THE POLITICS OF PEDIATRIC AIDS

Imagine having acquired immunodeficiency syndrome ("AIDS").[1] Now imagine your baby having AIDS. For a rapidly growing number of women in the United States,[2] there is no need to imagine — AIDS is a reality for them and their children. Many pregnant women with human immunodeficiency virus ("HIV")[3] are not even aware that they are HIV infected or that they have transmitted HIV to their children.[4] Although AIDS poses a significant threat to women of reproductive age[5] and women of color,[6] far too many of these women are not counseled about HIV or tested for the virus at any point during their prenatal care. Some of these women have spoken out, claiming that they wished they

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[1] The term "AIDS" is being used to refer to the entire spectrum of infection which begins with human immunodeficiency virus, commonly referred to as HIV, and results in AIDS.

[2] Between 1985 and 1990, the incidence of AIDS in women in the United States increased from 6.6 percent to 11.5 percent. Kevin J. Curnin, *Newborn HIV Screening and New York Assembly Bill No. 6747-B: Privacy and Equal Protection of Pregnant Women*, 21 FORDHAM URB. L.J. 857, 862 (1994) (citing AIDS POL'Y & L., June 26, 1991, at 9). In 1993, there were 16,995 female AIDS cases reported in the United States, constituting 16.3 percent of reported cases. *See* NEW YORK STATE DEP'T OF HEALTH, AIDS IN NEW YORK STATE 6 (Dec. 1993) [hereinafter AIDS IN NEW YORK]. Between 1982 and 1984, women constituted only nine percent of the total AIDS population in New York State. *See* NEW YORK STATE DEP'T OF HEALTH, AIDS SURVEILLANCE QUARTERLY UPDATE 7, 11 (June 1993) [hereinafter AIDS SURVEILLANCE UPDATE]. Between 1991 and 1993, this percentage had increased to 22 percent. *Id.*

[3] HIV is transmitted by sexual contact, intravenous drug use, blood transfusions, and by maternal transmission. For a more thorough discussion of HIV transmission, see Gerald H. Friedland & Robert S. Klein, *Transmission of the Human Immunodeficiency Virus*, 317 NEW ENG. J. MED. 1125 (1987). The predominant route of exposure for women is through intravenous drug use, which accounts for 60 percent of total cases among women. *See* AIDS SURVEILLANCE UPDATE, *supra* note 2, at 7, 12. For adolescent girls (13-19 years), the leading cause of transmission is heterosexual contact. *Id.* at 7.

[4] *See* Jim Dwyer, *They Want to Know; Law Kept Women in the Dark That Their Babies Had HIV*, NEWSDAY, June 13, 1994, at A2. *See also* Nat Hentoff, *When Good People Become Accomplices in Kids' Deaths*, THE VILLAGE VOICE, Jan. 10, 1995, at 21 (noting that permitting a mother, who has just given birth, to leave the hospital without knowing that she is HIV-infected could be considered child neglect and abuse by the hospital since the mother may inadvertently infect her child through her breastmilk).

[5] In 1991, the Center for Disease Control and the World Health Organization reported that HIV was the fifth leading cause of death in the United States for women of childbearing age. Carol Beth Barnett, *The Forgotten and Neglected: Pregnant Women and Women of Childbearing Age in the Context of the AIDS Epidemic*, 23 GOLDEN GATE U. L. REV. 863, 894 (1993). According to the Department of Health, AIDS is also the fifth leading cause of death for young women in New York State. *See* AIDS IN NEW YORK, *supra* note 2, at 1. AIDS is the number one cause of death for 20-39 year old women in New York City. *See* AIDS SURVEILLANCE UPDATE, *supra* note 2, at 7.

[6] Nearly 83 percent of women with AIDS are women of color: 52 percent are black and 30.6 percent are Hispanic. REPORT OF THE SUBCOMMITTEE ON NEWBORN HIV SCREENING OF THE NEW YORK STATE AIDS ADVISORY COUNCIL 5 (Feb. 10, 1994) [hereinafter SUBCOMMITTEE REPORT].

had known of their HIV status before they delivered.[7] Since it is unclear when HIV is transmitted from mother-to-child, early detection of the mother's HIV status yields the greatest chance that an HIV-infected newborn will receive treatment.[8] Furthermore, identifying a woman's HIV status early in the pregnancy would provide her with the fullest range of treatment options, and enable her to make more informed decisions about family planning.[9]

Despite the benefits of early HIV detection, efforts by the medical community in New York State to prevent the spread of AIDS through mandatory counseling and testing measures have been thwarted by powerful special-interest groups.[10] Unlike other epidemic diseases, there are unique social issues surrounding AIDS.[11] Most significantly, AIDS, which is commonly perceived as a "gay disease," not only carries the stigma of a sexually transmitted disease,[12] but also carries the stigma of homosexuality.[13] Even today, with all the publicity and attention surrounding AIDS, HIV-infected persons may be subject to discrimination and social ostracism.[14] Due to the sensitivity surrounding AIDS, the disease has

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7 *See, e.g.*, Dwyer, *supra* note 4 (interview with HIV-infected mothers).

8 SUBCOMMITTEE REPORT, *supra* note 6, at 13. This treatment may include prevention of pneumocystis carnii pneumonia and the use of immune globulin to prevent serious bacterial infections. *Id.* at 15.

9 *Id.* at 13.

10 Organizations such as the Gay Men's Health Crisis ("GMHC"), the National Organization for Women ("NOW"), the National Abortion Rights Action League and the American Civil Liberties Union, generally oppose mandatory counseling and testing programs. Jim Dwyer, *Politics is Killer of HIV Babies*, NEWSDAY, Sept. 21, 1994, at 2. The GMHC is concerned with eroding the confidentiality protections of gay males. NOW and the abortion group worry that mandatory testing measures could lead to fetal rights and thus expose legalized abortion to attack. John Leo, *Babies Have Rights, Too*, U.S. NEWS & WORLD REPORT, May 1, 1995, at 23.

