



news from assemblywoman **NETTIE MAYERSOHN**

27th ASSEMBLY DISTRICT

Date: FEBRUARY 1994

ASSEMBLYWOMAN MAYERSOHN ANNOUNCES FORMATION OF AN ADVOCACY GROUP FOR ADOPTIVE PARENTS OF AIDS CHILDREN

Two Brooklyn mothers bound together by similar tragedies have formed an organization known as "ADOPTIVE PARENTS OF CHILDREN WITH AIDS" - (APCA). The organization intends to hold regular meetings, share information about available services, and lobby for legislation that will advance the interests of the children.

Carol Ven Graevenitz and Pat Norton both accepted foster children into their homes and grew to love them, unaware that the children had a deadly disease. In each case, by the time the legal adoption was underway, the mothers knew that their foster children were seriously ill, but returning them to the state was an unthinkable option. In the Ven Graevenitz case, the doctor suspected the baby had AIDS, but could not confirm his diagnosis since the state requires consent for testing from the biological mother who could not be located.

Ms. Ven Graevenitz stated, "Since we couldn't find the biological mother, we had to wait for Child Welfare to authorize the testing. That took an additional five months. From the time of birth until the time my baby was finally tested for AIDS at age two and a half, he had ten episodes of LIP, a pneumonia associated with the AIDS virus, and was left severely brain damaged. Andrew is now four and a half years old and has to be fed by tube every three hours. If we had been able to get medical treatment early on, we are now told the disabilities and the suffering might have been avoided."

When two and a half year old Miles was placed in Ms. Norton's home, she had no idea that he was infected with the AIDS virus. It was obvious though that something was very wrong and that this was a very sick baby. His constant diarrhea and bloody noses -- all of which she attended to completely unprotected -- were ominous signs. Miles was diagnosed with AIDS at three years of age, after more than six months of delay in obtaining the necessary consent from the biological mother to give him the test.

Miles was more fortunate than Andrew. Despite his illness, he was a normal, happy child who with good medical care was able to live until he was nine years old, when he finally succumbed to the disease.

Carol Ven Graevenitz and Pat Norton met when a friend who knew their similar stories put them in touch with each other.

Recently the two women became aware of the fact that every baby in New York State is tested for the AIDS virus but that the parents or adoptive parents are not notified of the baby's condition, nor are the adoptive parents permitted

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to have their babies tested without the consent of the biological mother. They contact Assemblywoman Mayersohn who is the author of a bill in the Legislature which would require the Health Department to notify parents and adoptive parents of their children's HIV status.

"I was absolutely outraged," said Ms. Von Graevenitz. "With early medical treatment, my son could have enjoyed a normal childhood. I would like very much for the groups that are opposing Mayersohn's bill -- to see my son and to see what he has to go through every day of his life."

"We intend to do whatever we can to change the laws so that what happened to my son doesn't happen to any other child. We will be lobbying for the Mayersohn bill."

"Parents who are having a tough time dealing with the system have to meet, organize, support each other and fight for a sane AIDS policy, a policy where babies would have the right to the health care they need and where parents would have the right to have the necessary information about the health status of their children."

Parents interested in learning more about APCA can contact Carol Von Graevenitz at (718) 449-3674.

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news from assemblywoman **NETTIE MAYERSOHN**

27th ASSEMBLY DISTRICT

Date: **December 28, 1993**

MAYERSOHN MAKES STATEWIDE APPEAL; SAYS BABIES' LIVES ARE AT STAKE

Assemblywoman Nettie Mayersohn (D-Flushing, Queens) today called for support across the state for legislation she plans to reintroduce in the upcoming legislative session. The bill she is championing, A.6747-A, requires that parents of HIV infected newborns be notified of their baby's condition when the infant tests positive for the virus.

"Currently, hospitals test for the virus in all newborns, but the information is used for statistical purposes only in order to track the epidemic," Mayersohn said. "Incredibly, HIV positive infants are sent home and their parents are never notified of the test results. My bill requires that the Health Department notify the parents so that they can make informed decisions as to the care of the infant and other family members."

