, from the perspective of coming from a particular community, being Latino, that I am 32 years old, and I have very little contemporaries left. That if I look at the individuals that I grew up with, and including those individuals in my family and the ones that I've lost to HIV/AIDS, I'm an individual that has very little contemporaries. The individuals that are now in my life I have met in the last five or six years, and they now form the circle of my friends and family. But I do not have those individuals from the past. They have either died of drug use or AIDS. I think that is something to keep very much in mind. Again, I'm representative of a group that has very little contemporaries, and that is due to AIDS. That is the context that I want to talk about.

So, although the introduction of more effective treatments for HIV/AIDS have -- decreased in AIDS deaths, more people are living with HIV. That's simple. That means that the dollars that we do have now are inappropriate. Infection rates for individuals, like gay men of color, are on the rise. The campaign and the prevention messages of the past have failed. We are still living in a society where gay men of color, in the New York metropolitan area, around 50 percent of them, are infected with HIV. Hudson County and lower Bergen County are part of that New York metropolitan area.

Like the rest of the country, New Jersey continues to search for innovative ways to battle the epidemic. Although progress has been made, New Jersey still ranks fifth in the nation in the number of HIV/AIDS cases and has the highest proportion of women infected with HIV and the highest number of pediatric cases. Those are still our statistics.

The minority populations in the state are the hardest hit in the nation, according to the New Jersey Department of Health and Senior Services, and the CDC statistics concerning health disparities for minorities are daunting. The Department of Health has already talked about, in terms of the impact, that the average interval between diagnosis and death for minorities is four years. One in 20 die within the first month of diagnosis. And then, again, it's because many people access services and health care when it's absolutely too late or upon an AIDS diagnosis, I'm sorry, instead of HIV/AIDS.

I have a five-page testimony, because I work for Riki Jacobs, the Director of Hyacinth AIDS Foundation. So you can reference that with all the specific details. I took a quick look at my colleagues and know what they're going to talk about, so I'm going to let them talk about syringe exchange, which is very important, and some other issues.

I think I'm going to cover, just really quickly, Medicaid, which probably no one here is going to do -- everyone is going to do prevention and so forth, and so on. But, that, it is imperative that our legislators begin to work with Hyacinth and other community-based organizations to provide oversight for our managed health-care program. It's a battle -- in terms of the advisory board and, also, all the committees that work for Medicaid -- with the Office of Managed Health Care. We are the only HIV/AIDS representative. It is very difficult to bring our point across that our legislators should be involved in the oversight, as well. Those programs are currently not meeting the demand. That is unfortunate. We have a health-care crisis in New Jersey.

Today, alone, our physicians went on strike. Are the HMO's going to be solvent in New Jersey? Are they leaving? There's always constant-- Two

already have left from the managed health-care plans that contract with the State. Are more leaving? The way that we deliver health care in this state is absolutely appalling, and we need to be able to change that. But Hyacinth and other organizations cannot do that. Our Legislature has to provide oversight, as well.

And the last point is that it is also the responsibility of our Legislature to bring our voices to the Federal government. The current administration has decreased funding for every single program that has services for people living with HIV and AIDS. It is our responsibility, as a community, which includes the Legislature, to go back and say, "That is not enough, and that is inappropriate."

So I thank you. And again, all of the technical stuff is in the testimony, and I just ask you to review that. If you have any questions, you can give us a call.

Thank you.

ASSEMBLYWOMAN WATSON COLEMAN: Thank you, Mr. Marrero. Do we have your testimony?

MR. MARRERO: Yes.

ASSEMBLYWOMAN WATSON COLEMAN: Thank you very much.

Sharon Herring, Voice to Be Heard, Sister's Connect.

SHARON HERRING: Yes. Someone had raised a question earlier, and you wanted to know what they were doing about -- for pregnant women and prevention and, also, to bring down the number of people that are contracting AIDS from having sexual intercourse and things like that. This

summer I participated in this program. It's New Jersey Women and AIDS Network, and they have the program, here, in Jersey. We went for seven months. And when you've completed it, you receive a certificate like this. (indicating certificate) On the bottom of the certificate, it just said who it's presented to and, "is for completing the Sister's Connect peer treatment and educational program."

Within the program, we had instructors to come in -- nurses, and lawyers, and things. They had one session where a lawyer came in, and they told us questions and things that should be asked and what would be okay and weren't okay. Then we had presentations that were done, where they brought in dildos and condoms, and we were taught how to use them, the effects of them, and stuff like that, because you were asking about it. And as far as the pregnant women are concerned, we had a session where we talked about how many women are becoming pregnant with HIV, how many are receiving medical treatment and stuff like that. The only reason I came up is because you were asking those questions.

Like I was saying, this program is New Jersey Women and AIDS. It's located in Newark. But their only problem is, they don't mind giving the classes and the certificates, it's just that they have problems finding buildings and things that they can do it in. For incentives, they would give you bus passes, a 30-minute phone card, and a \$10 food certificate. Every week you would go to the class, and every time you went to the class you would receive those three things, and, in the end, the certificate. But that's what I wanted to say.

ASSEMBLYWOMAN WATSON COLEMAN: Thank you, Ms. Herring.

Ms. Dawn Day.

D A W N D A Y, Ph.D.: My name is Dawn Day. I'm a sociologist, and I have been studying AIDS prevention for the last six years. I am the author of several publications on HIV and AIDS, including "Health Emergency 2003: The Spread of Drug-Related AIDS and Hepatitis C Among African-Americans and Latinos."

I thank the forum sponsors for giving me an opportunity to speak today. I agree with the forum sponsors that there is an urgent need to do something about the high HIV/AIDS infection rate among African-American women in New Jersey. In New Jersey, as of June 2002, there were 6,600 African-American women living with HIV. The Department of Health and Senior Services could, undoubtedly, give us a more precise figure, but my estimate is that three-quarters of the HIV and AIDS cases among New Jersey's African-American women involved injecting drug use, three-quarters. This would involve either direct infection from an infected needle or indirectly through having sex with an injecting drug user.

