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MANDATORY HIV TESTING ISSUES IN STATE NEWBORN SCREENING PROGRAMS

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ABSTRACT

On May 23, 1991, an editorial by Dr. Marcia Angell, the executive editor of the New England Journal of Medicine, recommended that all newborns, health care workers, pregnant women and hospital patients be tested for human immunodeficiency virus (HIV) infection.[3] Dr. Angell noted that HIV infection in newborns is more common than phenylketonuria (PKU) which is routinely tested in all newborns.[4] This idea was rejected by Dr. June Osborn, chair of the National Commission on AIDS and Dean of the University of Michigan's School of Public Health. Dr. Osborn prefers voluntary testing with informed consent and counseling[5] and stated "'[t]here's nothing routine about an HIV test.'"[6] Newborn screening programs for serious but treatable diseases have achieved success and wide acceptance over the past thirty years. Development of these programs involved a struggle with legal and social policy issues as well as scientific and medical issues.[7] The possibility of establishing the nation's first newborn screening program for HIV occurred when the Michigan House of Representatives, in July of 1992, passed a Bill mandating non-anonymous HIV testing of newborns. Although it did not pass into law in 1992, a substantially similar bill has been introduced for 1993. Considering issues of informed consent, confidentiality, possible newborn screening refusals, and the potential for identifying HIV-exposed neonates through prenatal testing, the addition of non-anonymous HIV testing to routine

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[3]Marcia Angell, *A Dual Approach to the AIDS Epidemic*, 324 NEW ENG. J. MED. 1498, 1500 (1991).

[4]*Id.* at 1499.

[5]Janny Scott, *Top Medical Journal Calls for Routine AIDS Testing*, L.A. TIMES, May 23, 1991, at A1.

[6]*Id.*

[7]Marvin P. Natowicz & Joseph S. Alper, *Genetic Screening: Triumphs, Problems, and Controversies*, 12 J. PUB. HEALTH POL'Y 475, 475 (Winter 1991).

newborn screening appears to be neither efficient nor ethically defensible. This position is reviewed for states that may be considering the use of newborn screening to detect HIV infection.

I. INTRODUCTION TO NEWBORN (GENETIC) SCREENING

Currently, at least five major types of genetic screening programs have developed in the United States including: "1) disease detection in newborns; 2) carrier (heterozygote) detection; 3) prenatal disease detection; 4) genetic screening in the workplace; and 5) forensic testing of alleged or proven criminals [through DNA analysis]."[8] The National Academy of Sciences (NAS) recommends genetic screening only when carried out under controlled conditions and "[t]here is evidence of substantial public benefit and acceptance, including acceptance by medical practitioners."[9]

Disease detection in newborns is perhaps the largest and most successful screening program of the five. It became popular in the United States in the mid-1960's, when many states began universal screening of newborns for phenylketonuria (PKU). PKU is a severe genetic disease caused by an absence or alteration of the gene that produces phenylalanine hydroxylase.[10] This

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[8] *Id.* at 476.

[9] Committee for the Study of Inborn Errors of Metabolism, *Genetic Screening: Programs, Principles, and Research*, NATIONAL ACADEMY OF SCIENCES 1 (1975) [hereinafter GENETIC SCREENING].

[10] Ara Y. Tourian & J.B. Sidney, *Phenylketonuria*, THE METABOLIC BASIS OF INHERITED DISEASE 241-42 (John B. Stanbury, et al. eds., 4th ed. 1978). Phenylalanine hydroxylase is an enzyme involved in the metabolism of phenylalanine, "an essential amino acid for protein synthesis." *Id.* at 240 (citations omitted).

disease is easily treated with a diet low in phenylalanine. If untreated, PKU leads to irreparable and unnecessary mental retardation.

The newborn screening model is fairly straightforward. Typically, before the infant is discharged from the hospital (around 24 to 36 hours of age), heel stick blood is placed on special filter paper, dried, and mailed to the state health department for testing. Medical and laboratory research has led to the discovery that other diseases could also be screened in newborns using these dried blood specimens. Currently, all states and the District of Columbia test all newborns for at least PKU and congenital hypothyroidism.[11]

There are generally five criteria to satisfy before a disease is considered appropriate for newborn screening:

1. The disease must be well defined and serious enough to justify mass screening;
2. There must be an accurate testing method available;
3. The cost of the test must be reasonable;
4. There must be available treatment for the disorder; and
5. There must be adequate medical management facilities to refer infants for confirmatory diagnosis and treatment.[12]

Although newborn screening is often classified as genetic screening, these criteria do not require that the screened disorder have a genetic origin. In fact, congenital hypothyroidism, which is part of every newborn screening program in this country, is usually not a genetic disease.

