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For Immediate Release:
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HIV INFECTED BABIES HAVE RIGHTS TOO

After three years of debate on the issue of HIV testing of newborns, I am still astounded at the arguments of those opposing the "Baby AIDS" bill, legislation which I, together with Senator Velella, introduced in 1993. This legislation would simply require that mothers be told if their newborns test positive for HIV, the virus that causes AIDS.

In 1987, in order to track the spread of the AIDS epidemic, New York State began routinely testing all newborns for the HIV antibody. Since that time, over 12,000 babies have tested positive. Tragically, these tests are conducted on a "blinded" basis and the results are not revealed to the mother or to the child's doctor. As a result, almost 60% of these children are sent home from the hospital without ever being diagnosed or directed into treatment that can enhance, prolong and perhaps save their lives.

Fortunately, 75% of the newborns who test positive for the HIV antibody are not truly infected; they are simply carrying their infected mother's antibodies which their own bodies throw off in a matter of months. But the ultimate horror is that if the mother is not told that she, herself, is infected and she breastfeeds the baby, a known method of HIV transmission, she may actually infect her otherwise healthy newborn.

Opponents of my legislation have argued that since breastfeeding might take place before the mother had the information of the HIV status of her baby, the information would come too late to prevent transmission. This argument is misleading. First, if a woman suspects that she might be infected, she can defer breastfeeding until the results are certain.

Secondly, according to the Centers for Disease Control, the risk of HIV transmission increases with the duration of breastfeeding, so that the mother who breastfeeds for one year, as opposed to breastfeeding at birth, is four times more likely to transmit the virus to her child.

Significantly, the widespread availability and use of the Polymerase Chain Reaction (PCR) test now enables doctors to determine, in most cases within hours of birth, which children are truly infected. Having this information will allow health care providers to immediately direct infected infants and their mothers into appropriate medical programs. Doctors can begin treating these children with bactrim, an antibiotic that prevents pneumocystis carinii pneumonia (PCP), which is often fatal for infected infants. These deaths are preventable if an infected child is identified and if treatment is started prior to the onset of PCP. Once it sets in, it's simply too late.

Equally important, recent developments in the field seem to indicate that if infected infants are treated with AZT within hours of their birth, we may actually be able in some cases to eliminate the virus completely. The treatment must begin, however, no later than 24 hours after birth. Obviously, if the children are not identified, their one chance at life may be lost.

Opponents argue that because HIV transmission from mother to child can be reduced if she receives proper treatment during pregnancy, we should focus on counseling and voluntary testing in the prenatal period. This emphasis on counseling is not a new approach and is in fact included in my legislation. The problem is simply that it hasn't worked in the past. The Department of Health, aware that there was a public health disaster in the making, has, since 1988, invested millions of dollars in counseling programs in New York State hospitals where most high risk women give birth. While some programs were successful in persuading mothers to be tested, the overall results were abysmal. Despite a heavy concentration of money and resources, these programs were able to identify only about 40% of infected newborns -- and the other 60% were leaving the hospitals undiagnosed and unidentified.

In any event, prenatal counseling and testing are useless for babies whose mothers never received prenatal care, an all too common scenario for infected women who may also suffer from other societal problems such as poverty and drug abuse. That woman's infant is still entitled to treatment and a chance at life. As with any other disease, education and prevention are the preferable approach. Nonetheless, as with every other illness, we are still obligated to treat and care for all of those who fall victim to the disease, regardless of when it was discovered. Prevention and treatment cannot be presented as an either-or choice; we have the ability and the obligation to do both.

Most outrageous is the activists' contention that they alone are representing the interests of women, particularly poor women, by protecting their right "not to know" that they, themselves, are infected. Women need to know as soon as possible about their own condition and that of their babies. They need to know so that they can make important health care decisions; they need to know so that they can avoid infecting others; they need to know so that they can make decisions on future pregnancies; they need to know so that they can make arrangements for the care of their children when they, themselves, can no longer care for them. Denying women this information is discrimination in its worst form.