It is not surprising that AIDS among women of any racial group would be so highly linked to injecting drug use. True, some women do get HIV through having sex with a bisexual man or a man who does not consider himself bisexual, but who had sex with men while in prison, for example. But by and large, the most common way for a woman to get HIV is through injecting drug use, or having sex with a heterosexual man who injects drugs, or having sex with a man who had sex with a woman who had sex with a man who

had injected drugs. The longer the epidemic goes on, the more diffuse the epidemic is getting in our society. But, nonetheless, we still have this basic fact that three-quarters of those cases among African-American women in New Jersey are drug related.

To deal effectively with the drug-related AIDS epidemic among men and women, New Jersey needs to follow the Council for the Centers for Disease Control and Prevention, the U.S. Government's lead agency on disease control. The CDC says, "For injection drug users who cannot or will not stop injecting drugs, using sterile needles and syringes only once remains the safest, most effective approach for limiting HIV transmission."

Again, according to the CDC, in addition to expanded opportunities for drug treatment, effective prevention efforts for drug-related AIDS needs to include the creation of needle exchange programs, deregulation to permit over-the-counter sale of syringes at pharmacies, and changes in New Jersey's drug paraphernalia law to exclude syringes and related equipment. If we want people not to use infected needles, we have to have them have an opportunity to use sterile needles.

In New Jersey, none of those three policy recommendations from the CDC has been implemented. It is a small wonder that New Jersey's drug-related HIV and AIDS epidemic continues unabated.

ASSEMBLYWOMAN WATSON COLEMAN: Thank you, Dr. Day.

Any questions, comments? (no response)

Thank you.

Is Dr. Crystal Fuller here yet?

CRYSTAL M. FULLER, Ph.D.: Thank you for having me. It's a pleasure to come down from New York to Jersey to report on some of the things that we have going on in New York, and this is actually quite timely.

What I want to talk to you about today, quickly and briefly, is about our Expanded Syringe Access Demonstration program. Before I go into that, and prior to this particular program, we have had syringe exchanges. I think we have up to nine syringe exchanges in New York City now. In one, I believe that it took me upstate -- well, there is one upstate in Buffalo. These have been very successful. However, they've been underfunded because the money has come from the state, and there's a ban on Federal funding. So, with this limited access to syringes, there is a push for legislation to deregulate the prescription requirement.

So, as of January 1, 2001, ESAP -- as I'll refer to -- was enacted and implemented. As long as a pharmacy-- First, let me just tell you who can participate in ESAP. ESAP allowed for nonprescription sale or distribution of syringes, either through pharmacies; through hospitals; or Article 28 facilities, which are, like, treatment or AIDS primary-care facilities. I'm not going to talk about the hospital distribution, but I can, if you have some questions. It really didn't get off the ground. There were several barriers in place, but physicians are allowed to give out nonprescription syringes.

So, mostly, I'll talk quickly about the pharmacy programs. Pharmacists had to register for the program. They could only sell to persons who are over the age of 18. The registration was fairly simple. We were afraid that was going to be a barrier, but it wasn't. In the beginning of the program, the State Department of Health actually did a mass campaign with all of the

chain pharmacies. So all of our chain pharmacies registered for the program. It took a little while for all of the individual stores to become aware that they were registered, but they, in fact, caught on after, probably, about six-to-eight months into the program.

So it resulted in about 60 percent of all pharmacies registered for this program. We had quite a few that were registered in poor neighborhoods and places where drug users tend to be more commonly found. Part of this program mandated an independent evaluation. As a faculty member at Columbia University, I have a strong collaboration with New York Academy of Medicine. The New York Academy of Medicine was named as the lead evaluator, which I coordinated with the center director at the Center for Urban Epidemiologic Studies at the Academy.

We got together with about two other senior researchers or, actually, two other institutions in New York City who had been conducting research among drug users. We combined our data across all of New York City, and we were part of the evaluation mandated that we evaluate seven program outcome areas. One, being needle sharing to see if that were to decrease as a result of increasing access through pharmacies. Two, we were to look at pharmacy practices -- did they register and how did they participate in the program and what were their experiences? Three, disposal practices. Four, substance abuse. Five was accidental needle sticks -- was that going to increase? And the sixth one was crime, to see if there was any increase in drug-related crime as a result of this program. And the seventh was to evaluate education, disposal, and safe injection practices.

On January 15, we were required to submit the following report of this evaluation, which we did. And so, I can just give you the bullet points right off hand. There have been no negative impacts as a result of expanding syringe access through pharmacy sales. There has not been an increase in crime. There has not been an increase in drug-related arrests. There have not been an increase in discarded needles on the streets. We've done several surveys to examine this. There have not been any problems, for the most part, reported by pharmacists.

The other thing that I wanted to say, quickly, is that we are recommending that the legislation remove -- because the law sunsets in March, we're recommending that they remove the sunset and make the law permanent, as well as decrease the limit on syringe sales, because part of the law stated that only 10 syringes could be sold per transaction. We don't know where this magic number 10 came from, but they just felt like 10 should be a limit. It's not very practical, and we're asking for that to be removed. We're also asking that there be more education around the program, because there was a slow start-up in terms of awareness of the program.

That's all I'll say, since I (indiscernible).

ASSEMBLYWOMAN WATSON COLEMAN: Do you have any questions?

Thank you.

ASSEMBLYWOMAN WEINBERG: Dr. Fuller, you said you have nine locations in New York now, or New York City?

DR. FULLER: For syringe exchange programs, yes.

ASSEMBLYWOMAN WEINBERG: And that's where syringes are given out free, the exchange program?

DR. FULLER: Yes.

ASSEMBLYWOMAN WEINBERG: Are any of them hospital-based or--

DR. FULLER: None of them are hospital-based. As far as I know, and across the country, I'm not aware of any hospital-based syringe exchange programs. Tacoma, Washington, was the first legalized syringe exchange program, and that was run out of the Department of Health. But they didn't use the actual office building. They used some of their clinics, and it, actually, was quite successful.

