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THE “BABY AIDS” BILL

*Assemblywoman Nettie Mayersohn**

To begin with, I want to express my thanks to the Fordham University School of Law for giving me the opportunity to share with you the background of the “Baby AIDS” Bill,¹ a very controversial piece of legislation I introduced in 1993.

The legislation adds a new section, § 2500-f, to the Public Health Law requiring the New York State Commissioner of Health to establish a comprehensive program for the testing of newborns for the Human Immunodeficiency Virus (HIV) or the presence of HIV antibodies.² In addition, the Health Commissioner will be required to promulgate regulations governing testing implementations, counseling, tracking, disclosure of results pursuant to § 2783 of the Public Health Law, follow-up reviews and educational activities.³

The testing of newborns envisioned under this bill is specifically exempted from the informed consent requirements of Public Health Law § 2781, which requires pre-test counseling and written consent.⁴ These two requirements are obviously inappropriate for newborns. Under this bill, the Health Commissioner will be free to conduct the required HIV testing in the same manner as, and in conjunction with, the mandatory testing already done on newborns for seven other diseases pursuant to Public Health Law § 2500-a.⁵ Those diseases include PKU, sickle cell trait, syphilis, and hepatitis.⁶

The story begins with a meeting that I had with the State Medical Society. A representative from the State Medical Society told me that he had an issue that would make everything else I was doing pale in significance. He then proceeded to tell me about AIDS babies. Every child born in the state of New York is tested

* In 1977, Ms. Mayersohn was the New York State Delegate to the International Women’s Conference and the recipient of the National Conference of Christians and Jews “Builders of Brotherhood” Award. In 1989, Assemblywoman Mayersohn was awarded “Legislator of the Year” by the New York State Chapter of the National Organization for Women. Immediately prior to her election to the Assembly, Ms. Mayersohn was the Executive Secretary to the New York State Crime Victims Board.

1. Assembly Bill 6747 (1993 Legislation) (on file with author).

2. N.Y. PUB. HEALTH LAW § 2500-f (McKinney Supp. 1997).

3. *See id.*

4. N.Y. PUB. HEALTH LAW § 2781 (McKinney 1993).

5. N.Y. PUB. HEALTH LAW § 2500-a (McKinney 1993).

6. *See id.*

anonymously for the HIV antibody.⁷ Somewhere between 1,500 and 1,800 babies test positive every year.⁸ Yet, we were not permitted to tell anyone—not the mother, the doctor, nor the guardian—that the baby had tested positive and was at risk for a deadly disease.⁹

I am a pragmatic politician. I got into politics not by a law degree; I got involved as a community activist. I had a very extensive background in dealing with people and I felt that there had to be some rationale for a policy that seemed so cruel and irrational. I did not disagree with the need for such testing. The need was clear when one considered that New York State has the highest number of pediatric AIDS cases in the nation.¹⁰ I did take issue with the fact that when a newborn tested positive, nothing was done to get the infants into treatment.

Since 1987, the Department of Health has been routinely testing all newborns in the state for the HIV antibody.¹¹ The testing program was initiated by the Centers for Disease Control and Prevention in 43 states and its purpose is to track the spread of the epidemic among women of child bearing age and their children.¹² To date, over 12,000 people have tested positive for the HIV antibody in New York State alone.¹³ Tragically, these tests were conducted on a “blinded” basis and the results were not to be revealed to the mother or to the child’s doctor.¹⁴ Statistics compiled by the New York State Department of Health during 1993-94 reveal that almost 60 percent of these babies were sent home from the hospital without ever being diagnosed or directed into treatment that could enhance, prolong or even save their lives.¹⁵ Unlike children suffering from other diseases for which the state regularly tests at birth,¹⁶ children born with the HIV antibody were routinely denied the op-

7. NEW YORK STATE AIDS ADVISORY COUNCIL, REPORT OF THE SUBCOMMITTEE ON NEWBORN SCREENING 7 (January 31, 1994) (on file with author) [hereinafter ADVISORY COUNCIL REPORT].

8. *Id.*

9. *Id.*

10. CENTERS FOR DISEASE CONTROL AND PREVENTION, *National AIDS Clearinghouse Listing*, <http://www.cdcnac.org:72/00/4/midyear_96/table1.txt>.

11. See ADVISORY COUNCIL REPORT, *supra* note 7, at 7.

12. *Id.*

13. Request for Proposal from Diane Jones Ritter, Office of Public Health, New York State Department of Health to Nettie Mayersohn (Sept. 26, 1994) (on file with author)

14. See ADVISORY COUNCIL REPORT, *supra* note 7, at 6-7.

15. NEW YORK STATE HEALTH DEPARTMENT, Obstetrical Initiative Testing Data for the periods 7/1/93-9/30/93 and 4/1/94-6/30/94 (on file with author).

16. N.Y. PUB. HEALTH LAW § 2500-a (McKinney 1993).

portunity to receive treatment because of our strict adherence to confidentiality laws that say we cannot tell a mother that she is infected and that her child is at risk. This is just another example of how we have exempted HIV from the standard public health procedures that have worked so well with other communicable diseases.