11 Marcia Angell, *A Dual Approach to the AIDS Epidemic*, 324 NEW ENG. J. MED. 1498 (1991).

12 Even though HIV is transmitted by sexual contact - among other things - it is not classified as a sexually transmitted disease. *See* New York State Soc'y of Surgeons v. Axelrod, 555 N.Y.S.2d 911 (1990) (upholding decision by the Commissioner of Health not to designate AIDS as a communicable and sexually transmitted disease).

13 Angell, *supra* note 11. AIDS was at first almost exclusively a disease of homosexual men. *Id.* Gay men continue to constitute a majority of U.S. AIDS cases. *See* AIDS IN NEW YORK, *supra* note 2, at 6 (reporting that in 1993, 'men who have sex with men' constituted 46.6 percent of the total reported cases in the United States). *But see* Angell, *supra* note 11, at 1498 (pointing out that "AIDS is no longer an obscure disease known only to the medical and homosexual communities; it is now a household word, of concern to most Americans and frightening to many.").

14 *See* Roger Doughty, *The Confidentiality of HIV-Related Information: Responding to the Resurgence of Aggressive Public Health Interventions in the AIDS Epidemic*, 82 CAL. L. REV. 113, 124-25 (1994) ("[A] person with AIDS or HIV could lose his or her job, housing, health care, friends, family, and other necessities of life."). *See also* Curnin, *supra* note 2, at 879 ("AIDS victims and persons known to be HIV-positive are routinely subject to direct and indirect discrimination in many forms.") (footnote omitted).

become not only a medical concern, but also a political one.[15] As described by one commentator, AIDS is the first epidemic to be defined "socially and politically rather than medically."[16] While protecting HIV-infected persons against discrimination and stigmatization is a legitimate concern, allowing AIDS prevention and treatment to be controlled by political considerations, rather than medical ones, has cost many lives.

In order to spare others the tragedy of AIDS, routine HIV testing should be incorporated into prenatal care. Early HIV detection could help prevent transmission of the virus from mother-to-fetus. It could also mean early treatment that results in prolonged life for infected newborns. Undeniably, confidentiality, societal, and discriminatory concerns must be considered in implementing any such testing program. However, these concerns should be dealt with by social and political measures, not epidemiologic ones.[17]

Part I of this Note briefly discusses the medical background of pediatric AIDS. Part II explains New York State's anonymous newborn screening program, and analyzes current legislation that would require the newborn tests to be "unblinded" so that mothers could be told of the results. Part III examines the benefits of early HIV detection through routine testing incorporated into every woman's prenatal care. Part III also describes a recent study, known as ACTG 076, and analyzes how the favorable results of this study establish zidovudine treatment as a viable option for HIV-positive pregnant women. Part IV examines the disadvantages of alternative testing and counseling measures. Part V addresses the ethical and constitutional concerns related to routine HIV screening. These concerns include infringement of privacy rights, deprivation of liberty and equal protection. In conclusion, this Note urges that New York State health officials be less concerned with politics and more concerned with saving lives, thus incorporating routine HIV testing into every woman's prenatal care.

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15 *See* Hentoff, *supra* note 4 ("[W]here HIV is concerned, treatment becomes shaped and distorted by politics.").

16 Peter Hellman, *Suffer The Little Children: The Rising Storm Over The Law That Keeps HIV-Positive Newborns From Early AIDS Treatment*, N.Y. MAG., Feb. 21, 1994, at 26 (quoting former New York City Health Commissioner Stephen Loseph). *See also* Angell, *supra* note 11, at 1498 ("In addition to the medical and economic issues surrounding AIDS, there are social issues unique to this epidemic that have greatly complicated our response to it.").

17 Angell, *supra* note 11, at 1499.

PART I
HIV IN CHILDREN

The number of pediatric AIDS cases has grown rapidly in the past few years. Between 1982 and 1991, only 3,199 cases were reported to the Center for Disease Control;[18] today it is estimated that approximately 1,500 to 2,000 HIV-infected children are born in the United States each year.[19] The World Health Organization ("WHO") estimates that over one million children are infected with HIV worldwide.[20] Even more grim is WHO's prediction that there could be ten million pediatric AIDS cases worldwide by the year 2000.[21]

HIV is now the fifth leading cause of death in children under fifteen years of age in the United States.[22] The majority of HIV-infected children acquire the virus perinatally from their infected mothers.[23] HIV can be passed from mother to infant in the prenatal period (before birth), in the intrapartum period (during birth), or in the postpartum period (after birth).[24] Prenatally, HIV can be transmitted if a placental tear allows the virus to cross over to the fetal bloodstream.[25] Intrapartum transmission can occur when an infant's skin and mucous membranes are exposed to the mother's contaminated blood and other infected fluids in the birth canal.[26] Finally, HIV transmission can occur postpartum, through contaminated breast milk.[27]

Published studies from around the world indicate a wide variety of HIV-vertical transmission rates. European countries have the lowest transmission rates, ranging from fifteen to twenty-five per-

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18 Curnin, *supra* note 2, at 863.

19 *Id.* Some sources estimate this figure to be 1,750 infants per year. Paul Cotton, *Trial Halted After Drug Cuts Maternal HIV Transmission Rate by Two Thirds*, 271 JAMA 807 (1994).

20 Martha F. Rogers & Harold W. Jaffe, *Reducing the Risk of Maternal-Infant Transmission of HIV: A Door is Opened*, 331 NEW ENG. J. MED. 1222 (1994).

21 Curnin, *supra* note 2, at 858.

22 *See* Cotton, *supra* note 19.