Since 1987, when the policy of "blindtesting" newborns was initiated by the New York State Health Department, over 10,000 babies have tested positive for the HIV virus. Newborns are tested for a number of different diseases, yet this is the only disease where the results are not revealed to the parents, and the doctor has no knowledge of the infants' illness until they are brought back to the hospital, usually too late for treatment. Assemblywoman Mayersohn stressed the urgency of this legislation, particularly since recent medical advances enable doctors to enhance and prolong the lives of these infants if treatment is begun early enough.

Many groups have charged that "unblinding" the tests could be interpreted as an infringement of confidentiality and civil rights. Some feel that it's "backdoor testing" of the mother because when the infant tests positive, it means the mother has the AIDS virus. "But," Mayersohn pointed out, "while the policy of confidentiality may be appropriate in dealing with an adult population that can make decisions regarding their own health care, in the case of newborns, we are faced with a vulnerable population, incapable of giving consent, whose right to medical treatment is being violated."

According to the Assemblywoman, of the 10,000 infants who have tested positive, only 25% are estimated to be infected and will go on to develop AIDS; the other 75% have only the mothers' antibodies which they will throw off in a matter of months -- IF THE MOTHERS ARE INFORMED OF THE INFANTS' CONDITION AND WARNED NOT TO BREASTFEED. It is now recognized that the AIDS virus can be transmitted through breastfeeding and mothers must have this information to protect the infant.

"The opposition has taken the position that ignorance is bliss," Mayersohn said. "Well, tell me how blissful can it be for a child who is infected with the HIV

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virus, who is being denied necessary treatment because neither the parents nor the doctor know of the child's condition. To the contrary -- it is ignorance that has shaped our response to the epidemic and created the medical and societal calamity we face today. Only knowledge can enable us to deal with it as a family and as a society."

Mayersohn said that although the bill has 50 Assembly co-sponsors and broad support across the state, nevertheless, it must be approved by the Assembly and Senate Health Committees before it can be brought to the floor of either house.

Last year, it was held in the Assembly Health Committee by a vote of 10 to 9. "I am confident that if enough people begin questioning the current State policy and encourage their respective legislators to support this critical legislation, it will become law," Mayersohn said. "Who knows how many precious lives can be saved with just a small effort."

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news from
assemblywoman
NETTIE MAYERSOHN

27th ASSEMBLY DISTRICT

Date: July 1993

"IT'S A BABY, NOT A STATISTIC, STUPID"

Assembly Bill No. 6747 was introduced by me during the 1993 session of the Legislature; it provides for the unblinding of test results of newborns who have tested positive for the HIV virus. This legislation brought me face to face with a condition that for me was shocking and chilling and beyond belief. In fact, when the issue was first raised in a conversation with the State Medical Society, I did not believe the facts as they were related -- I was sure that there was some missing link that would make the policy more rational and less ruthless.

As you may know, babies in New York State are routinely tested at the time of birth for the HIV virus; the purpose of the blind testing program, initiated in 1987, is to track the epidemic. Those infants -- and the figures indicate that since 1987 approximately 7,500 infants have tested positive for the virus -- incredibly, those babies are sent home and their HIV status is never disclosed to the parents. (In 1992 there were 1,900 babies who tested positive.) My proposed legislation, Assembly Bill No. 6747, would have required the Health Department to notify the parents of the HIV status of their baby.

My involvement in this issue has introduced me to a whole new definition of illogical rationalization. I have been lectured at by countless people, who know with godlike certainty that by not revealing the test results, they are acting in the best interests of the mother. They assure me that the mother really did not want to know her own status and telling her would be an invasion of her privacy and her right not to know.

They completely dismiss the fact that there is now another human life involved whose right to medical care -- and, indeed to life, is being violated.

Interestingly, too, some of the same individuals who are demanding that AIDS treatment be made available even before the FDA is ready to approve such treatment -- were assuring me that it doesn't make much difference if the HIV baby is treated six months or a year later--when the disease becomes apparent.

But it does make a difference; 75% of the newborns who show up as HIV positive at birth -- are not true HIV cases; they have the mother's antibodies which their own bodies throw off in a matter of months; if the mother is aware of the condition and exercises caution, the babies can escape the virus. The fact is that when a baby tests positive for the virus, it means the mother has the virus -- and, under no circumstances, should she be breast feeding that baby.