I think, when you put a needle exchange or a syringe exchange program in place, you want to make sure that it's some place that's accessible to drug users, if they're going to feel comfortable using the program. That was something that came up around pharmacy sales. We noticed that there were some groups that didn't feel comfortable going into pharmacies to purchase syringes, and others do. The goal was to have multiple or, at least, more than one mode of access to safe syringes, one being syringe exchange, the other being pharmacy sales.

The good thing about syringe exchange, it's a one-to-one exchange. So there's no money involved. Other programs across the state don't have a one-to-one requirement. You can go in and sometimes they'll give out starters of a couple or two or three. And then they'll go into a one-for-one exchange, and do a one-for-two exchange. So there's a lot of different types of ways that you can do this.

ASSEMBLYWOMAN WEINBERG: Do they have counseling or

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DR. FULLER: Yes.

ASSEMBLYWOMAN WEINBERG: --or health components attached?

DR. FULLER: Right, they do. They are required, by law, to have a preimposed test counseling. There are some really fantastic syringe exchanges, and there's a lot of research out there describing it -- some of the programs that are connected with syringe exchange. Actually, just to give you an idea of something that's being implemented in New York City, I think in the lower -- it's either in Harlem or the Lower East Side syringe exchange program, they're actually trying to administer vaccinations. So there's lots of different-- It's easy access to provide public health care, as well as treatment. We find that many participants of the program do inquire about treatment, and maybe they're not ready the first time they come to the syringe exchange, but we find that, oftentimes, the second or third time they come through there, they're inquiring about treatment.

When the Baltimore syringe exchange program first opened in Baltimore City, they actually had about 10 treatment slots available on demand that was affiliated with their syringe exchange. I'm not sure if they still have that, but that was something that, I think, helped get the law pushed through.

ASSEMBLYWOMAN WEINBERG: And just one other quick question. Do you have any idea how many people are served through the nine programs?

DR. FULLER: It's hard to say. I sit on the board of one of the syringe exchange programs, and I just realized that some of the times these numbers are a little difficult to come up with, because people come in with different names and so forth. This one particular syringe exchange says that they see about 50,000 different people a year, and that's one syringe exchange. This is a very-- I should clarify. That's across two -- they have two sites. They have one in the Bronx and one in Harlem. So combined, they see about 50,000 different people per year, but I have to qualify that.

They told me that it's possible that there are a few duplicates, but not many. Maybe no more than, maybe, 10 percent. I'm not sure in terms of all the sites combined, but there is a report by Ruth Finkelstein, who actually evaluated the nine syringe exchanges, and I can, definitely, get that report to you. It was done in 1999. If I recall, there's somewhere in the neighborhood of, probably, 400,000 to 500,000 syringes exchanged per year.

ASSEMBLYWOMAN WEINBERG: Thank you.

ASSEMBLYWOMAN WATSON COLEMAN: Excuse me, one second. How long is the needle exchange program been in existence?

DR. FULLER: In New York City, I can't tell you that. I'm sorry. I just moved to New York two years ago. I know everything about ESAP, but someone else in the audience may know the answer to that. I want to say that they've been around for at least 10 years. They were one of the first exchanges in the country.

ASSEMBLYWOMAN WATSON COLEMAN: And you said that each exchange is only 10 syringes and how--

DR. FULLER: No.

ASSEMBLYWOMAN WATSON COLEMAN: Each transaction is?

DR. FULLER: For the pharmacy, under ESAP, the new legislation that was just passed.

ASSEMBLYWOMAN WATSON COLEMAN: How often can you go in and do this, then?

DR. FULLER: Go into the pharmacy? That's a good question. You can go in as many times as you like. But early on, when the law was initially passed, a lot of pharmacists thought it was a one time, one transaction per day. But technically, you can go in and buy 10, and you could go in again and buy 10, which, rarely, probably never happens, because drug users tend not to have that kind of money to purchase that many syringes at one time.

ASSEMBLYWOMAN WATSON COLEMAN: Or that much drugs.

Thank you. Thank you very much.

Keith Egan, South Jersey AIDS Alliance.

KEITH EGAN: Good evening.

ASSEMBLYWOMAN WATSON COLEMAN: Good evening.

MR. EGAN: Obviously, my name is Keith Egan. I'm with South Jersey AIDS Alliance. I'm the Executive Director. We are the largest, now, and oldest AIDS service organization in the southeastern part of the state. We currently serve, in some capacity, over 1000 HIV-positive individuals in Atlantic, Cumberland, and Cape May Counties. We, also, serve, literally, thousands more through prevention and education programs in those same areas.

On top of all that, we are also involved in the prison discharge program that Assistant Commissioner Ganges spoke of earlier, and we're in three State prisons in Cumberland County, including the largest prison in the state, South Woods. Generally, we provide a full range of HIV services. I'm not going to go into a laundry list, here, and waste your time, but -- essentially, all of the case management, transportation, food bank, etc., that you'll hear from anybody else.

Tonight, I'm not here, really, so much to provide any lasting, memorable testimony, as to make a couple of comments and a plea. Tonight, you're going to hear numerous points made, either by those people who have gone before me or those people who will come after, and I only ask that you listen to all of these points very carefully, and to what others have to say, and to make sure that you remember that all of those issues that affect the more populated parts of our state that all of these folks so ably serve, also, are just as true in the south.

We have a long history of being known as whiners in the southern part of the state, and if we don't get roads that are as good as the folks up north, we don't get a lot of the services that are up north. One time, people went, laughingly, through a process where they were talking about seceding, and they made a little flag with a star at the bottom. The bottom line is there is, though, a feeling that, very often, because of the rural nature that our part of state has -- boy, that two minutes went by quickly, didn't it -- that we would just like to be remembered.

I'll make my second point within this minute and leave some other things go for my testimony, the written part. We also asked that you please

don't forget the state's, sort of, hidden populations. Primarily, I speak of migrant workers and undocumented immigrants. We have tons of people in our part of the state who come there each year to work in the agricultural areas. Almost all the literature that you see says that, most of the time, when they come into this country, people are relatively unaffected. They come from very poor parts of the world. It doesn't take long for the predators to hit, though, in the camps, and before you know it, they have very high infection rates of HIV. Unfortunately, those folks also bring with them, since they're here in ways that are illegal, they bring people along with them who are not.

