STATEMENT OF ASSEMBLYWOMAN NETTIE MAYERSOHN
(PRESENTED AT A PUBLIC HEARING OF THE NEW YORK STATE AIDS ADVISORY COUNCIL SUB-COMMITTEE ON NEWBORN AND PRE-NATAL HIV TESTING)
NOVEMBER 8, 1993.

I would like to thank the committee for giving me the opportunity to testify on behalf of my legislation, Assembly Bill 6676, which was introduced during the last session of the legislature and which shall be reconsidered again during the upcoming session.

As you know, the Assembly Health Committee, by a vote of 10 to 9, held the baby AIDS bill pending a study by a panel convened by Dr. Rogers, Chairman of the AIDS Institute Advisory Council. There were at least two members of the Health Committee who were persuaded to withhold their votes in support of my legislation pending the panel's reviews of the Health Department's current policy on newborn testing. As far as the Senate is concerned, there is clear support for this legislation and I have been assured by Senator Velella, the bill's senate sponsor, that it will be considered again in that house during the coming year.

My introduction of this legislation has succeeded in making a previously uninformed public aware of the D.O.H. practice of anonymously testing newborns for the virus without any attempt to report back to parents about the results of those tests. As awareness of this policy has grown, it has become obvious that there is overwhelming support for unblinding these tests so that we can begin to try to give infants the same kind of medical care you would give to any human being who is the victim of a terrible disease. That growing opinion is evidenced by editorials written in support of my legislation by both The New York Times and Newsday, informed and respected newspapers that are considered part of the progressive establishment that supports protecting women's rights and gay rights on every other issue, as do I.

Because of this new public awareness, the policy of the Department is no longer a secret--and no longer can it avoid public scrutiny. I have received countless letters on this issue--and the support for my position is close to unanimous among your average citizen who cannot understand and will never accept a policy that conspires to deny medical treatment and care to any human being, particularly to the most vulnerable among us. Within the medical community, both the New York State Medical Society and the New York City Chapter of the American Academy of Pediatrics have urged passage of my legislation.

All the rationalizations created by the AIDS Institute and the Health Department can never explain to our satisfaction, the fact that, as a result of your policy, doctors have been unable to give HIV positive infants the medical care to which they are entitled or

to provide mothers with the information they need to protect their babies. The policy has been in effect since 1987 and while it is clear that voluntary testing, a process supported by many who oppose my legislation, has been a failure, they would ask you once again to cling to a policy that puts so many babies at risk.

In approaching the task which has been assigned to you, I urge you to disregard the dire predictions of a very small, but vocal group, of public health professionals about suicide rated among HIV mothers going up and women avoiding hospitals when giving birth and on and on. These arguments make little sense to those of us who understand that all you are doing is delaying the inevitable. Those mothers will eventually have to face their own medical condition and that of their babies. Despite all the medical information that has been placed before us, that clearly states that babies with HIV infection must be brought into treatment as soon as possible in order to save their lives or to enhance the quality of their lives--despite all this, this same group of care givers is attempting to dominate the debate by insisting that we ignore the medical truths in order to create some king of illusion that says: WHAT YOU DON'T KNOW WON'T HURT YOU.

So far, I have attended two meetings of the panel and I must tell you that it was an experience I will not soon forget. I have great respect for the people who work in the field of public health--but again I found the reaction of these health care professionals to my proposal very curious. While the medical evidence is conclusive on the benefits of early treatment of HIV infected children-and I will leave most of that testimony to pediatricians who will testify here today--I found myself looking at charts and studies and projections about the dire consequences of letting parents know that their infants have tested positive and may be victims of a deadly disease. After all, I'm told, isn't the suicide rate for male AIDS victims in California higher than that of cancer victims. I find it extraordinary that a health care professional was able to study the statistics on suicide rates among gay men infected with AIDS in California, and speculate on a parallel increase in suicides among pregnant women and mothers. And I have received telephone calls telling me how cruel it would be to give new mothers the terrible news of the child's condition at a time when they may be suffering from post partum depression. One very vocal public health professional whispered to me at a meeting--"Why are you going after the women; why not go after the guys?"

I am also very concerned about the climate of intimidation that seems to hang over the entire debate. I have been told by several people who oversee Health Department programs that they would like to see the tests unblinded--that voluntary programs are not effective and are not reaching enough mothers whose babies have tested positive--but they cannot make a public statement. There seems to be a very real concern about careers or programs or funding. And I have made it clear to Dr. Rogers and Dr. Britton that I do not know whether there can even be an honest debate and

an honest expression of opinion when people state a reluctance to publicly express their views on this issue.