What do the New York State Health Department and the Centers for Disease Control (CDC) say about breast feeding by HIV mothers: The Department of Health has issued pamphlets recommending that if a woman is known to be HIV infected, she should be warned about the risks of HIV transmission through breast milk and informed not to

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breast feed. The Centers for Disease Control recommended in 1985 that because the HIV virus has been found in human breast milk and because cases of HIV transmission through breast milk have been documented, women who are HIV infected must not breast feed their infants.

It has also been argued that since breast feeding would take place before the mother had the information of the HIV status of her baby, the information would not be relevant. Certainly we would want that mother to have the information immediately and work is now being done to speed up the process; nevertheless, it is not likely that the virus will be transmitted in the first instance -- but there is no question that prolonged breast feeding increases the risk.

And can you imagine the horror that mother will experience when one year later she discovers that her baby has AIDS -- and that she may, in fact, have needlessly transmitted the virus because she did not have the information she needed to protect the infant.

I also heard a colleague argue at a meeting of the Assembly AIDS Task Force that it would be unkind to notify the mother that the baby is HIV positive because that would stigmatize that baby for life; she/he would be labeled an HIV baby. Please understand that delivering the message for the purpose of saving the infant's life is essential -- and the sooner it is delivered, the better that baby's chance for survival. In the past when dealing with sexually transmitted diseases, we have been successful in protecting confidentiality; we can certainly keep all the same safeguards in place. In any event, any reasonable person would argue that the baby's right to survive must be our first concern.

Now let's talk about the 25% of the newborns who do have the virus and will develop full blown AIDS. Recent medical developments have led the Centers for Disease Control and the N.Y.S. Department of Health to conclude that early diagnosis of the infection is essential in determining the course of treatment.

One of the major concerns in early HIV, is pneumonia associated with the virus and doctors emphasize the importance of prophylaxis treatment to protect the newborn from pneumonia or pneumocystis carinii pneumonia (PCP). Mortality rates for these infants is high -- the median survival time from the first episode is 1 to 4 months. Many of these early deaths can be prevented. Prophylaxis treatment is available and involves administering antibacterial medication before the onset of PCP. However, because it strikes so early, the opportunity is lost if health care providers have no idea of an infant's HIV status. CDC determined that PCP prophylaxis is most effective when administered beginning at one month of age for HIV exposed children.

Another reason for knowing an infant's status at birth or soon thereafter is that HIV infants are subject to a different immunization schedule. For example, you would not use the Sabin or live polio vaccine since this puts the baby at risk for superinfection by the polio virus.

HIV children also require a more aggressive approach to every day childhood diseases which can be fatal because of their defective immune system.

And I'd like to talk to the issue of the mother not wanting to know. I have been repeatedly assured by well-meaning people that if the mother really wanted to know, she would get herself tested. Sounds logical -- but it isn't, of course. When any of us go even for a routine physical examination, there is a sense of dread, sometimes bordering on panic. It takes a certain kind of strength to volunteer to go through testing, particularly when you have reason to believe you have a serious illness -- and too many high risk women do not have that kind of strength, and may, in fact, be

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in denial. In addition, I think it is also true that most individuals will assume that the doctor would pick up on anything that may be wrong and share that information with them. There is no reason for a woman to believe her baby was diagnosed as carrying the HIV virus, and that the hospital would permit them to go home without telling the mother of the infant's condition; unfortunately, the fact is that the doctor does not have the information on the baby's HIV test and undoubtedly assured the mother that "everything was fine."

During my discussions of this issue with individuals who work with HIV cases, I found a sincere belief, particularly among public health workers, that if only more money and more staff were available to do more counseling, the problem would be cured.

Unfortunately, there is no evidence that counseling and voluntary testing initiatives have been successful. I have available in my file studies by the Health Department indicating that these initiatives have, in fact, had little success. In the three month period of time between January 1, 1992 and March 31, 1992, for example, the Health Department study shows there were 268 infants who tested positive through blind testing; of the 268 babies, only 68 were identified through the Department of Health initiatives. And even among the 68 mothers who agreed to be tested and therefore were identified as HIV positive, my conversation with the doctors indicate that a majority of these mothers never came back for the results -- and therefore we had no opportunity to put those babies into treatment.