I have been repeatedly told by opponents of the "Baby AIDS" bill that if the mother wanted to know the HIV status of her child she could request the test. But babies are routinely tested at birth, without the mother's consent, for seven different diseases -- and in each case, mothers were given the test results. New mothers have every right to assume that the doctor would pick up on anything as deadly as AIDS and would share the information with them. There is no reason for a woman to believe that her baby was diagnosed as HIV positive, and that the hospital would allow them to go home without telling the mother of the infant's condition. Instead, the mother is undoubtedly assured that "everything is fine," and is sent on her way unaware of the tragedy that faces her.

There are tremendous breakthroughs taking place in AIDS care today and it is medical abuse in its cruelest form to continue a policy that withholds vital medical information that can save the lives of the epidemic's most innocent victims. Passage of the "Baby AIDS" bill will make it clear that we will no longer allow infants to be used as statistical tools in some scientific study, and that the AIDS activists and their allies must stop playing games with children's lives. The time has come to recognize the HIV infant as a living, breathing human being whose right to medical treatment has been brutally violated.

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Date: JUNE 26, 1996

STATEMENT OF NETTIE MAYERSOHN
"BABY AIDS" BILL SIGNING -- JUNE 26, 1996

I WANT TO AGAIN EXPRESS MY HEARTFELT THANKS TO GOVERNOR PATAKI, SPEAKER SILVER, MAJORITY LEADER, BRUNO, AND MY FRIEND AND PARTNER ON THIS IMPORTANT PIECE OF LEGISLATION, GUY VELELLA, AND ALL OF THE LOYAL SPONSORS OF THE "BABY AIDS" BILL. DESPITE INTENSE POLITICAL PRESSURE, WE ALL KNEW THAT THE CURRENT POLICY OF BLIND HIV TESTING OF NEWBORNS HAD TO BE CHANGED AND THAT WE WOULD HAVE TO END A CRUEL PRACTICE THAT DENIED MEDICAL TREATMENT TO THE MOST INNOCENT AND HELPLESS VICTIMS OF THE EPIDEMIC.

AND LET'S MAKE NO MISTAKE ABOUT THIS BILL. IT IS A LANDMARK PIECE OF LEGISLATION. IT MEANS THAT INFANTS WILL NO LONGER BE SENTENCED TO A PREMATURE AND AGONIZING DEATH OF PREVENTABLE PNEUMOCYSTIS PNEUMONIA. IT WILL END A POLICY THAT MAKES US TREAT HIV BABIES DIFFERENTLY THAN WE TREAT BABIES WHO ARE INFECTED WITH SYPHILIS, P.K.U. AND ALL THE OTHER DISEASES FOR WHICH BABIES ARE TESTED; AND FINALLY, IT WILL END THE DISCRIMINATION AGAINST AIDS BABIES BY ALLOWING THEM TO ACCESS THE SAME STATE OF THE ART MEDICAL TREATMENT THAT ADULT AIDS VICTIMS ARE RIGHTFULLY DEMANDING AND RECEIVING FOR THEMSELVES.

JUST LAST WEEK, NEWSPAPERS CARRIED EXCITING AND ENCOURAGING NEWS ABOUT BREAKTHROUGHS IN THE TREATMENT OF HIV AND AIDS -- AND THE MOST IMPORTANT PART OF THE STORY IS THAT IF WE CAN IDENTIFY THE DISEASE EARLY ENOUGH, PARTICULARLY IN NEWBORNS, AND IF WE BEGIN IMMEDIATE DRUG TREATMENT, WE MAY ACTUALLY, IN SOME CASES, BE ABLE TO ELIMINATE THE VIRUS.