To the public Health Profession who said to me,"go after the guys", in spite of the rather large document you produced, you are way off base on the issues involved in this debate. It isn't about going after the guys or the women; it's not a feminist issue. I consider myself to be an ardent feminist--and hanging on my wall in Albany is the National Organization for Women Legislator of the Year Award that I received two years ago for my strong position on women's rights. No, this is not about women's rights. It is about the morality of allowing babies who have tested positive for the AIDS virus to go home without informing the mother of their condition. It is about allowing babies to go home without an attempt to bring them into treatment which may save their lives. It's about denying treatment to infants because they are too young to line up outside the halls of the AIDS Institute to demand the treatment which has been denied them.

And most important, it's about changing a policy that allows healthy babies to go home to be exposed to the AIDS virus by their infected mothers--only because we think the mother's mental state might be so delicate that she might become suicidal. As a woman who has had children and grandchildren, I have a very different perspective of women who have just given birth. There's a deep sense of concern that almost every woman experiences that her child be normal--have ten fingers, ten toes and be perfect in every way. There's also a knowledge that a certain number of children are born each year with handicaps, disabilities, Down Syndrome--and you pray that your child will not be among them. And there's a certain strength that you gain instantly with the realization that you are now completely responsible for the well being of another precious human being, and no matter what the circumstance, you are consumed with the determination to protect and care for that baby.

I have tried to understand why this disease is viewed so differently, why presumably good people are willing to collaborate to create an illusion--in the so called best interest of the mother--that everything is fine--and if you don't ask for the information, we're not going to do anything that will make you unhappy. The attitude seems to be that if you go home with your illusion and your denial intact, then we have served you well; We're not sure how that will affect the anticipated suicide rate in the long run, but for the present, we have discharged a happy mother.

But what about the long term tragic consequences to the mother and the infant? Will our good intentions in any way help that family survive a dread disease? We have the opportunity to provide that family with support services, with medical care, with counseling. We have the opportunity to help them make plans for the future. These are people who desperately need help--not happy illusions.

And what about the infant. What about his or her right to medical treatment. What about his or her right to be protected from the virus. Let's look at the statistics the Centers For Disease Control have provided. Not projections, not dire predictions, but hard statistics on the number of infants who are being needlessly exposed to the virus as a result of breast feeding by an infected mother.

I would like to read part of a paper presented at the AIDS Conference in Berlin this past winter. The paper was presented by Dr. C.C. Pekham of the Epidemiology And Biostatistics Unit of the Institute of Child Health in London.

"Children of mothers infected prenatally could be at a lower risk of infection from breast milk because of transplacental acquisition of IgG antibodies and because their mothers, unless symptomatic are probably less infectious.HOWEVER, OUR ANALYSIS SUGGESTS THAT, CONTRARY TO THE PREVAILING VIEW, THERE IS A SUBSTANTIAL RISK OF TRANSMISSION FROM MOTHERS WITH ESTABLISHED INFECTION. THE ESTIMATE OF AN ADDITIONAL RISK OF INFECTION THROUGH BREAST FEEDING OF 14% HAS A WIDE CONFIDENCE INTERVAL AND THE POSSIBILITY OF SYSTEMATIC BIAS CANNOT BE EXCLUDED."

And even way back in 1985, the Centers for Disease Control, recognizing the risks of transmission of the virus through breast feeding, recommended that women who are HIV infected must not breast feed their infants.

And I would like to read further the conclusion of the summary of and Italian Study recently provided by the C.D.C..

"RESULTS: BREAST FEEDING INCREASES THE RISK OF HIV-1 TRANSMISSIONS. THE ESTIMATED ADJUSTED ODDS RATIO FOR 1 DAY OF BREAST VERSUS BOTTLE FEEDING WAS 1.19 (95 confidence interval.1-1.28). THE INFECTION ODDS RATIO OF BREAST VERSUS BOTTLE FEEDING INCREASED WITH THE NATURAL LOGARITHM OF THE DURATION OF PRACTICE.'

"CONCLUSIONS: THESE RESULTS ARE THE FIRST TO PROVIDE AN APPRAISAL OF THE ADDITIONAL RISK OF HIV-1 TRANSMISSION ASSOCIATED WITH A SEROPOSITIVE MOTHER BREAST FEEDING HER CHILD. BIOLOGICAL SIGNIFICANCE OF THIS ROUTE OF TRANSMISSION WAS SUPPORTED BY DEMONSTRATION OF A RELATIONSHIP BETWEEN DURATION OF BREAST-FEEDING AND RISK OF HIV-1 TRANSMISSION"

More and more we are seeing statistics that healthy babies--infants who have a chance at escaping the virus--are being needlessly exposed to the virus by an AIDS policy that puts a higher priority on the mother's right not to know than on the life of the infant.

In conclusion, I ask each and everyone of you on the panel who are parents and those of you who are not parents --if this were your child, wouldn't you be outraged at the knowledge that your baby was infected or at risk for an infection, and the AIDS

Institute, in conjunction with the Health Department, had created a policy that, in effect, denies you the information you needed to protect your child?