In conclusion, it must be obvious that once we undertook to do testing of newborns, we cannot walk away from the results; we cannot say: "Well, it's only for statistical purposes; we have to track the disease" -- and then deny those infants the care they need. We cannot claim an invasion of the mother's privacy if we attempt to get that child into treatment as quickly as possible -- and indeed in 75% of the cases to give those babies who are not infected a chance at life.

Those babies, if they were able to give consent, would be pleading for protection from the AIDS virus -- just as adult AIDS victims are insisting on State of the Art medical treatment. We here, in the State Legislature, have to make the determination that we stand in the place of that infant -- and that our highest priority has to be the life of that infant. The secret is out -- that the State of New York has been using babies for statistical purposes -- but has been denying them treatment and the protection they need to save their lives.

NOTE: THE ASSEMBLY HEALTH COMMITTEE ON JUNE 15, 1993 BY A VOTE OF 10 TO 9 VOTED TO HOLD THE BABY AIDS BILL PENDING A STUDY PANEL TO BE CONVENED BY DR. DAVID ROGERS, CHAIRMAN, AIDS INSTITUTE ADVISORY.



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news from
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NETTIE MAYERSOHN

27th ASSEMBLY DISTRICT

Date: June 26, 1996

**BABY AIDS SIGNED INTO LAW
 NEW YORK TO BECOME FIRST STATE IN NATION
 TO MANDATE HIV TESTING OF NEWBORNS**

At a Wednesday morning ceremony in the State Capitol attended by over 50 legislators, Governor George Pataki signed into law legislation sponsored by Assemblywoman Nettie Mayersohn (D-L Queens), known as the "Baby AIDS" bill. The new law will make New York the first state in the nation to authorize the mandatory testing of newborns for HIV, the virus that causes AIDS.

"The Baby AIDS law brings common sense into the testing of infants for HIV," the Governor said. "This legislation will ensure that parents and physicians get the potentially lifesaving information they have been denied for far too long. Every mother should know whether her child has been exposed to HIV so that she and her doctor can take steps to protect the child's health. Now they will."

The State Health Department already tests all newborns for HIV, but because of outdated confidentiality laws surrounding the disease, the results were not given to the mother or to the baby's physician unless the mother specifically requested them. Under the new law, the Governor has already directed the Health Commissioner, Dr. Barbara DeBuono, to add HIV to the state's Newborn Screening program, which routinely tests all infants for eight metabolic conditions.

Mayersohn, who had waged a three year battle against well financed and organized opponents of the legislation, said, "It would have been medical abuse in its cruelest form to continue a policy that withheld vital medical information that can save the lives of the epidemic's most innocent victims. With this new law, we are making it clear that we will no longer allow infants to be used as statistical tools in some scientific experiment. Today we recognize the HIV infant as a living, breathing human being whose right to medical treatment must be respected." X

State Senator Guy Velella, who sponsored the legislation in the State Senate, described the legislation as the "highlight of his legislative career because it would actually save lives." He went on to described the new law as "a victory for common sense"

An estimated 1200 to 1400 infants test positive for the antibody every year in New York, by far the highest rate in the nation. Only 25% of these infants are truly infected while the other 75% are simply carrying their infected mothers' antibodies which their bodies will throw off within 18 months. Unfortunately, if the infected mother breastfeeds, she may transmit the virus to an otherwise healthy child. Under the old system which the new law will replace, almost 60% of these infants left the hospital unidentified and untreated.

Mayersohn and Velella, supported by a growing number of medical, public health and child care organizations, have argued for years that keeping the results secret has caused serious delays in getting the infected infants and mothers identified and directed into appropriate medical and counseling services.



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news from assemblywoman **NETTIE MAYERSOHN**

27th ASSEMBLY DISTRICT

Date: April 14, 1994
FOR IMMEDIATE RELEASE

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MAYERSOHN CALLS FOR REVAMPING OF PRENATAL COUNSELING BILL

Calling it a "proposal with no teeth", Assemblywoman Nettie Mayersohn (D-Queens) called for major revisions in legislation sponsored by Senator Michael Tully and Assemblyman Richard Gottfried, Chairmen of the Senate and Assembly Health Committees respectively, that would mandate health care providers to counsel all pregnant women about AIDS.