OBVIOUSLY, SCIENCE STILL HAS A LONG WAY TO GO BEFORE A CURE FOR AIDS IS FOUND, BUT MODERN MEDICINE HAS PUT US WELL ON THE WAY TO TREATING AIDS AS A CHRONIC DISEASE RATHER THAN AN IMMEDIATE DEATH SENTENCE. THE KEY, HOWEVER, IS EARLY IDENTIFICATION AND TREATMENT. INFECTED BABIES, IF GIVEN THAT CHANCE, MAY ACTUALLY BE ABLE TO LIVE LONG ENOUGH FOR US TO FIND A CURE. WITH THE GOVERNOR'S SIGNATURE TODAY ON THE "BABY AIDS BILL," WE WILL GIVE THEM THAT CHANCE AT LIFE.

I WOULD LIKE TO ADD A NOTE TO WHAT THE GOVERNOR HAS TOLD YOU ABOUT MICHELLE FAUST. SHE WAS ONE OF THE GUTSIEST WOMEN I HAVE KNOWN. I SPOKE TO HER SOCIAL WORKER AT MT. SINAI AND SHE TOLD ME HOW EVERYONE AT THE HOSPITAL WAS IMPRESSED WITH HER COURAGE AND HER STRENGTH. I HAD BEEN IN TOUCH WITH HER DOCTOR, AND WHEN HE TOLD HER THAT THE BABY AIDS BILL WAS GOING TO BECOME LAW, SHE TOLD THE DOCTOR TO RELAY A MESSAGE BACK TO US; THAT MESSAGE WAS "GREAT NEWS, BUT'S IT'S JUST A START.

HER SON, TERRY, IS NOW LIVING WITH MICHELLE'S SISTER IN NORTH CAROLINA WHERE, I AM TOLD, HE IS BEING WELL CARED FOR. MICHELLE WENT TO GREAT LENGTHS TO MAKE SURE THERE WAS SOMEONE WHO WOULD LOVE TERRY AND CARE FOR HIM. OUR PRAYERS ARE WITH HIM.

THERE WERE MANY INDIVIDUALS AND ORGANIZATIONS THAT SUPPORTED THIS LEGISLATION THROUGH THE YEARS, BUT THERE ARE SOME THAT STAND OUT AND REALLY DESERVES A SPECIAL MENTION BECAUSE OF THEIR WILLINGNESS TO TESTIFY AT HEARINGS, GO TO COURT WHEN NECESSARY AND ANSWER ANY QUESTIONS THAT CAME UP.

THEY INCLUDE:

THE NEW YORK STATE MEDICAL SOCIETY
THE NEW YORK STATE ASSOCIATION OF PUBLIC HEALTH OFFICIALS
THE COUNCIL OF FAMILY AND CHILD CARING AGENCIES
THE INDEPENDENT WOMEN'S FORUM
THE ASSOCIATION FOR A SANE AIDS POLICY
ALLIANCE FOR RIGHTS AND RESPONSIBILITIES

DR. C. EVERETT KOOP
DR. MARK RAPOPORT, HEALTH COMMISSIONER, WESTCHESTER COUNTY
DR. MARVIN THALENBERG, HEALTH COMMISSIONER, ROCKLAND COUNTY
DR. STEVEN NICHOLAS, MEDICAL DIRECTOR, INCARNATION CHILDREN'S CENTER.
DR. CONRAD FISHER, COMMUNITY FAMILY PLANNING COUNCIL

AND MOST OF ALL, DR. KEITH KRASINSKI, WHO HAS BEEN A CONSTANT SOURCE OF INFORMATION AND ENCOURAGEMENT. I FIRMLY BELIEVE THAT ALONG WITH THE APPOINTMENT OF DR. DEBUONO AS COMMISSIONER, THE GOVERNOR'S DECISION TO APPOINT DR. KRASINKSI TO THE AIDS ADVISORY COUNCIL IS AN IMPORTANT STEP THAT WILL HELP CHANGE OUR APPROACH TO THE WAY WE TREAT THIS EPIDEMIC.