Fortunately, approximately 75 percent of newborns that test positive for the HIV antibodies are not truly infected; they are simply carrying their infected mothers' antibodies which their own bodies throw off in a matter of months.¹⁷ But the ultimate horror is that if the mother is not told that she is infected and she breast-feeds a healthy baby, there is a 14 percent additional risk that the virus will be transmitted through breast-feeding.¹⁸

Opponents of my legislation argue that since breast-feeding 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.¹⁹ This argument is specious. First, if a woman suspects that she might be infected, she can defer breast-feeding until the results are certain. Secondly, according to the Centers for Disease Control and Prevention, the risk of HIV transmission increases with the duration of breast-feeding, so that the mother who breast-feeds for one year, as opposed to breast-feeding at birth, is four times more likely to transmit the virus to her child.²⁰

Significantly, the widespread availability, and use of, the Polymerase Chain Reaction (PCR) test now enables doctors to determine more quickly which children are truly infected.²¹ Having this information will allow healthcare providers to more quickly direct infected infants and their mothers into appropriate medical programs. Doctors can begin treating these children with Bactrim, an antibiotic that helps to prevent *Pneumocystis Carinii* Pneumonia (PCP), which is often fatal for infected infants.²² These deaths are often preventable if an infected child is identified, and treatment is started prior to the onset of PCP.²³

17. See ADVISORY COUNCIL REPORT, *supra* note 7, at 14.

18. *Id.* at 16.

19. *Id.* at 18-19.

20. *Id.* at 16 (Table 4).

21. See *New Test Detects Aids Viral Load* <<http://hightech.cplaza.or.jp/1996/19960715/19960718/02/emain.htm>>.

22. R.J. Simonds et al., *Prophylaxis Against Pneumocystis Carmini Pneumonia Among Children With Prenatally Acquired Human Immunodeficiency Virus Infection in the United States*, 332 NEW ENG. J. MED. 786 (1995).

23. *Id.* at 789.

Opponents argue that because HIV transmission from mother to child can be reduced if the mother receives proper treatment during pregnancy, we should focus on counseling and voluntary testing in the prenatal period.²⁴ This emphasis on counseling is not a new approach. In fact, I included funding for counseling in earlier versions of my legislation.²⁵ The problem, however, is simply that it has not worked in the past.

Since 1988, the New York State Department of Health had invested millions of dollars in counseling programs in the City hospitals where most high risk women gave birth.²⁶ The goal of these programs was to try to encourage pregnant women and new mothers to agree to voluntary HIV testing for their infants and themselves. While a few programs succeeded in persuading mothers to be tested, the overall results were dismal.²⁷ Despite a heavy concentration of money and resources, these programs were able to identify only about 40 percent of infected newborns.²⁸ The other 60 percent left the hospitals undiagnosed and untreated.²⁹

In any event, prenatal counseling and testing are useless for those babies whose mothers never received prenatal care, an all too common scenario for HIV infected women who may also suffer from other societal problems, such as poverty and drug abuse.³⁰ That woman's infant is still entitled to treatment and a chance at life. As with any other disease, education and prevention are the important first steps. 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 is discovered. We have the ability and the obligation to focus our resources on both prevention and treatment.

I was outraged by a policy that completely violated the rights of infants to medical care. Immediately upon becoming aware of the situation, I introduced the "Baby AIDS" bill.

24. Janet Massaro, *Don't mandate HIV-Test Disclosure*, THE RECORD (Troy, N.Y.), Nov. 15, 1995, at 33A.

25. See Assembly Bill 6747 (1993 Legislation) (on file with author).

26. New York State Budgets (1988-1992) for the Department of Health Obstetrical Initiative.

27. NEW YORK STATE DEPT. OF HEALTH, Obstetrical Initiative Testing Data by Hospital Site (July 1, 1993) (on file with author).

28. See *supra* notes 15-16 and accompanying text.

29. *Id.*

30. See ADVISORY COUNCIL REPORT, *supra* note 7, at 25.

As soon the information became public, the support across the state was incredible.³¹ Editorial boards of every major newspaper in New York State: The New York Times, The New York Post, The Wall Street Journal, The Albany Times Union, The Washington Post, all supported my legislation.³² I also received countless letters, including support from C. Everett Koop who said "absolutely mothers should be told when their babies are infected."³³ However, not all rejoiced over this legislation. I found myself at war with many of the groups that I had, in the past, supported.

I was disappointed by the position taken by the gay activist organizations, civil libertarians, and some feminist groups. Listening to the opposition to the legislation, you would think I was giving these women the disease, rather than giving them the information they needed to make vital healthcare decisions. Underlying their concern about civil rights was a paternalistic attitude which implied that poor women were incapable of dealing with bad news about their own health and that of their children. The argument was made over and over that these women would flee the healthcare system.³⁴ My own experience as a mother and as a grandmother is that women, no matter what their economic status—rich or poor—if confronted with a threat to the health of their babies, will do everything to protect and care for their children.