23 Perinatal transmission of HIV accounts for 93 percent of pediatric cases. SUBCOMMITTEE REPORT, *supra* note 6, at 5. For a general discussion of perinatally acquired HIV in children, see Gwendolyn B. Scott et al., *Survival in Children with Perinatally Acquired Human Immunodeficiency Virus Type 1 Infection*, 321 NEW ENG. J. MED. 1791 (1989).

24 Curnin, *supra* note 2, at 864; Martha A. Field, *Pregnancy and AIDS*, 52 MD. L. REV. 402, 407 (1993). There is evidence that transmission may occur during one or all of these periods. Friedland & Klein, *supra* note 3, at 1130-31.

25 *Mother-to-Child-Transmission of HIV Questioned*, AIDS WEEKLY, Aug. 22, 1994.

26 SUBCOMMITTEE REPORT, *supra* note 6, at 11.

27 Since HIV-infected mothers are advised not to breastfeed, this route of infection is uncommon in the United States. *Mother-to-Child Transmission of HIV Questioned*, *supra* note 25. However, a mother who is unaware that she is HIV-positive may inadvertently infect her healthy newborn. *See* Hentoff, *supra* note 4 (reporting that Elizabeth Glaser, who died of AIDS on December 4, 1994, was unaware that she was HIV infected, and inadvertently infected her daughter through breastfeeding).

cent, while the highest rate is in Kenya, where about forty-five percent of infected pregnant women have babies who are infected.[28]

If tested at birth, the majority of infants born to HIV-positive mothers will test HIV-positive,[29] since maternal HIV antibodies freely cross the placenta.[30] Although newborns carry their mothers' HIV antibodies at birth, only about one-quarter of newborns who test positive actually have the virus.[31]

The survival rate for HIV-infected newborns is very low. Most children become symptomatic before one year of age[32] and approximately ten percent of HIV-infected infants die within their first year of life.[33] Pneumocystis carinii pneumonia ("PCP") is the primary cause of death for children with HIV.[34] Children who do not die of PCP may develop serious bacterial infections, interstitial pneumonia, gastrointestinal disorders, and neuro-developmental impairment.[35]

Because HIV-infected infants have such a poor prognosis and will probably become symptomatic before one year of age, early diagnosis is critical to effective treatment.[36] While AIDS is brutal in adults, it is even more ruthless in newborns who have not had time to develop protective antibodies before their immune systems are hit with the deadly disease.[37] Knowing a child's HIV status would enable parents and doctors to make more informed decisions about the baby's medical care and treatment, thus prolonging and improving the quality of life for HIV-infected newborns.[38]

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28 SUBCOMMITTEE REPORT, *supra* note 6, at 8. As of 1991, the HIV mother-to-child transmission rate in Bronx, New York, was 21 percent. *Id.* at 9.

29 In the U.S., about 7,000 newborns test positive each year. Christine Gorman, *Moms, Kids and AIDS: Can Testing and Treatment Before and After Birth Help Thousands of Youngsters Threatened by HIV?*, TIME, July 4, 1994, at 60. A positive test merely indicates that antibodies produced in the mother's blood have moved to the child during pregnancy. *Id.*

30 SUBCOMMITTEE REPORT, *supra* note 6, at 3.

31 *Id.* at 9.

32 Scott et al., *supra* note 23, at 1791.

33 SUBCOMMITTEE REPORT, *supra* note 6, at 15.

34 *Id.* at 15-17. In one study, PCP presented itself at a median age of five months, with a median survival time thereafter of only one month. *See* Scott et al., *supra* note 23, at 1791. For a general discussion of PCP and its prevention in children, see R.J. Simonds, et al., *Prophylaxis Against* Pneumocystis Carinii *Pneumonia Among Children With Perinatally Acquired Human Immunodeficiency Virus Infection in the United States*, 332 NEW ENG. J. MED. 786 (1995).

35 SUBCOMMITTEE REPORT, *supra* note 6, at 17-18. Bacterial infections have been cited as the second most common AIDS-defining condition. Rogers & Jaffe, *supra* note 20, at 1222.

36 *See* Scott et al., *supra* note 23.

37 *See* Gorman, *supra* note 29 ("[Babies] have such immature immune systems that HIV makes them much sicker, much more quickly than it does adults."); Hellman, *supra* note 16.

38 *Infants' Rights; Tell Mothers Their HIV Status*, NEWSDAY, March 17, 1995, at A36; SUBCOMMITTEE REPORT, *supra* note 6, at 18. Recommended care and treatment for HIV-infected children includes: use of immune globulin to prevent serious bacterial infections, changing the schedule of immunizations, administering influenza and pneumoccocal vac-

PART II

NEW YORK STATE'S CURRENT SCREENING PROGRAM

Recent statistics indicate that urban areas have been hit the hardest by the AIDS epidemic. In some New York City neighborhoods AIDS case rates may exceed 2,500 per 100,000 residents.[39] Currently, New York City ranks first in pediatric AIDS cases, with nearly twenty-three percent of the nation's total number of cases.[40] Despite the prevalence of HIV in New York, the state does not currently mandate HIV testing for anyone.[41] While hepatitis B and syphilis screening are mandatory for pregnant women,[42] there is no such screening program for HIV. The New York State Department of Health, however, as part of a nationwide program funded by the Center for Disease Control, tests newborn infants anonymously to see if they have been exposed to HIV.[43] This testing pro-

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cines and administering zoster immune globulin if exposure to chicken pox has occurred. SUBCOMMITTEE REPORT, *supra* note 6, at 15, 18-19.

39 AIDS IN NEW YORK, *supra* note 2, at 1.

40 NEW YORK CITY AIDS SURVEILLANCE REPORT 3, 10 (July 1995). The most recent figures estimate the cumulative number of pediatric AIDS cases in New York City at 1,544, with over 920 known deaths. *Id.* at 10.