I ALSO WOULD LIKE TO THANK SOME MEMBERS OF THE PRESS, WHO, THROUGH THEIR COLUMNS, KEPT THIS ISSUE ALIVE. WRITERS SUCH AS JIM DWYER, FORMERLY OF NEWSDAY AND NOW OF THE DAILY NEWS, HELEN MATHEWS SMITH OF THE WALL STREET JOURNAL, NAT HENTOFF OF THE VILLAGE VOICE AND ED KOCH OF THE NEW YORK POST. THEIR WRITING MADE THE PUBLIC AWARE OF THE ISSUE IN THE FACE OF A WELL ORGANIZED LOBBYING EFFORT AGAINST THE BILL.

WITHOUT THE EFFORTS OF ALL THESE PEOPLE, WE WOULD NOT BE HERE TODAY. AND I AM VERY GRATEFUL TO ALL OF YOU.

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news from assemblywoman
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27th ASSEMBLY DISTRICT

Date: June 13, 1996

BABY AIDS BILL SENT TO GOVERNOR
(NEW YORK TO BECOME FIRST STATE IN NATION TO MANDATE HIV TESTING OF NEWBORNS)

After three years of often bitter debate, the State Legislature Thursday passed and sent to the Governor for approval, a bill sponsored by Assemblywoman Nettie Mayersohn (D-L,Queens) and Senator Guy Velella (R-C,Bronx) that will authorize the mandatory testing of newborns for HIV, the virus that causes AIDS. Governor George Pataki, a long time proponent of the legislation, has already stated that he would sign it into law.

The bill had passed the Assembly on Thursday, June 13 by a vote of 123-20. During the debate on the bill, Mayersohn described the state's response to the AIDS epidemic as one of the "darkest periods in the history of infectious disease control." She went on to say that its passage would send a signal that "the state recognizes these babies as living, breathing, human beings who have been denied their right to medical treatment and that we are prepared to right the wrong that we have inflicted upon them."

After the bill passed the Senate that same evening by a vote of 53-6, Velella said, "With all the bills that are passed and signed into law each year, it is rare that we are able to say that what we did actually saves lives, and for that reason, it is perhaps the most significant legislation that I have ever sponsored."

Since 1987, New York has been anonymously testing newborns for the presence of the HIV antibody in order to track the epidemic among women. However, because the state's strict confidentiality laws which prohibit involuntary testing, new mothers have not been given the results. As a result almost 60% of these infants leave the hospital unidentified and untreated.

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.

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.

As an example, Velella pointed to the early administration of bactrim, an inexpensive drug that prevents a particular form of pneumonia often fatal to infected infants. "It's very simple," he said. "If the babies are identified and treated early, they live longer."

"It's been a long haul," said Mayersohn, "but the bottom line is that the safety net will be in place to insure that these infants are given a chance to live long enough for a cure to be found."

FOR IMMEDIATE RELEASE
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MAYERSOHN AND VELELLA RENEW EFFORTS ON BABY AIDS

Signaling the start of a new round of debate over New York State's strict AIDS confidentiality laws, Assemblywoman Nettie Mayersohn(D-Queens) and State Senator Guy Velella (R-Bronx) have reintroduced legislation that will "unblind" the results of HIV antibody tests now conducted anonymously on all newborns in New York State hospitals and inform the mother of the result.

The tests, which have been used to track the spread of the disease since 1987, reveal that 1500 to 1800 infants test positive for the disease every year in New York. State Health Department Statistics reveal that almost 60% of infected newborns leave the hospital unidentified and without being directed into treatment.

The legislation, sponsored by 91 members of the 150 member Assembly and 32 members of the 61 member Senate, has also received support from numerous medical organizations, writers, child advocacy groups and editorial boards throughout the state. Dr. C. Everett Koop, a former U.S. Surgeon General and a leading expert on AIDS, has also come out in support of the bill. Early identification of infected infants is vital in providing the newborns with treatment that can enhance and prolong their lives. In some cases, lives may even be saved by the early identification of infants "at risk" for the virus but not actually infected.