Mayersohn, who is sponsoring legislation that would require mothers to be notified when their newborns test positive for H.I.V., favors the concept of mandatory pre-natal counseling but maintains that the Tully/Gottfried legislation simply expands already existing programs that have failed miserably in identifying H.I.V. positive babies and their mothers. New York State Department of Health statistics indicate that these programs fail to identify 60% of the newborns who tested positive in the anonymous tests.

According to the veteran lawmaker, most health care professionals, including many who oppose her legislation, have expressed the belief that a major reason for the failure of these programs is the stringent pre-test counseling procedures mandated by Section 27F of the Public, more commonly known as the "AIDS Confidentiality Law". Mayersohn described 27F as "the cornerstone of the Tully/Gottfried proposal."

Section 27F sets up very elaborate "informed consent" procedures for HIV testing, requiring that mothers be notified of the non-medical consequences of testing positive for the virus, such as possible loss of housing and employment. It also suggests the possibility of using anonymous testing centers in order to

protect privacy and confidentiality. "While this type of counseling might have been appropriate in dealing with the AIDS victims of six or seven years ago who were predominantly gay men, it is detrimental to efforts aimed at persuading pregnant women to undergo medically warranted testing because it actually scares them away from testing."

Mayersohn has called upon Senator Tully and Assemblyman Gottfried to amend their legislation so that HIV counseling and testing for pregnant women would become a routine standard of care, exactly as is done for several other diseases, including Hepatitis B and syphilis, where the rules of "informed consent" are less antagonistic to identification and treatment. "Since recent studies conducted by the National Institute of Health indicate that HIV+ women who are placed on a regimen of AZT during pregnancy can protect the fetus from the disease, pre-natal testing becomes crucial," Mayersohn stated.

"If we can get past 27F", she said, "the doctors with whom I have spoken feel that most pregnant women will agree to be tested. This will enable us to concentrate our resources on those women who resist testing and on those who test positive so that we can make certain that they get the intensive counseling, family support services and medical care for themselves and their babies that they desperately need."

Mayersohn pointed out that her proposal to unblind the anonymous HIV test currently conducted on all newborns in New York State would not conflict with any program of pre-natal care but would simply assure that an infected newborn baby will be given the same medical care as adult victims of this terrible disease.

1"Those newborns cannot give informed consent for testing", she said, "but we in the State Legislature have to make an assumption that they want and are entitled to the same state of the art medical care and treatment that the adult victims of AIDS are demanding for themselves. It is unconscionable for us to continue treating helpless babies as useful, but expendable, statistical tools."



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news from
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NETTIE MAYERSOHN

27th ASSEMBLY DISTRICT

Date:

January 22, 1994

Contact Person:
 William Viscovich

GIVE HIV BABIES A CHANCE

A letter from Assemblyman Richard Gottfried of Manhattan opposing legislation which I introduced on HIV newborns merits careful analysis and discussion.

We begin with the fact that every baby in New York State is tested by the Health Department for the HIV virus along with a number of other diseases; in every case, the test results are given to the parents, except for those unfortunate infants who test positive for the HIV virus. Incredibly, the parents are never notified of the babies' condition -- and those infants and their mothers are sent home without this crucial information. This inhumane policy of neglect has been a virtual death sentence for hundred of infants who have gone untreated and uncared for, yet opponents of my legislation would have us continue a Health Department and an AIDS Institute policy that has failed dismally to identify and treat HIV babies.

Since 1987, when the policy of anonymous testing of newborns was initiated by the Department of Health as a means of tracking the AIDS epidemic, over 10,000 babies have tested positive for the HIV virus. Of the 10,000 babies, 25% are estimated to be infected with the AIDS virus and require immediate medical intervention. But the other part of this tragedy is that 75% of the babies have only the mothers' antibodies -- when the babies test positive, it means the mother has the virus - which they will throw off in a matter of months. These babies can be completely protected from this deadly disease -- if the mother is warned not to breastfeed. We now know that the AIDS virus can be transmitted through breastfeeding, and the urgency of the mother being aware of her condition and that of her baby is acknowledged by everyone on both sides of the debate.

My legislation, Assembly Bill No. A-6747, will require the Health Department to notify parents of their babies' HIV status, just as they do for every other disease for which the babies are tested.