41 New York State Public Health Law, Article 27-F, requires that HIV testing be administered with written informed consent. *See* N.Y. PUB. HEALTH LAW § 2781 (1) (McKinney 1993) ("A physician or other person authorized pursuant to law to order the performance of an HIV related test shall certify, in order for the performance of an HIV related test, that informed consent required by this section has been received prior to ordering such test by a laboratory or other facility."). *But see* ARK. CODE ANN. § 20-15-905(c) (1991) ("Informed consent, information, and counseling are not required for the performance of an HIV test when, in the judgment of a physician, such testing is medically indicated to provide appropriate diagnosis and treatment to the subject of the test provided that the subject of the test has otherwise provided his or her consent to such physician for medical treatment."). Federal law does provide for HIV testing without informed consent for federal prisoners, military personnel, and Job Corps applicants. SUBCOMMITTEE REPORT, *supra* note 6, at 23.

42 SUBCOMMITTEE REPORT, *supra* note 6, at 23. *See* N.Y. PUB. HEALTH LAW § 2308 (McKinney 1993) (mandating testing of pregnant women for syphilis). Mandatory screening is also done on newborns for a variety of congenital diseases. *See* N.Y. PUB. HEALTH LAW § 2500 (a) (McKinney 1993) (mandating newborn testing for several congenital disorders, including phenylketonuria, sickle cell anemia, congenital hypothyroidism, branched-chain ketonuria, galactosemia, and homocystinuria).

43 On October 10, 1995, Governor Pataki announced a new policy that would permit mothers to learn the results of HIV tests given to all newborn babies. James Dao, *Mothers to Get AIDS Test Data Under Accord*, N.Y. TIMES, Oct. 10, 1995, at A1. Under the new regulations, doctors would be required to counsel pregnant women to receive an HIV test. *Id.* Immediately after giving birth, the mother would be required to sign a consent form indicating whether or not she wants to be informed of her infant's HIV test results. *Id.* If a women checks "yes," she would be entitled to follow-up counseling and treatment for her child. Letta Tayler, *New Rights for Moms in HIV Tests*, NEWSDAY, Oct. 11, 1995, at A4. If she checks "no," the testing would remain anonymous. *Id.* Various groups, including the New York Civil Liberties Union and the Long Island Association for AIDS Care, have expressed concern about the new policy, arguing that it may have a disproportionate effect on minority women. *Id.* The new policy is the result of an out-of-court settlement with the Association to Benefit Children, which had filed suit to force the state to give mothers the results of the anonymous HIV tests. *Id.* *See infra* notes 56-59 and accompanying text.

gram — the Newborn HIV Seroprevalance Survey ("Survey") — was initiated in New York in 1987, and is currently conducted in forty-four other states.[44] The Survey operates under the strict confidentiality requirements of New York State Public Health Law, Article 27-F, which protects HIV and AIDS related information.[45] The data from the Survey is used for purely statistical purposes to track the spread of AIDS,[46] and even parents cannot learn of the test results.[47] As a consequence of the strict confidentiality requirements, it is estimated that forty to sixty percent of HIV-positive newborns leave the hospital without being identified.[48] In most cases, these newborns are not identified as being HIV-positive until they become visibly sick and or symptomatic. For most of these children, treatment comes too late.

Recent legislation, which would require disclosure to all parents whose infants tested HIV-positive, has been introduced in both the New York State Legislature[49] and Congress.[50] Opponents of the legislation argue that mandatory disclosure is unconstitutional because it would effectively inform the mother of her own HIV status without her consent, thus invading her privacy and rendering her vulnerable to discrimination.[51] Organizations such as

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44 SUBCOMMITTEE REPORT, *supra* note 6, at 3. The testing is done by drawing a dollop of blood from the baby's heel. Gorman, *supra* note 29.

45 *See* N.Y. PUB. HEALTH LAW art. 27-F (McKinney 1993).

46 Kevin Sack, *A Bill to Require H.I.V. Counseling Backed in Albany*, N.Y. TIMES, July 3, 1994, § 1, at 1. *See also* SUBCOMMITTEE REPORT, *supra* note 6, at 3 (reporting that New York uses the data from the Survey in making decisions about allocation and funding of HIV prevention and treatment services for women, infants, and families).

47 Sack, *supra* note 46; Nicholas Goldberg & John Riley, *Silver Opposed AIDS Test Plan*, NEWSDAY, June 29, 1994, at A26. Under the new policy announced by Governor Pataki on October 10, 1995, this would change. *See supra* note 43.

48 Goldberg & Riley, *supra* note 47.

49 Last year, State Assemblywoman Nettie Mayersohn introduced Bill No. 6747-B. The pertinent part of the proposed bill states: Section 1. Section 2782 of the public health law is amended by adding a new subdivision 10 to read as follows: The department shall disclose to the mother . . . of a newborn child confidential HIV related information obtained as a result of any testing done for any purpose whatsoever on such child. N.Y. ASSEMBLY BILL No. 6747-B, § 1 (1993) (proposed). On July 3, 1994, the New York State Legislature rejected Bill No. 6747-B by agreeing instead to a compromise bill that would require physicians and other health-care providers to counsel pregnant women and new mothers about the benefits of HIV testing and to offer them testing. Goldberg & Riley, *supra* note 47; Sack, *supra* note 46. Under the compromise bill, both the woman and health care providers would have to sign a form acknowledging that the counseling had taken place. Sack, *supra* note 46.

50 The bill is co-sponsored by Congressman Gary Ackerman and would withhold federal AIDS money for any state that does not unblind the HIV test. Jane Gottlieb, *Mom May Get Results of Baby's HIV Test*, TIMES UNION, Aug. 8, 1995, at B2. The legislation would also prohibit insurance carriers from terminating or altering the terms of health insurance on the basis that an individual is HIV-positive. *U.S. Government Policy of Secrecy for AIDS Babies Unethical and Deadly, New Legislation Major Step Forward, Says Womens Group*, PR NEWSWIRE, June 27, 1995.