"It's time to stop using infants as nothing more than statistical tools." said Mayersohn. We cannot continue a policy that treats newborns as non-persons and withholds from them the medical treatment they so desperately need. We want to establish that every HIV infant has a right to the same medical care that adults are demanding and receiving and that do not have to suffer agonizing, premature and even unnecessary deaths.

"The faces of the epidemic have changed." said Velella "What was once a disease that effected predominantly gay males is increasingly striking women and children and laws that may have been appropriate seven or eight years ago are wreaking havoc upon the most vulnerable victims of the virus. We have got to begin to treat AIDS as the public health issue that it is rather than the political issue that some have turned it into."

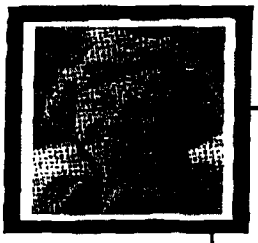
Both Mayersohn and Velella called the position of special interest groups opposing the Baby AIDS bill "inconsistent."

"If we did to adult victims of the virus what we are doing to the children," said Velella, "AIDS activists would be knocking down the doors of the capital in protest, threatening to close down the legislature."

Commenting on the opposition to the legislation, Mayersohn said, "As a mother, as a grandmother, and as a feminist, I deeply resent that certain groups purport to be representing women when they speak out against the Baby AIDS bill. They insist we are violating a woman's privacy and her right "not to know" that she too is HIV positive. Caring, responsible mothers want to know about their own condition and that of their babies. And if a mother is an IV drug user, frightened and in denial, the right of the infant to medical care must take priority over all other considerations."

After two years of often heated debate, 1995 may be the year that the bill finally is passed into law. The Senate Health Committee has already reported the bill to the floor where it is expected to pass and as a member of the State Senate, Governor George Pataki was a co-sponsor of the bill.

Assemblywoman Mayersohn and Senator Velella also announced that the Association to Benefit Children, an agency that cares for children with AIDS, has started a class action law suit on behalf of HIV babies to compel the New York State Health Department to disclose results to parents.



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news from assemblywoman NETTIE MAYERSOHN

27th ASSEMBLY DISTRICT

Date: For Immediate Release: May 4. 1995

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MAYERSOHN APPLAUDS MEDICAL SOCIETY POSITION ON NEWBORN HIV SCREENING

Describing their action as a "common sense approach to a problem that has been defined by twisted logic", Assemblywoman Nettie Mayersohn (D-Queens) expressed her gratitude to the House of Delegates of the Medical Society of the State of New York for adopting a resolution that supports universal testing of newborns for the HIV antibody. (Copy of Resolution Attached). Last week's resolution, passed unanimously by the House of Delegates, reinforces the Medical Society's commitment to insisiting that AIDS be treated as a public helath issue rather than a political one.

Mayersohn, who is sponsoring legislation that would require health officials to identify newborns who test positive for the HIV antibody and to inform their mothers so that they could get appropriate treatment, pointed out that it was the medical society that had first brought the issue to her attention in 1993. Since that time she has been involved in a battle with opponents of the legislation, led by the Gay Mens Health Crisis, the National Abortion Rights Advocacy League, the National Organization for Women and other AIDS activists who claim that such testing violates the mother's right to privacy and would drive women away from the health care system. Mayersohn called these arguments "politically correct but medically and ethically bankrupt" since they totally disregard the right of the newborn to the same state of the art medical treatment that adults are demanding for themselves.

Supporters of the legislation, including the New York State Association of County Health Officials, The Conference of Family and Child Caring Agencies and New York State Health Commissioner, Dr. Barbara DeBuono, believe that early identification of newborns is vital in assuring that they are provided with treatment that can both enhance and prolong their lives.