Any responsible, caring parent would want to have that information. Why do some caregivers take the patronizing position that poor women who give birth in city hospitals feel differently. At Harlem Hospital we were told that they had a very high success rate on voluntary testing, and they believe they were successful because they posed the question in a manner directed towards the child rather than the mother. They did not simply ask the mothers if they themselves wanted to be tested for the AIDS virus. Instead, the mothers were asked,"do you agree to have your child tested for the virus?"... and the overwhelming majority of those mothers agreed because the concern that they had for the wellbeing of the infant overwhelmed any fears that they might have regarding their own condition. To me, that's a very clear indication that given a choice, these parents do not want illusions that put the lives of their babies at risk.

We have an opportunity now to address this issue--and no one recognizes better than I do--the stress and the pressures that many of you are subject to. But this is your opportunity to change a senseless policy of illusion and denial. I appeal to you. Help us change this policy and let's do it now. Let's not add any more helpless victims to our list.

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Public Hearing on Newborn Screening

November 8, 1993

Good morning, my name is Diana Correa, I am an attorney and presently the Senior Associate and policy analyst for the Latino Commission on AIDS. Thank you for the opportunity to speak with you today.

The Latino Commission on AIDS, functions as the advocacy arm to those Latino AIDS organizations that provide direct service throughout the state. Our mission is to effectuate public policy, build local and national coalitions, advocate on behalf of community-based organizations, participate in legislative initiatives and give testimony before committees such as this one.

Let me begin with some basic guidelines and truths which will set the framework for the discussion at hand. The face of AIDS has changed. Ten years ago we anticipated that the public health crisis confronting us, that is, the AIDS epidemic would affect the general population. Well, ten years later we know that this is just not the case. AIDS remains an epidemic among gay males and has affected lesbian and heterosexual communities across class and racial lines throughout the state, but in New York as in the rest

of the United States, AIDS is now endemic to Latino and African-American populations. A fact which is critical to how we understand the implications of "unblinding" the New York State newborn seroprevalence study.

With this as the backdrop, we believe that it is incumbent on the Subcommittee to view the prospect of "unblinding" the newborn seroprevalence study through lenses that accommodate not only a public health perspective but incorporate the political and social realities that make up this city and state. I implore everyone here to wear these lenses throughout the day as it will help guide all of us through this important and difficult process.

The goals behind unblinding the study includes identifying HIV infection in infants to provide early medical intervention, prevent HIV transmission from mother to infant and to give women the opportunity for early diagnosis and treatment. I'm positive that there is no one in this room today that doesn't think these goals are important or that they shouldn't be met. The central questions here are whether unblinding the study is the only way to achieve these goals and whether the ends justify the means. Simply put, "unblinding" the study at what cost and who will pay.

Going back to our guiding principles, that is, the face of AIDS in 1993, it is clear who is going to pay. According to the New York State Department of Health Surveillance Report during the period of 1987 through 1992 over 2700 babies born to Latino families and over

5300 babies born to African-American families tested positive of which 10-20% have or will become HIV infected. These numbers are disproportionately high as compared to babies born to white families throughout the States.

Now that we know who will be directly affected, at what cost? "Unblinding" the seorprevalence survey, that is linking the HIV test with the name, and telling the parents of the HIV test result would mean the women who didn't even know that they or their babies were being tested would be told that their infants tested positive for HIV before they left the hospital.

What are the implications here? 1) Unblinding means that it makes women, primarily women of color, the first group to receive mandatory testing other than federal prisoners. 2) Unblinding means that without counseling and support services it will only serve to discourage people from seeking HIV-related care, services and health care generally. This will be particularly true of undocumented and immigrant families who shun traditional health settings for fear of deportation. 3) Unblinding means that scared families will never return to health care settings, making tracking impossible.

Whether inadvertently or by design the fallout from such a proposal wreaks of all the ism's - sexism, classism, racism and maybe most importantly de-humanism. I urge everyone on the committee and in the audience to take it outside what we have categorized here as

the "profiled" group and literally take this scenario home with you - personalize the experience. That is, imagine yourself just giving birth to a baby and without warning, you and your partner are told your baby had been tested without your knowledge or consent and that your newborn is HIV positive. I predict you would feel not only devastated, but unprepared, deceived and scared.

The proposal to "unblind" the seroprevalence study is a poor substitute for the expansion of prevention · education, and treatment programs which work hard to create a safe and confidential environment so women can feel comfortable about getting tested or treated on their own accord and without punitive repercussions. Therefore, we urge you to oppose any attempts to unblind the newborn seroprevalence study and to understand this issue within the context of social justice which needs a humane response, not one that is "blind" to the realities of women and families infected and affected by the epidemic.