51 Sack, *supra* note 46; Goldberg & Riley, *supra* note 47.

the National Organization for Women argue that giving an infant the right to be tested at the expense of the mother's privacy could lead to fetal rights and be used to undermine *Roe v. Wade*.[52] The Gay Men's Health Crisis is concerned that indirectly testing the mother could erode the confidentiality of HIV status.[53] The New York Civil Liberties Union has even threatened to sue if mandatory disclosure becomes law.[54]

On the other hand, the majority of the physicians on the Committee for the Care of Children and Adolescents with HIV Infection, who represent the only doctors with direct, long-term experience treating HIV-infected children, support disclosing the results.[55] Another organization that has stepped forward to voice their support for disclosure is the Association to Benefit Children, a Manhattan-based advocacy group. In April 1995, the Association filed suit against the Governor of New York and the State of New York seeking to force the State to give mothers the results of the anonymous HIV tests.[56] The suit alleges that by not notifying parents of the results of the HIV tests, HIV babies are being denied equal protection under both the State and Federal Constitutions.[57] It has been reported that state officials have been in negotiations with the advocacy group,[58] and although neither party will discuss the negotiations, it has been suggested that an agreement may include "unblinding" the tests for those women who sign a form requesting to see the results.[59]

PART III
EARLY HIV DETECTION THROUGH ROUTINE SCREENING

Although "unblinding" the newborn tests may be useful in determining which infants are in need of early medical treatment, it would not be effective in preventing maternal HIV transmission since testing would not take place until after transmission had occurred.[60]

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52 *See* Leo, *supra* note 10.

53 *Id.*

54 Gottlieb, *supra* note 50.

55 Nat Hentoff, *All Mothers Must Be Informed If Their Newborns Have AIDS*, HOUSTON POST, Aug. 15, 1994, at A13.

56 Dena Bunis, *Parents May Get AIDS-Test Results*, NEWSDAY, Aug. 8, 1995, at A7.

57 Gottlieb, *supra* note 50; Leo, *supra* note 10.

58 Bunis, *supra* note 56.

59 *Id.* *See supra* note 43.

60 Rogers & Jaffe, *supra* note 20, at 1223.

In light of the current AIDS crisis, routine screening of all pregnant women is warranted;[61] it is not surprising that an increasing number of health care providers have advocated such testing measures.[62]

Routine HIV testing is generally conducted under conditions of presumed consent.[63] When a woman seeks prenatal care, her blood is drawn and tested for a variety of things.[64] A routine HIV screening program would include a test for HIV antibodies and counseling services once the test results are returned. Once an infected woman has been informed of all of her options, it would then be up to her to decide whether or not to undergo treatment.

There are ample benefits for both a mother and her child in early HIV detection through routine testing. Early diagnosis could help prevent mother-to-child transmission during the prenatal or intrapartum periods, when transmission is most likely to occur.[65] Perhaps the most significant reason for prenatal versus postnatal testing is the recent finding that the drug zidovudine can successfully prevent transmission of HIV from infected mothers to newborns. A recent study, known as ACTG 076, conducted by the United States National Institute of Allergy and Infectious Diseases, has revealed that zidovudine, previously called AZT,[66] reduces the risk of maternal transmission by two-thirds.[67] The study began in April 1991, and involved approximately 750 HIV-infected women

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61 The HIV-antibody test is a simple blood test which poses no significant medical risk to women. Taunya Lovell Banks, *Women and AIDS- Racism, Sexism, and Classism*, 17 N.Y.U. REV. L. & SOC. CHANGE 351, 369 (1989-90).

62 *See* Angell, *supra* note 11, at 1500.

63 Banks, *supra* note 61, at 358.

64 *See supra* note 42 and accompanying text.

65 *See supra* notes 24-27 and accompanying text; SUBCOMMITTEE REPORT, *supra* note 6, at 13.

66 The long term effects of AZT are unknown. *In the Interest of the Child; Protect Newborns from HIV*, NEWSDAY, August 10, 1994, at 30. James F. Balsey, who helped conduct the study, stated that "[w]e only know that it's better for a child to risk the vagaries of this drug than to run a needlessly large risk of HIV infection." *Id. See also Birth Defects in AZT Users Mirror General Population*, 9 AIDS ALERT 116 (1994) (reporting that the Center for Disease Control confirms earlier findings that pregnant women taking AZT do not increase the risk of birth defects. Only four births from 121 women resulted in birth defects — a proportion that is no greater than the rate for the general population).

67 JEFFREY LAURENCE, AMERICAN FOUNDATION FOR AIDS RESEARCH, KEEPING INFANTS SAFE FROM HIV 2 (1994); Cotton, *supra* note 19. AZT reduces the number of HIV particles in the women's bloodstream, thereby decreasing the chance of AIDS transmission from mother to newborn. *Mother-to-Child Transmission of HIV Questioned*, *supra* note 25. For a general discussion of a similar study, conducted by the Pediatric AIDS Clinical Trials Group Protocol 076 Study Group, which revealed identical results, see Edward M. Connor, et al., *Reduction of Maternal-Infant Transmission of Human Immunodeficiency Virus Type 1 with Zidovudine Treatment*, 331 NEW ENG. J. MED. 1173 (1994).

with a median age of twenty-five years.[68] The trial was randomized and controlled, with some women taking zidovudine orally for an average of twelve weeks prior to giving birth and intravenously during labor.[69] Their babies were also started on the drug in syrup form within twenty-four hours after birth and for the first six weeks of life.[70] Results of the study showed that only 8.3 percent of the infants were infected when their mothers received zidovudine, compared to the 25.5 percent infection rate for babies when mother and child received a placebo.[71] In light of the favorable results, the trial was halted and all the women were offered zidovudine.[72] Other than temporary anemia, the study revealed little negative impact of zidovudine-therapy on newborns or mothers in the short-term.[73]

The success of the ACTG 076 study is an important advance in the prevention of HIV.[74] However, an HIV-infected woman cannot avail herself of the option of zidovudine treatment if she is unaware that she is infected with the virus.[75] This is just one reason to implement a routine HIV-screening program which would identify HIV-infected women before maternal transmission occurs.