At the heart of the current controversy is the issue of the mother's right "not to know." I am advised by a well organized opposition that it would be a violation of the mother's civil rights and an invasion of her privacy if we give her the information on the HIV status of her baby -- without her requesting that information. Completely ignored in their arguments is the fact that there is another, helpless, human being involved whose basic right to treatment is being violated.

They raise the specters of driving a wedge between a mother and her baby or chasing women out of the health care system, and assure me they are really representing the best interests of the mother and her baby when, in fact, nothing could be further from the truth. As a parent and a grandparent, and as a strong feminist, I have no doubt that the overwhelming majority of women are fiercely protective of their children -- and even those who may be in denial about their own condition -- would want to have

information necessary to provide care and treatment for their babies. Too many babies, mostly poor and minority children, never had a chance. They were sent home only to come back to the hospital months later too late for treatment.

And I must point out the misrepresentation of the success story of the voluntary testing programs initiated by the Health Department in 17 hospitals in New York City where most of the high risk women give birth. According to Health Department statistics for 1992 and up until March, 1993, approximately 17% of the babies were identified through the voluntary testing programs; 33% of the women knew their condition upon admission, leaving 50% of the babies unidentified. One of the hospitals described by Assemblyman Gottfried, Harlem Hospital, achieved a higher success rate because of the determination of the staff to get the mothers to volunteer to be tested; the same program was in place at all of the other hospitals with very dismal results.

One also has to wonder what the AIDS Institute and the Department of Health were doing for HIV infants and their mothers when year after year, since 1987, the grim statistics came in on HIV babies dying premature and agonizing deaths from PCP, the pneumonia that strikes untreated HIV infants usually within the first four months of life. We are advised by the Centers for Disease Controls that those babies, with proper medical care, could have lived into their teens, perhaps long enough to see a cure.

It wasn't until I stumbled upon the Health Department's little secret last year about the use of babies as a means of tracking the AIDS epidemic that suddenly the AIDS Institute and the Department of Health rushed in with new initiatives and new funding -- but with the same old philosophy; if you have a program that doesn't work, throw more money at it.

My legislation is supported by the New York State Medical Society, the New York City Chapters of the Pediatrics Society (where more of the HIV cases are found), by the Association to Benefit Children, a foster care facility that has its own collection of horror stories of attempts to get voluntary consent from biological mothers who cannot be located, and a group of mothers with AIDS who are very supportive and who feel that current policy is completely at odds with their concerns.

Assembly Bill A-6747 will allow us to use current funding in a way that makes sense. When the identity of an HIV baby is revealed to the mother, we can proceed to provide extensive and comprehensive support services for that baby and that family. We have an opportunity now to stop using babies as statistical tools and to give them the same state of the art medical care that adult AIDS victims are rightfully insisting upon and getting. We have to be the voice of those babies who cannot give "informed consent, and who have not been able to communicate their concerns in a way that the AIDS Institute and the Department of Health understand. We have an opportunity to save precious lives, and I and the 50 sponsors of my legislation in the State Legislature intend to do just that.

However, we need the support of ordinary people who have to make it clear that "enough is enough." I urge you to contact your state legislator, and urge their support for Assembly Bill A-6747. For further information or documentation, please call my office, 518-455-4404, or 718-463-1942.



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news from
 assemblywoman
NETTIE MAYERSOHN

27th ASSEMBLY DISTRICT

Date: July 3, 1993

STATEMENT OF ASSEMBLYWOMAN MAYERSOHN
 ON AIDS NOTIFICATION LEGISLATION
 ASSEMBLY BILL NO. 6747

(Prepared for a meeting of the Assembly Health Committee on
 June 15, 1993.)

Assembly Bill No. 6747 -- dealing with the disclosure of information to parents of a newborn who has tested positive for the HIV virus -- introduced me to an issue that for me was shocking and chilling and beyond belief. In fact, when it was first brought up in a conversation with the Medical Society, I did not believe it -- I was sure that there was something here that they were not telling me that would make the policy more rational and less ruthless.

As you may know, babies in New York State are routinely tested at the time of birth for the HIV virus; the purpose of the blind testing program, initiated in 1987, is to track the epidemic. Those infants -- and the figures indicate that since 1987 approximately 7500 infants have tested positive for the virus -- incredibly, those babies are sent home and their HIV status is never disclosed to the parents. (In 1992 there were 1900 babies who tested positive.)