So, in Cumberland County alone, each year, you'll have 6,000 migrant workers through the growing season, which is about eight months there, if you count the nurseries, and 4,000 to 7,000 undocumented immigrants. Those are large numbers, when you start to think about very high -- 3 percent, for example-- It's been noted by some researchers, as high as 3 percent infection rates among Mexican immigrants, and most of ours are.

Finally, I ask you to keep in mind that, because we are rural, that we are not unaffected by some of the other ills of the state. For example, one of the ones that we worry about a great deal, right now, is increase in drug use, particularly heroin. A recent study -- in which, I believe, it was Deputy Commissioner DiFerdinando was involved -- mentioned how much faster heroin rates, the use of heroin, has grown in the rural part of the state versus those in urban parts.

So, with that, I will relinquish the seat and ask you to please consider all of my colleagues. Thank you.

ASSEMBLYWOMAN WATSON COLEMAN: Thank you, Mr. Egan. Just a moment.

MR. EGAN: Yes.

ASSEMBLYWOMAN WEINBERG: In terms of the migrant farm workers that you talked about, were becoming infected when they come here?

MR. EGAN: Yes.

ASSEMBLYWOMAN WEINBERG: Is that sexually transmitted, generally?

MR. EGAN: Well, there are several things that happen. One of the things that happens is that these folks come in from very, very poor areas in Mexico -- Oaxaca, Pueblo, that area. I sat on a committee, an ad hoc committee, with the regional Mexican Consulate, out of Philadelphia, in 1998 and 1999. It was on migrant health issues. This was one of the phenomenons that we noted in there when we were having discussions on this, that folks come from areas where they're so poor -- I mean, there's just no money -- you don't really have a lot of the behaviors that lead to HIV. You're just not seeing a lot of-- It's not profitable to sell drugs or be a prostitute in an area where people have no money.

So what happens is that folks get hired to come here, and the first thing you know, they've got money in their pocket. There are predators from -- and this is no reflection on my earlier statement -- the northern part of the state, who come down from Newark and that area, bringing with them drugs and prostitutes. I guess, this week we call these folks who are -- exchange sex for resources. The point is that over time, with shared partners, yes, there is a very high rate that comes from heterosexual transmission. However, there

is also a high rate that comes from IV drug use, because that gets introduced at the same time.

And one of the phenomenons that has also been noted among migrant workers, is that migrant workers share needles for vitamin therapy. The whole notion of sharing needles, that coupled with a very strong machismo ethic that comes with folks from that part of Mexico, leads to a very volatile situation in that population.

ASSEMBLYWOMAN WATSON COLEMAN: Thank you very much, Mr. Egan.

Claire Griffon, Life Network Center, Jersey City.

How are you?

CLAIRE GRIFFIN: Fine. Thank you very much for giving me an opportunity to speak. Basically, I don't have anything that I've prepared or anything like that. I'm, basically, coming as not only a provider of service, but I'm also coming to you as a resident of this State, as a woman, and a woman who is an out lesbian.

There is very little information that you can find that specifically addresses women-to-women transmission. The CDC has been very consistent over the years in minimizing the fact that women do transmit, can transmit, have transmitted the virus to each other through unprotected sex. We really have to understand that women's sexual practices, which are not studied on a national basis -- it is assumed that women's sexuality is determined by their behavior with men. Men are not monolithic in their sexual practices, and that's very much accepted and understood today. However, women's sexual practices are not so understood. It is not even talked about.

As an HIV/AIDS educator, when I am doing workshops and I am talking to women, specifically, about safer sex practices, I often talk to the women with regard to the fact that we do engage in sex with other women, regardless of your sexuality. Okay. Because HIV doesn't have any one specific name on it. It's not who you are, it's what you're doing. We need to really keep in touch with the fact that women need information. Our numbers are growing, and it's not just through heterosexual sex.

If you look at the women's prison system, the number of women who have STDs, of which HIV is just one, is growing. It has been a long-time myth that women in the prison system are not engaging in sex. That's almost hysterical. It is a fact that women are engaging in same-gender sex, regardless of their orientation. Women need information with regard to other STDs, more specifically, information with regard to HPV, trichomoniasis-- I may not be pronouncing these right. I'm a little nervous. Trichomoniasis, bacterial vaginosis-- Glory, my brain is practically frozen, but there are a lot of other STDs -- chlamydia, it's very insidious. When you don't have information-- Some of these STDs don't have symptoms. Some of them don't have symptoms, so we need our medical profession to get really prolific in understanding more about these kinds of STDs, so when women come in, they will have something.

I really would like to see the testing, when it's done with regard to women -- that there be also a standard of care with regard to HPV. It's been known that some women who have been exposed to HPV have also been exposed to HIV, and it's unknown. That needs to be a part of the testing system.

I really thank you so much for this opportunity to speak today.

ASSEMBLYWOMAN WATSON COLEMAN: Thank you very much.

Robin Williams, Princeton, NEXT Campaign.

ROBIN WILLIAMS: Hi. My name is Robin Williams, and I'm here with Nida Parks, and we are both students at Princeton University and are Directors of the NEXT Campaign for Needle Exchange Today, which is a program of the Princeton Justice Project.

We've come today, mostly, to address the emergent nature of the HIV crisis in New Jersey. We are two decades, now, into an HIV/AIDS crisis, and it is not just a health crisis, but it's a health and economic, a political, and a family crisis. Something has to be done. Over the last two decades, programs have been implemented, but more needs to be done, and, especially, in terms of the drug-using community.

New Jersey was one of the first states in the country to register or to have adults who have been infected with a virus -- that we now know as HIV -- because of intravenous drug use. Now we are the most dangerous state in the country for a woman to be infected with HIV. We have one-sixth of the country's AIDS orphans just in this state alone, and women are dying right and left because of using drugs and being infected with HIV -- not the drug use and sleeping-with-men-who-have-been-using HIV.

The number one thing that the State can do to reduce the harmful effects of HIV and the transmission of HIV is to breakdown the barriers to syringe access within the State.