"We know that with proper care these children can live into their teens," said Mayersohn, "The current policy of not identifying infected newborns immediately is taking away that chance. If we did to adult victims of the virus what we are doing to the babies, they would be closing down the capitol with protests; since the infants cannot protest and organize, we intend to be their voice."

For the last two years, the legislation has fallen one vote short in the Assembly Health Committee despite the fact that it is being sponsored by 93 members of the 150 member body. But with increasing public awareness of the issue and with recent polls indicating that almosty 80% of the public supports mandatory testing of newborns, Mayersohn believes that the bill will finally be reported to the full Assembly for a vote this year. It has already passed the Senate by a vote of 49-9 and Governor Pataki has stated that he will sign it into law when it reaches his desk.

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news from assemblywoman NETTIE MAYERSOHN

27th ASSEMBLY DISTRICT

Date: **FOR IMMEDIATE RELEASE**
April 1, 1995

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NORTHEAST QUEENS LEGISLATORS SUPPORT MAYERSOHN ON BABY AIDS

The entire Northeast Queens state legislative delegation has joined in sponsoring legislation introduced by Assemblywoman Nettie Mayersohn (D-Flushing) known as the "Baby AIDS" bill. The measure requires that mothers be notified of the results of HIV (AIDS) antibody tests now conducted anonymously on all newborns in New York State hospitals. Assembly Members Barbara Clark (D-Jamaica), Brian McLaughlin (D-Flushing), Mark Weprin (D-Fresh Meadows) and Doug Prescott (R-Bayside) along with Senators Leonard Stavisky (D-Flushing), George Onorato (D-Bay Terrace), Emmanuel Gold (D-Flushing) and Frank Padavan (R-Bayside) have all signed onto the bill.

The tests, which have been used to track the spread of the disease since 1987, reveal that 1500 to 1800 infants test positive for the disease every year in New York. State Health Department Statistics indicate that almost 60% of them leave the hospital unidentified and without being directed into treatment. "It offends the senses," said Weprin,"to send home sick children without even letting their parents know that they are ill."

According to Senator Gold, the legislation has received support from numerous medical organizations, writers, child advocacy groups and editorial boards. The legislators' efforts have also been endorsed by Dr. C.Everett Koop, a former U.S. Surgeon General and a leading expert on AIDS.

Early identification of infected infants is vital in providing the newborns with treatment that can enhance and prolong their lives. "In some cases", according to Stavisky, "lives may be saved by the early identification of infants at risk of contracting the virus but not actually infected."

"It's time to stop using infants as statistical tools." said McLaughlin. We cannot continue a policy that treats newborns as non-persons and withholds from them the medical treatment they so desperately need."

According to Onorato, the legislators want to establish that every HIV infant has a right to the same medical care that adult victims are demanding and receiving. "They do not have to suffer agonizing, premature and even unnecessary deaths." he said.

"The faces of the epidemic have changed." said Clark, "What was once a disease that affected predominantly gay males is increasingly striking women and children. Laws that may have been appropriate seven or eight years ago are wreaking havoc upon the most vulnerable victims of the virus. We must begin to treat AIDS as the public health issue rather than a political issue."

Mayersohn called the position of special interest groups opposing the Baby AIDS bill "inconsistent."

"If we did to adult victims of the virus what we are doing to the children," she said, "AIDS activists would be knocking down the doors of the capital in protest, threatening to close down the legislature. As a mother, as a grandmother, and as a feminist, I deeply resent that certain groups purport to be representing women when they speak out against the Baby AIDS bill. They insist we are violating a woman's privacy by telling her that she is HIV positive, but caring, responsible mothers want to know about their own condition and that of their babies. Even if a mother is an IV drug user, frightened and in denial, the right of the infant to medical care must take priority over all other considerations."

According to Padavan and Prescott, 1995 may be the year that the bill finally is passed into law. The Senate Health Committee has already reported the bill to the floor where it is expected to pass.