Opponents of this legislation argue that if the mother wanted to know about her condition or that of the baby, she could request a test.³⁵ But why in the world would she? She knows that she and the baby have gone through a battery of tests, and she has every right to assume that they were tested for HIV. Further, she has every right to assume that if they had tested positive, she would have been given the test results. Instead, the mother undoubtedly was told that everything was fine and sent home, only to return

31. See *Aids Babies*, WALL ST. J., Mar. 26, 1996, at A18; *Aids Babies Deserve Help, Now*, N.Y. TIMES, June 25, 1995, at A14; *Aids Babies Pay the Price*, N.Y. TIMES, Aug. 13, 1993, at A26; *Aids Tests for Babies*, WASH. POST, June 17, 1995, at A16; *Albany Flunks its AIDS Test*, DAILY NEWS (N.Y.), Mar. 19, 1995, at 34; *Clocks Ticking on AIDS Babies*, DAILY NEWS (N.Y.), June 27, 1995, at 24; *Finally Sanity About Aids*, ALB. TIMES UNION, Oct. 12, 1995, at A14; *If Only Babies*, DAILY NEWS (N.Y.), May 15, 1995, at 22; *Mothers Babies and AIDS Tests*, WASH. POST, May 26, 1995; *Saving Babies*, N.Y. NEWSDAY, Mar. 20, 1995, at A26.

32. *Id.*

33. Letter from C. Everett Koop, M.D., Senior Scholar, Koop Institute at Dartmouth, to Nettie Mayersohn, Assemblywoman 27th District, The Assembly State of New York (Dec. 15, 1994) (on file with author).

34. See Massaro, *supra* note 24, at 33A.

35. *Id.*

months later to hear the devastating news about her own condition and that of her baby.

My opponents would have the public believe that mandatory testing harms the "trusting relationship" between the doctor and the mother.³⁶ I have spoken to mothers who discovered their children's condition months after they left the hospital who believe that they have been lied to by the healthcare system. No one can truly believe that a healthcare system that lies to parents is a healthcare system that anyone would ever trust again.

By relying on blinded testing, we are in no way protecting women. Women need to know as soon as possible about their own condition and that of their babies so they can make immediate healthcare decisions; so they can make decisions on future pregnancies; so they can make arrangements for the care of their children if or when they, themselves, can no longer care for them. Denying women this information is discrimination in its worst form. Any woman entering the hospital to give birth understands that the baby may be born with medical problems. What she does not need is a paternalistic society that decides what information she can cope with and how much should be withheld.

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. Enactment of the "Baby AIDS" legislation made it clear that we will no longer allow infants to be used as statistical tools in some scientific study. We must now question the nationwide policy of treating a communicable disease as deadly as AIDS as a privacy and civil rights issue rather than the extremely serious health problem it has become. Despite billions of dollars on education and research, the rate of infection among women is on the rise which, if unchecked, will result in a growing population of infected women and children.³⁷ New York State decided to stop playing politics with children's lives and began recognizing the HIV infant as a living, breathing human being whose right to medical treatment had been brutally violated.

In conclusion, it must be obvious that once we undertook to test newborns for statistical purposes, we could not walk away from the results. We could not say: "Well, we needed the data to track the

36. *Id.*

37. THE WORKING COMMITTEE ON HIV, CHILDREN, AND FAMILIES, FEDERATION OF PROTESTANT WELFARE AGENCIES, INC., FAMILIES IN CRISIS REPORT OF THE COMMITTEE ON HIV, CHILDREN, AND FAMILIES 7-8 (1996).

disease," and then deny those infants the care they need. These babies, if they were able to give consent, would be pleading for protection just as adults living with AIDS are insisting on state of the art medical treatment. We in the State Legislature decided to stand in place of the infant.

Under the new law, the New York State Health Commissioner will now be authorized to treat pediatric HIV and AIDS in the same manner as other diseases for which newborns are tested.³⁸ Mandatory testing will end the discrimination now faced by HIV exposed and infected infants. By mainstreaming the disease in this manner, much of the fear and stigma now surrounding HIV testing will be removed. Now that the public is aware that the failed policies of the past are a premature death sentence for helpless infants, there is much closer scrutiny and a recognition of the urgent need to change direction in the way in which we deal with this disease.

Recent statistics received from the Health Department on the number of HIV infants identified and linked to treatment indicate an astounding success rate of 98.8 percent.³⁹ The follow-up further shows women are not fleeing the healthcare system. Rather, they and their infants are being directed into treatment.⁴⁰ Mandatory testing of infants and notification to parents of test results is working—even beyond our expectations.

38. N.Y. PUB. HEALTH LAW § 2500(a) (McKinney 1993 & Supp. 1997).

39. NEW YORK STATE DEPARTMENT OF HEALTH, NEWBORN HIV TESTING PROGRAM UPDATE (Feb. 1 to July 31, 1997).

40. *Id.*