My involvement in this issue has introduced me to a whole new definition of illogical rationalization. I have been lectured at by countless people, who know with godlike certainty that they are acting in the best interests of the mother. They assure me that the mother really did not want to know her own status and telling her would be an invasion of her privacy and her right not to know.

They completely dismiss the fact that there is now another human life involved whose right to medical care -- and, indeed to life, is being violated.

Interestingly, too, some of the same individuals who are demanding that Aids treatment be made available even before the FDA is ready to approve such treatment -- were assuring me that it doesn't make much difference if the HIV baby is treated six months or a year later--when the disease becomes apparent.

But it does make a difference; 75% of the newborns who show up as HIV positive at birth -- are not true HIV cases; they have the mother's antibodies which their own bodies throw off in a matter of months; if the mother is aware of the condition and exercises caution, the babies can escape the virus. The fact is that when a baby tests positive for the virus, it means the mother has the virus -- and, under no circumstances, should she be breastfeeding that baby.

What do the New York State Health Department and the Centers for Disease Control say about breast feeding by HIV mothers: The Department of Health has issued pamphlets recommending that if a woman is known to be HIV infected, she should be warned about the risks of HIV transmission through breast milk and informed not to breast feed. The Centers for Disease Control recommended in 1985 that because the HIV virus has been found in human breast milk and because cases of HIV transmission through breast milk have been documented, women who are HIV infected must not breast feed their infants.

It has also been argued that since breast feeding would take place before the mother had the information of the HIV status of her baby, the information would not be relevant. Certainly we would want that mother to have the information immediately; nevertheless, it is not likely that the virus will be transmitted in the first instance -- but there is no question that prolonged breast feeding increases the risk.

And can you imagine the horror that mother will experience when one year later she discovers that her baby has Aids -- and that she may, in fact, have needlessly transmitted the virus because she did not have the information she needed to protect the infant.

I also heard a colleague argue at a meeting of the Assembly Aids Task Force that it would be unkind to notify the mother that the baby is HIV positive because that would stigmatize that baby for life; she/he would be labeled an HIV baby. Please understand that delivering the message for the purpose of saving the infant's life is essential -- and the sooner it is delivered, the better that baby's chance for survival. In the past when dealing with sexually transmitted diseases, we have been successful in protecting confidentiality; we can certainly keep all the same safeguards in place. In any event, any reasonable person would argue that the baby's right to survive must be our first concern.

Now let's talk about the 25% of the newborns who do have the virus and will develop full blown AIDS. Recent medical developments have led the Centers for Disease Control and the NYS Department of Health to conclude that early diagnosis of the infection is essential in determining the course of treatment.

One of the major concerns in early HIV, is pneumonia associated with the virus and doctors emphasize the importance of prophylaxis treatment to protect the newborn from pneumonia or PCP. Mortality rates for these infants is high -- the median survival time from the first episode is 1 to 4 months. Many of these deaths can be prevented. Prophylaxis treatment is available and involves administering antibacterial medication before the onset of PCP. However, because it strikes so early, the opportunity is lost if health care providers have no idea of an infant's HIV status. CDC determined that PCP prophylaxis is most effective when administered beginning at one month of age for HIV exposed children.

Another reason for knowing an infant's status at birth or soon thereafter is that HIV infants are subject to a different immunization schedule. For example, you would not use the Sabin or live polio vaccine since this puts the baby at risk for superinfection by the polio virus.

HIV children also require a more aggressive approach to every day childhood diseases which can be fatal because of their defective immune system.

And I'd like to talk to the issue of the mother not wanting to know. I have been repeatedly assured by well-meaning people that if the mother really wanted to know, she would get herself tested. Sounds logical -- but it isn't, of course. When any of us go even for a routine physical examination, there is a sense of dread, sometimes bordering on panic. It takes a certain kind of strength to volunteer to go through testing, particularly when you have reason to believe you have a serious illness -- and too many high risk women do not have that kind of strength, and may, in fact, be in denial. In addition, I think it is also true that most individuals will assume that the doctor would pick up on anything that may be wrong and share that information with them. There is no reason for a woman to believe her baby was diagnosed as carrying the HIV virus, and that the hospital would permit them to go home without telling the mother of the infant's condition; unfortunately, the fact is that the doctor does not have the information on the baby's HIV test and undoubtedly assured the mother that "everything was fine."