N I D A P A R K S: At this time, New Jersey is one of only six states without needle exchange programs--

ASSEMBLYWOMAN WATSON COLEMAN: Excuse me, can you say your name again.

MS. PARKS: Oh, I'm sorry. I'm Nida Parks. I am also a Princeton University student.

--with syringe access or needle exchange programs. There is, clearly, judging from the rates of infection within women and drug users, and children who have been orphaned because their parents have died, there is a need for widespread support and immediate attention, really, for this issue.

The hospital program proposed by the Governor seems like a start, but as Dr. Fuller actually mentioned before, this really is -- no other needle exchange program exists within the structure, and that's for a reason. It's because it really doesn't work. Drug users are very isolated, and I think the last thing they would probably want to do is use some kind of transportation, get themselves to a hospital, and expose themselves to that type of environment. It just really is, kind of, counterproductive.

So there is a priority now to find a system that does work. Needle exchange programs by themselves are very effective, but they also do need to be combined, as in states such as New York and Connecticut, and Baltimore, with syringe deregulation. Syringes need to be taken off the drug paraphernalia list. I think it's almost shocking to hear, as one of the previous speakers said, that needles are so widely available in states like New York. Drug users and drug use is not increasing in New York. In fact, if anything, because of these programs and because of deregulation, it's decreasing.

Because, as she said, these drug users are coming into contact with social workers with the idea that they can get better. They can enter treatment programs. Whereas, without these programs, they would probably largely exist within a very, very small and enclosed area.

I think the more important thing is that needle exchange programs need to come in conjunction with deregulation. One by itself is not going to do the best job. I think if human life is the priority, then we need to be looking for the best system, and it needs to be multi-faceted.

So the Governor has addressed this issue, but, really, it falls in the responsibility of the Assembly people to make this a priority. Reed Gusciora has, actually, or is introducing a bill the next two weeks that is going to promote both needle exchange programs -- legalize needle exchange programs and deregulate syringes. There has been many, many different people working on this bill and to make it the most effective as possible.

We are both very -- we have been working since last year on this, and are strongly in support of this issue and Reed's bill, specifically. There's really no more time to delay with this when people are, literally, being infected and dying as a consequence every day. It's just tragic, basically. I think that it's the responsibility of a government within New Jersey, a Federal government, to protect the lives of the people. So it's a moral obligation, at this point, to pass this bill.

MR. WILLIAMS: We would like to thank you for having this hearing, in particular, and also for having us out tonight.

ASSEMBLYWOMAN WATSON COLEMAN: Thank you for coming.

Roseanne Scotti, Drug Policy Alliance.

I have two additional people who wish to testify. If someone has come in and has not filled out this form, but wishes to testify, please do so. Thank you.

Good evening.

ROSEANNE SCOTTI: Good evening. My name is -- am I on here (referring to PA microphone) -- Roseanne Scotti, and I am the Director of New Jersey Drug Policy Alliance. I would, first of all, like to thank the esteemed Assemblywomen for calling this hearing on this most critical issue.

New Jersey is facing a public health catastrophe because of the spread of HIV/AIDS in New Jersey. We have the fifth highest rate of adult HIV, the third highest rate of pediatric AIDS. We have one of the highest rates of HIV among women in the nation, and more than 22,000 of our children have lost their parents to injection-related AIDS.

One of those AIDS orphans, Michele Giordano, will talk later in the evening about what it was like to lose her father to a totally preventable disease. But what makes New Jersey most unique in terms of HIV/AIDS is the percentage of cases that are related to injection drug use. Nationally, 25 percent of AIDS cases are related to injection drug use. Here, in New Jersey, the percentage is 53.

ASSEMBLYWOMAN WATSON COLEMAN: What percentage did you say?

MS. SCOTTI: Nationally, the percentage is 25. Here, in New Jersey, it's 53. This is the heart of our epidemic, and this is where we have to act if we want to stop the spread of HIV/AIDS in New Jersey. We know

there's no cure for AIDS, so the best defense is prevention, and the best prevention for injection-related AIDS is clean needles.

I've brought with me a packet of information, and I have a lot of information in here about syringe access and syringe exchange. I would be more than happy to supply additional information to any legislators who would like it. I'd also like to take the opportunity to offer, on behalf of Drug Policy Alliance, that we would be more than happy to provide transportation to any legislators who would like to visit a syringe exchange in Philadelphia, in New York City, in Baltimore, in any of the places where syringe exchange has been done successfully for many, many years.

I, myself, on a voluntary basis, have been involved with Prevention Point Philadelphia, the Philadelphia's city-run and funded needle exchange program. I am, currently, on a voluntary basis, the legal director of that program.

The evidence is overwhelming, from research in this country and countries around the world, that sterile syringe access reduces the incidence of HIV/AIDS and does not increase drug use. As a matter of fact, access programs have proven to be a bridge to treatment and other social services for drug users. These programs have also been endorsed by numerous medical and scientific bodies, and just a brief list: The Federal Centers for Disease Control and Prevention, the American Medical Association, the American Pharmaceutical Association, the American Public Health Association, the National Institutes on Health Consensus Panel, the National Academy of Sciences, the Associations of the Boards of Pharmacy, the Association of State

and Territorial Health Officials, the National Alliance of State and Territorial AIDS Directors.

Yet, despite this evidence and despite these endorsements, New Jersey is almost alone among states in this country in allowing for no form of sterile syringe access whatsoever. We are one of only six states that requires a prescription to get a syringe, and we are one of the few states that has no legally mandated syringe exchange programs.

We, at the Drug Policy Alliance--

ASSEMBLYWOMAN WEINBERG: Can I just ask a question?

MS. SCOTTI: Yes, absolutely.

ASSEMBLYWOMAN WEINBERG: You said we're one of the few states. Do you know how many other states, or which states, do not have a needle exchange program, as New Jersey?

MS. SCOTTI: There are about 20 states now who have no legal needle exchange programs, so I don't know the exact states, but there's 30 states, altogether, that provide needle exchange programs. And, as I say, in the vast majority of states, 44 states, you can walk into a pharmacy and use your own money to buy a syringe.