Governor Pataki, who cosponsored the bill during his tenure as a State Senator, has indicated his continuing support for the legislation and has indicated that he will sign it into law if the bill is passed by the legislature.

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Special News Release
New York State Legislature

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FOR IMMEDIATE RELEASE
May 23, 1994

MAYERSOHN/VELELLA: AIDS INSTITUTE IGNORED REPORT ON BABY AIDS

Assemblywoman Nettie Mayersohn (D-Queens) and Senator Guy J. Velella (R,C-Bronx/Westchester) are demanding to know why a report from the AIDS Institute supporting their Baby AIDS legislation was never publicly released.

The legislators say the never-released report, which supports their legislation to unblind the currently anonymous HIV test performed on all newborns across the State (S.5617B/A.6747B), is yet another example of AIDS being the only politically protected disease.

The existence of the report written in December 1993 by the AIDS Institute Standing Committee on the Care of Children and Adolescents with HIV Infection, was discovered only recently by Newsday reporter Jim Dwyer during an interview with the Standing Committee Chairman.

The lawmakers say the lack of public attention to the report is no surprise since it contradicts the position of another arm of the AIDS Institute, the Sub-Committee on Newborn Screening, which has vocally opposed the Velella/Mayersohn bill.

"It's obvious to me that the AIDS Institute created a new sub-committee that would oppose our legislation when it became clear the original standing committee supported the Baby AIDS bill," said Mayersohn. "I'm quite sure this was an intentional strategy by the special interest groups that control policy at the AIDS Institute to hand-pick members who would produce a report opposing our bill."

The Standing Committee report, prepared by members who are mostly pediatricians involved with the care of infants and children with HIV, unanimously agreed that " the identification of newborns with HIV infection is a desirable goal...that is not being met adequately at this time." A majority of its members went further and recommended that the unblinding of the current test would be the first step in that direction.

"We want to know why legislators who will consider this legislation and certainly we as sponsors of the bill, were not aware of this report," said Velella. "I would like to hear an explanation as to why this report was not considered by the full AIDS Institute Advisory council in the same manner as the sub-committee that opposed our bill."

Mayersohn and Velella have formally requested an investigation into the matter from New York State Health Commissioner Mark Chassin and AIDS Institute Director Nilsa Gutierrez.

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Note to Editors: Assemblywoman Mayersohn's and Senator Velella's letter is included for your information. Copies of the report are also available.

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August 30, 1993

HIV BABIES HAVE RIGHTS TOO

Anyone, even those among us who have never been exposed to the issue of HIV testing of newborns, could reject out of hand the arguments made by Catherine Lynch, Assistant Director of Public Policy, Gay Mens Health Crisis, in her recent Viewpoint article (With Advice and Consent, Newsday, August 24, 1993). These same arguments have been repeated time and time again by people who are determined that there be no deviation from the orthodoxy of strict confidentiality surrounding the AIDS issue, even if it means sacrificing the most innocent and most vulnerable among us.

Assembly Bill 6747, which I introduced during the 1993 legislative session of the legislature, would provide for the unblinding of currently anonymous HIV tests now conducted on every newborn in New York State so that mothers could be informed of their child's HIV status. Among the "misguided legislators" (Ms. Lynch's description) who support the legislation are liberals, conservatives, Democrats, Republicans, upstate and downstate representatives, most of whom have a track record of support on gay rights and civil rights issues. However, in this instance, we refuse to be so rigid as to defy common sense and our own sense of morality. We refuse to accept the point of view that children are appendages with no rights and entitlements of their own.

In 1987 the New York State Health Department set up an anonymous HIV testing program for newborns in order to track the AIDS epidemic in the state. Since its inception, close to 8,000 infants in New York State have tested positive for the virus, 1900 of them in 1992 alone. Incredible as it may seem, the parents of the children who test HIV positive are never notified of the results. Among all the tests that are routinely done on newborns, this is the only area in which vital medical information is withheld from parents.