Early diagnosis is also important because, if a woman knows that she is HIV infected, there are measures which could be taken during labor and delivery to reduce the risk of mother-to-child transmission. These measures include cesarean section, passive immunization (with hyperimmune globin or a neutralizing antibody), and washing the vagina and the baby, in order to reduce the likelihood of infection by the mother's contaminated blood or other infected fluids.[76]

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68 LAURENCE, *supra* note 67, at 2. The study took place at various sites in the United States and France. *Id.* at 1, 2.

69 *Id.*

70 *Id.* at 2. The infants were followed for 18 months and will continue to be followed until the age of 21. Huntly Collins, *AZT Can Reduce Risk Newborn Will Have HIV,* CHI. TRIB., Sept. 11, 1994, at 11.

71 LAURENCE, *supra* note 67, at 2; Cotton, *supra* note 19.

72 Cotton, *supra* note 19.

73 LAURENCE, *supra* note 67, at 2.

74 *See* Rogers & Jaffe, *supra* note 20. The favorable results of the ACTG 076 study have brought one of the few signs of hope in more than a decade of AIDS research. *See* Collins, *supra* note 70; Gorman, *supra* note 29. The Food and Drug Administration recently approved zidovudine to reduce maternal-fetal transmission of HIV. Fred Gebhart, *Sparks of Hope, World AIDS Conference Offers Mild Optimism,* 138 DRUG TOPICS 30, Sept. 5, 1994; Abi Sekimitsu, *Practical Help for AIDS Babies Still Seems Remote,* THE REUTER BUSINESS REPORT, Aug. 9, 1994.

75 Rogers & Jaffe, *supra* note 20, at 1223.

76 *See supra* notes 25-27 and accompanying text; SUBCOMMITTEE REPORT, *supra* note 6, at 13.

Informing a woman of her HIV status may also prevent her from inadvertently transmitting HIV after birth, through her breastmilk.[77] Further, early HIV detection gives a woman the opportunity to designate a legal guardian for her child if and when she becomes sick, and to make other arrangements for family care, assets, and legal or medical services.[78] Finally, knowledge of her HIV status enables a woman to prevent transmission to her partner and to make an informed decision regarding future pregnancies.[79]

Early identification offers an HIV-infected pregnant woman the fullest range of treatment and planning options for herself and her baby. Women who know that they are HIV infected can avail themselves of zidovudine therapy and take preventive measures during labor and delivery. While nothing is guaranteed to prevent an infected mother from transmitting HIV to her child, there is sufficient evidence indicating that certain measures may reduce the likelihood of maternal transmission. The most effective way to identify HIV-infected pregnant women is through routine HIV screening. New York State health officials should require that routine HIV testing be incorporated into prenatal care, thereby giving HIV-infected women a chance to help themselves and save their children.

PART IV
FAILURE OF THE COUNSELING APPROACH

Opponents of routine HIV screening argue that voluntary HIV counseling and testing are less invasive, since there is no infringement of the mother's right to confidentiality when she agrees to be tested.[80] However, recent evidence suggests that the voluntary approach does not work. New York State presently sponsors voluntary counseling programs for pregnant women and new mothers in twenty-four hospitals in AIDS-impacted areas,[81] but these programs typically fail to identify HIV-infected mothers and newborns.[82] Proponents of voluntary AIDS counseling and testing, however, point to the program at Harlem Hospital Center, which gets approximately ninety percent of new mothers to agree to counseling.[83]

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77 *See supra* note 27 and accompanying text.
78 SUBCOMMITTEE REPORT, *supra* note 6, at 20.
79 *Id.* at 21.
80 *See, e.g.*, Curnin, *supra* note 2, at 894.
81 *AIDS Babies Deserve Testing*, N.Y. TIMES, June 27, 1994, at A16.
82 It has been reported that only one out of every five HIV-positive women is identified through New York State's voluntary testing and counseling programs. Jim Dwyer, *HIV Results Not Positive*, NEWSDAY, July 14, 1995, at A2.
83 *See*, Curnin, *supra* note 2, at 894-95.

But the success at Harlem is the exception among New York hospitals. It is among the only fully-staffed, fully-funded programs in the city, and therefore very unlikely that the Harlem program can be replicated.[84] At Metropolitan Hospital in East Harlem, for instance, only thirty to forty percent of HIV-infected women are being identified.[85]

Other organizations, such as the New York State AIDS Advisory Council's Committee on Newborn HIV Screening, propose mandatory prenatal and postnatal counseling which strongly encourages voluntary HIV testing.[86] While this recommendation is an important step toward reinforcing an accepted standard of care for women and children, "it is insufficient to offer the protection which every infant deserves, protection which has been guaranteed newborn infants in New York State for other serious diseases."[87]

Thus, despite the argument that voluntary HIV counseling and testing is less intrusive than any routine testing measure, this approach should be rejected by state health officials since it fails to give every HIV-infected newborn the benefit of comprehensive care and treatment.

PART V

ETHICAL ISSUES AND CONSTITUTIONAL CONCERNS

Incorporating routine HIV testing into prenatal care raises a number of reproductive freedom issues and other constitutional concerns. It is these concerns, including infringement of privacy rights, deprivation of liberty and equal protection, that are the greatest barrier to any proposed legislation seeking to impose a routine screening program to help prevent the transmission of HIV.