This is the heart of our proposal. Drug Policy Alliance is proposing legislation, and we're working on draft legislation, to allow for the sale of syringes in pharmacies and to remove syringes from the drug paraphernalia law -- as many, many other states have done -- so doctors and other public health professionals can distribute syringes as part of a comprehensive AIDS prevention program.

Nothing we could do would do more to protect the lives and health of the people, the children, the families, the communities of New Jersey. And let me emphasize, this would cost the State absolutely nothing, not one penny. It would save thousands of lives and millions of dollars.

I know I'm running short on time, so let me just, in closing, mention, I know in the past in New Jersey, people have said that syringe access sends the wrong message. The only message that syringe access sends is that all life is worth protecting. Everyone's life has value. People can recover from drug addiction. There is no cure for AIDS. We, in New Jersey, are fighting the battle against AIDS with one hand tied behind our backs, and we are losing. The time has come for us to untie our hands and untie the hands of our public health professionals so that we can fight this battle to the best of our ability. The people of New Jersey deserve no less.

Thank you.

ASSEMBLYWOMAN WATSON COLEMAN: Thank you very much.

Michele Giordano.

MICHELE GIORDANO: Good evening.

ASSEMBLYWOMAN WATSON COLEMAN: Good evening.

MS. GIORDANO: As Roseanne said, my name is Michele Giordano. I currently direct an HIV prevention program here in the city of Trenton, and I am a member of the New Jersey HIV Prevention Community Planning Group. However, I come to you, today, as a child and orphan affected from injection-related AIDS. My father would have been 43 this month. It's been seven years since his death, and seven years that I've been

fighting for syringe exchange in hopes that other children do not have to watch their parents die like I did. It's seven years, and still I'm here fighting for approving a public health measure, like syringe exchange, that would have kept my father alive and here with me today.

In '96, after a 10-year heroin addiction and repeated efforts to get clean, my father died. He lived and died in Jersey City, which we know has one of the highest rates of injection-related AIDS. In a two-page journal my father titled, "A Diary of an AIDS Patient Ready to Die," his first line wrote, "Drug addict, dope fiend, and junkie are many of the names I have been called, mostly behind my back." In only two pages and in the first line, after 36 years of his life, the only feelings my father felt strong enough to express were about the shame and stigma he felt as a injection drug user, here in New Jersey.

I know the shame and stigma could have been prevented with syringe exchange and harm reduction. Syringe exchange would have provided my father a safe space to receive clean syringes, a safe space to discuss his drug use without societal judgments clouding his thoughts, and where he would have felt less isolated and alone. Syringe exchange would have prevented him from contracting HIV. I would have had a better relationship with him and not be here today remembering him. But instead, my father was left to die in a field of dirty needles, poverty, and shame, while the war on drugs deemed my father the enemy, criminalized his symptoms, and continued to spread HIV.

I am left with the memory of my father in his last days. Lesions covering his entire body, a mouth so consumed by thrush he could hardly speak, and weight loss so drastic that he could barely stand. I know, as do the

other 22,000 orphans from injection-related AIDS, that my parent did not have to die because of drug use or addiction.

There are politicians who claim syringe exchange sends the wrong message to children. It's easy to support that claim when, as a child, you did not watch your parent die a little more every day, when you haven't walked into a hospital as a child, filled with families that, in a glance, you were speaking the same language of lost hope. I asked these politicians, "What children are they speaking to?" Because I am sure they did not talk to me or the 47,000 other American children, mostly of color, who lost their mothers to the epidemic. When is someone going to ask or speak to us?

The message that I continue to receive and other families continue to receive is clear: we're not worth helping, our families are not worth saving, and our voices do not matter here in New Jersey. Not one more family should be torn apart from injection-related AIDS. Not one more child should have to cry by their parent's deathbed, watching as their mother or father deteriorates in front of their eyes, watching AIDS take away their role model they were supposed to have, and facing the truth that their parent's life was not worth saving.

I don't want to wait another seven years. I don't want to wait to watch another child suffer the loss of their parents. I don't want to see more money wasted on the war on drugs -- a war that fought against my father and fights against parents and not in defense of them.

Bringing syringe exchange and harm reduction into New Jersey would have valued my father's life. It would have valued my life, and it values all children's lives.

I just want to say, on a side note, that a lot of the discussion here is about bringing syringe exchange into medical communities, and although that's a step for New Jersey -- and New Jersey needs anything at this point -- there is something about bringing syringes to the community of people we are talking about. We have seen this work with condoms. We hear Project IMPACT bringing vans into the community. Why wouldn't we do that with syringes? When drug users are walking down the street to get their next bag, they're not going to stop into a hospital. You need to be there before they go get that next bag of heroin. My father needed someone to be on that corner with him, giving him the resources he needed before he went and spent his money on another dose of heroin.

So I just close with that.

ASSEMBLYWOMAN WATSON COLEMAN: Thank you very much for sharing what is a very painful story, but is information that we can all benefit from knowing.

Thank you.

MS. GIORDANO: Thank you.

ASSEMBLYWOMAN WATSON COLEMAN: MaryLou Freund.
Is that Freund?

MARYLOU FREUND: Freund.

ASSEMBLYWOMAN WATSON COLEMAN: Oh, Freund. Oh, I'm sorry. I thought that was an E-U.

MS. FREUND: It is.

ASSEMBLYWOMAN WATSON COLEMAN: Oh, okay.

MS. FREUND: Good evening. Thank you for having us here tonight. My name is MaryLou Freund. I have the privilege of being the Coordinator of HIV Counseling and Testing Programming, and also of the Healthy Project Returns (*sic*), which is one of the prison demonstration projects. I work at Henry J. Austin Health Center, here in Trenton. However, I've been involved with the HIV/AIDS epidemic for over 15 years here in Mercer County.

At the 14th international conference that was held this past July, it was stated that HIV/AIDS can never be cured by the existing therapies. They also heard that the virus is hitting young people the hardest around the world. Nearly one-third of all people living with the virus today are between the ages of 15 and 24. The life expectancy in 51 countries, mostly in Africa, but also in Asia, Latin America, and the Caribbean, are going to drop within this decade due to this disease.