When I first learned of this situation in a conversation with the State Medical Society, (which fully supports my legislation), I found the policy so unbelievable that I checked and rechecked the information with the State Health Department. The Department indeed confirmed that we were sending HIV positive babies home without informing their parents of the test results, and so I introduced this legislation, convinced that there could be no real opposition. After all, how in the world can anyone justify denying HIV infected children the same access to specialized care and treatment that AIDS activists are rightly demanding in demonstrations across the country?

Things, however, did not work out as I expected. My involvement in this issue 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, we are acting in the best interests of the mother. They assure me that these mothers really do not want to know their own status -- HIV babies are born to infected women -- and telling them would be an invasion the mother's privacy and her right not to know.

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But the same people who are involved in a desperate struggle to enhance medical treatment for AIDS victims are willing to completely dismiss the fact that there is now another human life involved whose fundamental right to medical care and indeed to life itself is being violated.

These same individuals who are demanding that AIDS treatment be made available even before the FDA is ready to approve such treatment are 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 matter. It matters to the 25% of the newborns who are truly infected; pediatricians tell us they should be brought into treatment as soon as possible in order to ease their suffering and prolong their lives. But, most importantly, it matters to the 75% of these babies who show up as HIV positive at birth who are not infected but are only carrying the mother's antibodies which their own bodies throw off in a matter of months. Those babies can escape the virus if the mother is aware of the condition and exercises caution. The Federal 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 well documented, women who are HIV infected should be warned not to breast feed their infants.

Ms. Lynch makes the argument that since breast feeding would have taken place within the three weeks before the mother had the information regarding the child's HIV status, notification would be useless; the virus would have already have been transmitted. Ms. Lynch is being disingenuous in presenting this argument; she is, I am certain, aware that it is not likely that the virus will be transmitted immediately, but it is also well known that prolonged breast feeding increases the infants's risk of infection.

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. 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. Nevertheless, I cannot be convinced that these women would not want to have the information that we are withholding from them. And I can readily imagine the horror a mother will feel when one year later she discovers that her baby has AIDS -- and that she may, in fact, have needlessly transmitted the virus because she was denied the information she needed to protect the infant.

But even if there are some women who would insist that their right "not to know" be considered sacrosanct, the most ardent feminists, and I count myself among them, would argue that once a woman has brought her baby to term, she has a legal and moral responsibility to provide the care the infant needs to sustain life.

Ms. Lynch then goes on to cite the cases of two pregnant woman who were given erroneous information on their HIV test results. They had been mistakenly told they tested positive, and the impact on their lives was dramatic; one considered an abortion, while the other contemplated suicide. One could make the same argument for withholding information on any terminal illness, but the cases Ms. Lynch cites only point up the importance of accuracy in testing procedures; they have little to do with the debate on withholding vital information from parents on the health of their baby.

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It is inconceivable that Ms. Lynch cannot distinguish between the message and the messenger. The fact is that women with AIDS do have a disease from which there is no escape; I am only asking that the message be delivered in time to give their babies the medical treatment they need, and to give those infants who are not yet infected, a chance at life.

Ms. Lynch talks about the importance of voluntary testing and counseling programs now operating in the State. While these programs are certainly important, there is no evidence that any of the Health Department initiatives have been impressively successful. A recent Health Department study indicates that in the three month period between January 1, 1992 and March 31, 1992, there were 268 infants who tested positive in hospitals where high risk women and counseling services are concentrated. Only 68 of these children were identified through the voluntary programs. My legislation would, in fact, give us an opportunity to identify and provide intensive counseling and support services to those mothers whose babies have tested positive.

In any event, 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 continue to deny those infants the care they need. We cannot cling to the claim of 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 in the State Legislature have to make the determination that we stand in the place of the infant who is unable to give consent -- and that our highest priority has to be the life of the 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.

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