During my discussions of this issue with individuals who work with HIV cases, I found a sincere belief, particularly among public health workers, that if only more money and more staff were available to do more counseling, the problem would be cured. Unfortunately, there is no evidence that counseling and voluntary testing initiatives have been successful. I have available in my file studies by the Health Department indicating that these initiatives have, in fact, had little success. In the period of time between January 1, 1992 and March 31, 1992, for example, the Health Department study shows there were 268 infants who tested positive through blind testing; of the 268 babies, only 68 were identified through the Department of Health initiatives. And even among the 68 mothers who agreed to be tested and therefore were identified as HIV positive, my conversation with the doctors indicate that a majority of these mothers never came back for the results -- and therefore we had no opportunity to put those babies into treatment. SEE EXHIBIT "A".

In conclusion, it must be obvious that once we undertook to do testing of newborns, we cannot walk away from the results; we cannot say: "Well, it's only for statistical purposes; we have to track the disease" -- and then deny those infants the care they need. We cannot claim an invasion of the mother's privacy if we attempt to get that child into treatment as quickly as possible -- and indeed in 75% of the cases to give those babies who are not infected a chance at life.

Those babies, if they were able to give consent, would be pleading for protection from the AIDS virus -- just as adult AIDS victims are insisting on State of the Art medical treatment. We here, in the State Legislature, have to make the determination that we stand in the place of that infant -- and that our highest priority has to be the life of that infant. The secret is out -- that the State of New York has been using babies for statistical purposes -- but has been denying them treatment and the protection they need to save their lives.

NOTE; THE HEALTH COMMITTEE ON JUNE 15, 1993 BY A VOTE OF 10 TO 9 VOTED TO HOLD THE BABY AIDS BILL PENDING A STUDY PANEL TO BE CONVENED BY DR. DAVID ROGERS, CHAIRMAN, AIDS INSTITUTE ADVISORY COUNCIL.

PLEASE BE ASSURED THAT THIS ISSUE WILL BE BACK ON THE AGENDA DURING THE NEXT SESSION.

NEWS from Senator Serphin R. Maltese Chairman, NYS Senate Elections Committee

FOR RELEASE:

April 6, 1995

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SENATOR MALTESE'S CABLE SHOW FOCUSES ON BABY AIDS BILL

Senator Serphin R. Maltese (Queens) speaks with Assemblywoman Nettie Mayersohn (Queens) on his weekly cable television program about their championing legislation that would help safeguard innocent babies born with HIV by "unblinding" the results of AIDS testing now conducted anonymously on all newborns. The bill was just passed by the Senate after vigorous supporting debate by Senate co-sponsors Senator Guy Velella and Senator Maltese.

"It is an incredible tragedy that these babies are used as statistical guinea pigs with no regard for their welfare," said Senator Maltese. "Early identification can not only enhance and prolong their lives, it can also protect infants who have been exposed but not actually infected.

"What we have done to HIV infants is absolutely, utterly shameful," said Assemblywoman Mayersohn. "The argument that in identifying the infant as HIV positive means we are identifying the mother as HIV positive and thus violating her right not to know is absolutely nonsense. Responsible, caring parents want to know everything there is to know about the condition of their children even if it means facing the truth about their own condition."

The legislators explained that almost 60% of infected newborns leave the hospital unidentified, thus not receiving treatment. Since 1987 all babies born in New York State have been tested for HIV to study the scope of the maternal-newborn AIDS epidemic. As a baby's HIV result also discloses the mother's HIV status, the results are kept secret because of illogical HIV confidentiality laws that allegedly protect the mother's right not to know. That means that the test results cannot be given to parents or doctors.

The bill (S. 2704) now goes to the Assembly it remains in the Health Committee and Assemblywoman Mayersohn and the other Assembly sponsors are using their best efforts to pry it loose so that no more innocent babies lose their lives.

The Senator's show is broadcast on Queens Cable Channel 35 every Wednesday between 8:30 p.m. and 9:00 p.m.

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