Women represent the fastest growing group of all new HIV infections in the United States. In 1999, women constituted 23 percent of all new AIDS cases. African-American and Latina women, who represent less than one-quarter of all women in the United States, accounted for more than 77 percent of all reported AIDS cases in this country.

One in every 50 African-American men and one in every 160 African-American women in this country are HIV positive. African-Americans comprise 13 percent of the population, but 57 percent of all new infections nationally, and 49 percent of all deaths due to this disease. African-Americans die at a rate 10 times higher than those of whites, due to lack of medical care access. AIDS remains the leading cause of death among African-American men

and women ages 25 to 44. One out of every 66 African-Americans living in New Jersey is living with HIV or AIDS.

Trenton, a city of just over 85,000 people, ranks seventh in New Jersey in the number of cumulative AIDS cases, and fifth in the number of those living with HIV and AIDS currently. Seventy-five percent of all HIV infected individuals in Trenton are African-American, and 79 percent of all pediatric AIDS cases in Trenton are African-American. These are the known statistics. These are people who have gotten tested and that we know about.

Education of our youth is still greatly needed. Our recent survey of some college men showed that 42 percent reported they wanted to use a condom but didn't have one available. Sixty percent had not discussed the use of condoms with their partner before sex. Thirty percent put it on wrong.

The government is now spending over \$50 million each year on HIV prevention programs. President Bush, in his Union address, requested an additional \$15 billion to turn the tide against AIDS in Africa and the Caribbean. On the 31st, however, he also spoke again, and he did announce that he is asking for a 7 percent increase in his Fiscal Year 2004 budget for HIV and AIDS, of which \$93 million will increase AIDS research, an additional \$100 million to support the AIDS drugs distribution program.

He also recognized the important connection between HIV diagnostics and treatment by posing the following rhetorical questions: "How can you get help if you don't know?" and "How can you know if you don't get a test?"

As Mr. Ganges alluded to, the OraQuick has been waived, so it will probably be available for us to use in the near future -- bringing this very important test to the people so we can get answers quickly.

One of the problems that we have are the barriers that occur with testing. One of those is testing of minors. Again, Mr. Ganges will attest the fact that he and I have had this discussion on many occasions. The current law, under which we test and treat minors for sexually transmitted diseases, was written before I was born. In fact, it doesn't even call them STDs. It calls them VD, and does not recognize, in the law, many of the currently diagnosed diseases that we treat today. HIV had not been umbrellaed under that law. We are not allowed to test our minor children who are sexually active and practicing unsafe sexual practices for this sexually transmitted disease.

ASSEMBLYWOMAN WATSON COLEMAN: Thank you.

In October of 2002, the Assembly did pass a bill that would permit treatment and testing of minors. So the bill passed -- without consent of their parents. The bill did pass the Assembly. We're waiting on some action in the Senate. The Senate could use some help.

Thank you very much.

Edward Martone, New Jersey Association of Corrections.

How are you?

EDWARD MARTONE: I'm very well. Thank you so much.

I was sitting back-- I wasn't certain I wanted to add anything. I figured that everybody before me would cover anything that I wanted to say, and it's largely been the case. I must tell you I agree with everything that every

speaker has said so far. There were just two points I wanted to highlight, if I could, but I don't think it has been touched upon as yet.

First of all, as I suggested on my sheet there, I'm representing the New Jersey Association on Corrections. And among other programs, we run a number of AIDS and HIV programs, including two shelters for folks with AIDS, and we have some scattered-site housing program in Newark for folks with AIDS. I'm also one of the cofounders of a group called North Jersey Community Research Initiative, NJCRI, in Newark. We've been around for about 11 or 12 years now, and -- actually, no, I should say it's been about 15 years, and I continue to serve on the board. I'm the current Vice Chair of the board. In that organization, in addition to providing social services for people with HIV and AIDS -- has been and continues to be the site, if you will, of the agency in the state that does most of the drug trials for folks with HIV in New Jersey. It's also a private nonprofit.

I wanted to commend the Health Committee not only for having this hearing, but the Health Committee, for those of us who follow it, has long been focused on this issue and has taken it very seriously and has made it a priority -- as evidenced not only by this hearing, but earlier in this voting term, the Health Committee voted out Assembly Bill No. 2444, which had earlier been merged with Assembly Bill No. 1933, which requires Medicaid coverage of HIV drug resistance testing. Assemblywoman Weinberg was one of the sponsors of that bill. It's an important measure. It's out of Health Committee, as you know. It's out of Appropriations Committee, and it's ready for a floor vote in the Assembly. I hope that with a nudge, we may get that through as well.

Anecdotal evidence suggest that there are a number of people with AIDS in the state who are not getting phenotype and genotype testing because the doctors have decided that it's too expensive, and they don't have private health coverage that covers the testing. So this was a very good measure, and I commend the Health Committee for passing it out of Committee.

I wanted to mention two bills. I realize we're not holding hearings on these bills, so I won't go into any details, but I would ask you to hold off on Assembly Bill No. 2980. Its Senate companion, unfortunately, has passed the Senate, but A-2980 would permit health-care workers, EMT people, to compel a blood test of people and to disclose their HIV status to those health workers. The bill has a number of problems with it, and I won't go into those now, but I do think that this Committee has long understood the necessity of not only providing resources for people with AIDS in the state, but also protecting their privacy and protecting them against discrimination. This bill is fraught with problems, I think, which would, ultimately, hurt people with AIDS. And it would drive people who should be getting medical attention -- and drive them away from medical care, because of their fear of disclosure and, possibly, discrimination.

And, finally, I would commend your attention to Assembly Bill No. 2077, which I hope that the Committee will take up soon. It's been coprime sponsored by the chair, Assemblywoman Weinberg, along with Sam Thompson. It's got two or three other Democratic and Republican sponsors. In a nutshell, it would require insurers and State health benefits programs to cover the cost of an AIDS vaccine. We don't, as yet, have an AIDS vaccine. The idea is that you create an incentive, at least in this case, for pharmaceutical

companies to do AIDS vaccine research, knowing they have a market available when one is developed. I think it's a forward-looking proposal. I commend the chair, Weinberg, on coprime sponsoring the bill. I hope that this bill will receive the attention of the Health Committee, in short order.