Opponents of routine HIV screening contend that any non-voluntary testing measure substantially infringes upon a woman's right to privacy. Although the Constitution does not explicitly mention any right to privacy, the Supreme Court has recognized

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84 *Id.* at 895; Hellman, *supra* note 16. *See also* SUBCOMMITTEE REPORT, *supra* note 6, at 3 (dissenting comments) ("[B]ased on the available details of [Harlem Hospital] research-oriented and research-funded program and the low acceptance of testing rates achieved in pilot programs involving many thousands of women through the State, there is ample evidence for serious doubt that the 'Harlem Hospital model' can be replicated on a state-wide basis."). *But see* Curnin, *supra* note 2, at 895 ("[T]here is nothing to indicate that the Harlem program cannot be duplicated . . . the effort to do so could begin with increasing staffing and funding in all hospitals and initiating a program of routine pre- and post-natal counseling that strongly encourages testing.").

85 Hellman, *supra* note 16.

86 *See generally* SUBCOMMITTEE REPORT, *supra* note 6.

87 *Id.* at 2 (dissenting comments).

such a right.[88] Moreover, the Court has recognized the right to be free from "unwarranted governmental intrusions into matters . . . fundamentally affecting a person."[89] These "matters" have included activities relating to marriage;[90] procreation;[91] and contraception.[92] In *Roe v. Wade*,[93] the Supreme Court extended the right of privacy in the abortion context. Subsequently, in *Whalen v. Roe*,[94] the Court declared that this right included an "individual['s] interest in avoiding disclosure of personal matters."[95] However, the Court emphasized that "disclosures of private medical information to doctors, to hospital personnel, to insurance companies, and to public health agencies are often an essential part of modern medical practice even when the disclosure may reflect unfavorably on the character of the patient."[96]

When a privacy right is involved, the state must demonstrate a compelling interest for burdening that right.[97] There can be little doubt that New York state has a compelling economic interest in preventing the transmission of HIV from mother-to-baby. The cost of caring for HIV-infected infants has been estimated at one billion dollars annually.[98] In addition, by virtue of its police powers,[99] the state has the authority to legislate and enforce regulations to preserve the public health and safety.[100] By declining to prevent mother-to-child transmission of HIV through the necessary means, namely routine screening, the state is neglecting its duty as the protector of public health and welfare.

While protecting a woman's right to privacy is a legitimate concern, a mother who chooses not to be tested "cannot evade

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88 *See* Roe v. Wade, 410 U.S. 113, 152 (1973).

89 Eisenstadt v. Baird, 405 U.S. 438, 453 (1972).

90 Loving v. Virginia, 388 U.S. 1, 12 (1967).

91 Skinner v. Oklahoma, 316 U.S. 535, 541-42 (1942).

92 Eisenstadt, 405 U.S. at 453-54.

93 410 U.S. 113 (1973).

94 429 U.S. 589 (1977).

95 *Id.* at 599.

96 *Id.* at 602 (footnote omitted).

97 *See, e.g.*, Carey v. Population Servs. Int'l, 431 U.S. 678, 686 (1977); Roe v. Wade, 410 U.S. 113, 155 (1973).

98 Howard L. Minkoff, *AIDS in Obstetrics*, 32 CLINICAL OBSTETRICS & GYNECOLOGY 421 (1989). Since 1987 total HIV/AIDS expenditures in New York State have increased more than 223 percent, rising from $557 million to $1.8 billion. AIDS IN NEW YORK, *supra* note 2, at 131.

99 U.S. CONST. amend. X ("The powers not delegated to the United States by the Constitution, nor prohibited by it to the States, are reserved to the States, respectively, or to the people.").

100 Linda Farber Post, Note, *Unblinded Mandatory HIV Screening of Newborns: Care or Coercion?*, 16 CARDOZO L. REV. 169, 199 (1994). *See, e.g.*, Jacobson v. Massachusetts, 197 U.S. 11 (1905) (holding that the state may use its police power to compel vaccinations).

knowing her child's or her own HIV status."[101] Moreover, New York has some of the strictest confidentiality laws in the United States.[102] The results of the HIV test would be disclosed confidentially and kept between the state and the mother.[103]

It is further argued that routine screening deprives pregnant women of their liberty interest under the Fourteenth Amendment.[104] Various commentators have contended that the "right not to know" should be seen as a protected liberty interest.[105] However, allowing people at risk of being infected with HIV to choose voluntarily not to know whether they are HIV infected has been described as "a perversion of human rights and a formula for HIV disaster."[106] Health officials insist that knowledge is the first step in fighting the disease.[107] A mother who decides not to be tested prevents early and effective treatment for herself and her child.

Additionally, opponents of routine screening measures claim that these measures violate the Equal Protection clause of the Fourteenth Amendment[108] since most HIV-infected women are indigent women of color.[109] For a racial classification, the state is subject to strict scrutiny and must show that a compelling state interest can only be achieved by means of this classification.[110] While statistics indicate that black and Hispanic women are disproportionately HIV infected,[111] this Note advocates routine screening for all pregnant women in New York, regardless of race, color or geo-

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101 Hentoff, *supra* note 55.

102 *See* N.Y. PUB. HEALTH LAW art. 27-F (McKinney 1993). *But see supra* note 43.

103 Curnin, *supra* note 2, at 876.

104 U.S. CONST. amend. XIV, § 1 ("[N]or shall any State deprive any person of life, liberty, or property, without due process of law. . . .").

105 *See, e.g.*, Field, *supra* note 24, at 411 (arguing that the "right not to know" an individual's HIV status should be seen as "part of the constitutionally protected liberty interests that the current Supreme Court has recognized. . . .").

106 Robert T. Jensen, *HIV Testing of Pregnant Women and Newborns*, 265 JAMA 1525, Mar. 27, 1991 (letter to editor).

107 Dwyer, *supra* note 10 ("[T]he best weapon is knowledge." (quoting C. Everett Koop)).

108 U.S. CONST. amend XIV, § 1 ("[N]or shall any State . . . deny to any person within its jurisdiction equal protection of the laws.").