Thank you so much.

ASSEMBLYWOMAN WATSON COLEMAN: Thank you, Mr. Martone.

ASSEMBLYWOMAN WEINBERG: Thank you.

Just to correct the record -- Ed is a very old friend of mine--

MR. MARTONE: Yes.

ASSEMBLYWOMAN WEINBERG: --but this is not the Health Committee.

MR. MARTONE: Oh.

ASSEMBLYWOMAN WEINBERG: We represented three different committees here, and it is just a group gathering evidence now, so we will know on which road to travel to, hopefully, come up with some answers. It was inspired, as I said at the outset, by Assemblywoman Bonnie Watson Coleman, who is Chair of the Appropriations Committee that released some of these bills that you spoke about. Hopefully, we will engage -- the three of us -- the Family, Women and Children's Issues; Health and Human Services; and Appropriations in trying to come up with the appropriate way to stem the tide here in New Jersey.

MR. MARTONE: Well, I appreciate that correction. That's even better -- isn't it -- that more than one committee are involved. I found out

about the meeting at a quarter to five when I called poor Meredith to ask her about it. So I appreciate that information.

Thank you.

ASSEMBLYWOMAN WATSON COLEMAN: Thank you for coming and thank you for testifying.

ASSEMBLYWOMAN WEINBERG: Thanks, Ed.

ASSEMBLYWOMAN WATSON COLEMAN: Ms. Dottie Rains, St. Francis Medical Center.

This is the last person who has signed up to testify.

D O T T I E R A I N S: Good evening.

ASSEMBLYWOMAN WATSON COLEMAN: Good evening.

MS. RAINS: As you already stated, I'm Dottie Rains, and I work as a Case Manager at St. Francis Medical Center. There are two issues -- there are a lot of issues -- but I'm just going to name two, for right now, that is a major concern to the people that I work with and work for. One is the ADDP program, which is AIDS Drug Distribution Program. It is a program that allows people with HIV and AIDS to receive their HIV medications, basically, for free, and also other medications as well. There is an income limit that is very liberal for even those who may work and still may not be able to afford the co-pay that the insurance -- that if they get the drug through the insurance, they would have to pay.

In the next year or so, the government wants a cut in funding for this program.

ASSEMBLYWOMAN WATSON COLEMAN: State or Federal government?

ASSEMBLYWOMAN WEINBERG: Is that the State or the Federal government?

MS. RAINS: I believe it's the--

UNIDENTIFIED SPEAKER FROM AUDIENCE: Federal government.

MS. RAINS: Thank you. --that would like to cut the funding for this program. We have to do something now about this program, because there are a lot of people on this program that are in need of this program. This allows them to maintain their HIV, to receive medications -- well, basically, for free. I believe that we need to get started as soon as possible and not wait until the moneys are dried up to do something about it.

I have some information here. You can read a little more in detail about it, just to know what the program is and what kind of deficit -- will be.

The other issue that I just want to state, briefly, is housing, and that's just not inclusive of people who are HIV positive, but especially here in Mercer County. I have a lot of clients on my caseload that are homeless, and it makes it very impossible for them to even think about HIV, when you don't have a place to live. So I just wanted you to, please, consider that on behalf of the people who are infected and affected.

Thank you so much for your time.

ASSEMBLYWOMAN WATSON COLEMAN: Thank you very much.

ASSEMBLYWOMAN WEINBERG: Thank you.

ASSEMBLYWOMAN WATSON COLEMAN: No one else has signed up to testify, so that concludes the testimony this evening.

Do you have any closing statement you'd like to make first?

ASSEMBLYWOMAN WEINBERG: Yes. Certainly, the idea of needle exchange has come through very clearly. I am glad that the Assistant Commissioner Ganges has remained to hear all of this. There's some very thorny issues that we have to address here. There's been this resistance for a number of years to the idea of a needle exchange program, even though, under Governor Whitman, her own Advisory Council, I believe, came up with that recommendation. It was never implemented. I would hope that this is something that we can work with the Health Department to finally address.

And, again, I would just like to accentuate that I think we need so much more education on this field among young people -- and my own particular feeling that, because the disease is being managed, that there is a feeling among young people that they don't have to be fearful of it anymore. I think that needs a lot more education on how to avoid contracting the disease, whether we're talking about education in the schools, or just general education through the TV program spots, those kinds of things.

I'm kind of looking at you, Mr. Ganges. We're putting the whole thing on your shoulders, here, to help us come up with some answers, and thank you for staying for the evening.

ASSEMBLYWOMAN WATSON COLEMAN: Thank you.

I want to associate myself with all of my colleague's remarks, because I agree with each and every one of them. We're very lucky to have her as the Chairperson of the Health and Human Services Committees.

This is really an important area for us. It's very important to the quality of life to each and every one of us. I thank you all for coming here and

giving of your time tonight, some from as far away as Jersey City and New York and Atlantic City and in between, and certainly those of you who are from Mercer County. I thank you for coming here. I thank you for the information that you've shared.

I thank the Commissioner for staying the entire time, but I also thank him because he's really taken up this mantle, and he is doing a great job in ensuring that those who have been underrepresented, underserved, undereducated are going to get an opportunity to enjoy whatever quality of life exists for all people who are experiencing this awful disease. New Jersey has so much more to do, and you've helped us to formulate some of the important arguments, given us the opportunity to work with the administration in bringing forth some, maybe, new ideas -- and, very much so, fighting for those that mean so much -- make so much sense to do, but we've just not been able to get there. I'm sure it's going to help Mr. Ganges. It's certainly going to help us as we move forward and advocate for the right thing to do.

I thank you, and I thank Assemblywoman Weinberg for being a part of this with me. I thank Meredith for her staffing in this Committee, and getting information out to you, and helping to get you here today. Thank you, and have a good evening and a safe trip home. (applause)

(FORUM CONCLUDED)