109 *See* Banks, *supra* note 61, at 354 ("[G]iven the racial composition of the women currently thought to be at risk, HIV screening and counseling proposals designed to somehow prevent perinatal transmission have genocidal overtones.") (footnote omitted). *See also* Working Group on HIV Testing of Pregnant Women and Newborns, *HIV Infection, Pregnant Women, and Newborns*, 264 JAMA 2416, 2418 (1990) [hereinafter Working Group on HIV Testing] ("[E]vidence suggests that poor, minority women risk the devastation of their personal and family relationships, the loss of social and medical services, the loss of control of their own medical decisions, and even the loss of their children.") (footnote omitted).

110 Carey v. Population Servs. Int'l, 431 U.S. 678, 686 (1977).

111 *See supra* note 6.

graphic location. In *Washington v. Davis,*[112] the Supreme Court held that a classification will not be suspect unless the court finds that the legislature had a discriminatory intent. A routine screening program that tested all pregnant women as part of their prenatal care would lack the requisite discriminatory intent.

There are some members of the medical community who advocate targeting HIV information and screening resources in areas with the highest concentration of infection.[113] Although such a program would be based on statistics — not racial or social class prejudices — opponents argue that this is clearly an equal protection violation.[114] A potentially more significant problem of the "targeted" approach is that it would send "the false and dangerous message that, among women, only persons of this racial and ethnic description are at risk for HIV infection."[115] Thus, the "targeted" approach should be rejected in favor of a routine screening program that tests all pregnant women, regardless of statistics and sociodemographic criteria.

A further concern is that routine screening for HIV infection will discourage poor persons from seeking federally funded prenatal care.[116] As of yet, no evidence of such avoidance by mothers has been observed.[117]

Finally, many fear that HIV screening designed to prevent perinatal transmission will lead to abortion for pregnant women[118]

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112 426 U.S. 229 (1976).

113 *See* Robert M. Wachter, et al., *HIV Testing of Pregnant Women and Newborns,* 265 JAMA 1525, Mar. 27, 1991 (letter to editor) ("[B]y opting for the approach of informing and testing everyone without targeting, we may be ensuring that those at highest risk of disability and death would remain undereducated and undertreated.") (footnote omitted). *See also* Field, *supra* note 24, at 435 (rejecting the targeting approach, but noting that targeting makes more sense economically than universal mandatory testing).

114 *See* Working Group on HIV Testing, *supra* note 109, at 2419. *See also* Field, *supra* note 24, at 435 (targeting based on socioeconomic criteria is highly discriminatory).

115 Working Group on HIV Testing, *supra* note 109, at 2419. *See also* Field, *supra* note 24, at 435 (targeting encourages a "false sense of security in other women regarding their risk of infection. . . .").

116 *See* Banks, *supra* note 61, at 370 (warning that "routine HIV prenatal screening may prompt many HIV-infected women to forego needed prenatal care to avoid detection of their antibody status.").

117 Hentoff, *supra* note 55. Opponents of mandatory testing cite the experience in Illinois, when the state mandated HIV testing as a precondition to obtaining a marriage license. The Illinois law discouraged some people from marrying at all, and encouraged others to marry out of state. Field, *supra* note 24, at 433-34. *But see* Hentoff, *supra* note 55 ("But is the value of an infant the same as that of a marriage license? Will a marriage license get terminally ill if it is not treated in time?").

118 *See* Field, *supra* note 24, at 414 ("Many health professionals . . . believe that a woman should abort upon learning she is HIV positive, rather than take the approximately thirty percent chance of giving birth to a child who is infected.") (footnote omitted). *But see* Banks, *supra* note 61, at 369 (noting that many women, upon learning that they are HIV-infected, "voluntarily choose to either terminate or forego pregnancy.") (footnote omitted).

and sterilization for infected fertile women.[119] However, the recent finding that zidovudine reduces maternal-fetal transmission by up to two-thirds introduces an acceptable alternative.[120] Today, HIV-infected women may be offered zidovudine therapy in an effort to reduce the risk of mother-to-child transmission — abortion and sterilization are no longer the only options for women who are HIV infected.[121] An HIV-infected pregnant woman must, however, make an informed decision whether or not to be treated with zidovudine. The obligation of the health official is simply to give "full and fair information."[122]

CONCLUSION

Considering the scope of the AIDS epidemic, New York State health officials and policymakers should be less concerned with politics, and more concerned with saving lives.

Study after study indicate that early HIV detection is essential for effective treatment of a mother and her baby. "Delay in diagnosis is literally a matter of life versus preventable, early death."[123] Consequently, state health officials should require that routine HIV testing be incorporated into prenatal care. Such a policy would identify the majority of HIV-infected pregnant women who seek prenatal care, thus enabling mother and child to benefit from early diagnosis and treatment.

While alternative measures, such as voluntary counseling and testing, are arguably less intrusive, these approaches typically fail to identify HIV-infected pregnant women. As a result, numerous infants forego the benefits of early HIV diagnosis and treatment.

For too long, HIV-positive women have been forced to deal with their own victimization by AIDS, and for some, the reality that they have infected their child. Politics will not help these women or their children, but early diagnosis and medical treatment will. The incorporation of routine HIV testing into every woman's prenatal care would allow for early HIV detection and comprehensive

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119 *See* Field, *supra* note 24, at 417 (contending that use of Norplant — an implanted contraceptive that prevents conception for about five years, or Depo Provera — a shot that prevents pregnancy for about three months, might also be encouraged).

120 *See supra* note 67 and accompanying text.

121 *See* Banks, *supra* note 61, at 354 (stating that there are only two possible outcomes resulting from routine screening and mandatory counseling: abortion and sterilization).

122 Field, *supra* note 24, at 416.

123 SUBCOMMITTEE REPORT, *supra* note 6, at 2 (dissenting comments).

care, thus providing a better and longer life for children born to mothers with HIV.

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