In Michigan, newborn screening is mandated by Mich. Comp. Laws Ann. § 333.5431, which states that all infants born in Michigan shall be tested "for phenylketonuria, galactosemia, hypothyroidism, maple syrup urine disease, biotinidase deficiency, sickle cell anemia, congenital adrenal hyperplasia, and other treatable but otherwise handicapping conditions as designated by the department."

Strict quality assurance guidelines in state newborn screening programs have been developed to assure program proficiency.[13] Many of these programs have developed with the assistance of the American Bar Foundation and the Centers for Disease Control and Prevention (CDC). Program success is the result of drafting of adequate laws and establishing clear guidelines. Proper

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[11] The Council of Regional Networks for Genetic Services (CORN), *Newborn Screening Report: 1990*, Table NBS 1A (Final Rept. Feb. 1992).

[12] H.S. Cuckle & N.J. Wald, *Principles of Screening*, ANTENATAL AND NEONATAL SCREENING 19 (N.J. Wald ed. 1984). *See also*, *Genetic Screening*, *supra* note 9 at 2.

[13] A detailed discussion of this topic is found in *Legal Liability and Quality Assurance in Newborn Screening*, AMERICAN BAR FOUNDATION (Lori B. Andrews, ed. 1985).

laws and guidelines require careful consideration of the many issues that surround these programs.[14]

II. MATERNAL HIV SEROPREVALENCE STUDY BY THE CENTERS FOR DISEASE CONTROL AND PREVENTION

Studies have shown the median time from human immunodeficiency virus (HIV) infection to the development of acquired immunodeficiency syndrome (AIDS) in adults is approximately ten years.[15] Many infants with perinatally acquired HIV infection, however, become symptomatic in the first year of life.[16] Women infected with HIV are able to transmit the infection not only to their sex partners but also to their offspring.[17] Evidence suggests that this vertical transmission of HIV infection to infants can occur prior to delivery (congenital/transplacental, similar to rubella), during delivery (similar to hepatitis B), or after delivery (through breast feeding).[18] The rate of perinatal transmission of HIV has ranged from 12.9 to 39 percent in various studies,[19] and is thought to be close to 30 percent overall.[20] In short, approximately 30 percent of HIV infected women who give birth transmit the infection to their newborn.

In 1988, the CDC began a surveillance study to anonymously measure the HIV infection rate of child bearing women in the United States (including Michigan) and Puerto Rico using the dried blood collected for newborn screening.[21] Under CDC guidelines, personal identifiers from the newborn screening cards are removed before the actual HIV test is performed.[22] Certain

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[14]The Michigan Department of Public Health expects the development stage of adequate screening protocols for the disease congenital adrenal hyperplasia, which became a mandated screen as of June 1, 1992, may take up to one year.

[15]Marta Gwinn, et al., *Prevalence of HIV infection in Childbearing Women in the United States; Surveillance Using Newborn Blood Samples*, 265 JAMA 1704 (1991) (citations omitted). HIV infection alone denotes presence of the causative agent for AIDS within a person who may not have any signs/symptoms of immune deficiency. AIDS denotes the development of signs/symptoms of immune deficiency (e.g., decreased white blood cell counts, opportunistic infections).

[16]Task Force on Pediatric AIDS, American Academy of Pediatrics, *Guidelines for Human Immunodeficiency Virus (HIV)-Infected Children and Their Foster Families*, 89 PEDIATRICS 4, 681 (1992) (citations omitted) [hereinafter *Guidelines for Foster Families*].

[17]*Id.*

[18]Task Force on Pediatric AIDS, American Academy of Pediatrics, *Perinatal Human Immunodeficiency Virus (HIV) Testing*, 89 PEDIATRICS 4, 791 (1992) (citations omitted) [hereinafter *Perinatal HIV Testing*]. The descriptive terms specified in the parentheticals are taken directly from this source.

[19]*Id.* (citations omitted).

[20]Gwinn, *supra* note 15, at 1706.

[21]*Id.* at 1704.

[22]*Id.* at 1705.

demographic data such as mother's age group, race, and geographic region of residence are retained. Although a newborn's dried blood specimen is tested, the current testing method actually measures HIV infection in the mother, not the newborn. This is because the test measures the presence of maternal HIV antibodies in the newborn's blood. These antibodies are produced in the mother in response to her HIV infection and cross through the placenta and into the blood of the fetus. These maternal HIV antibodies can remain in the newborn's blood for up to 18 months.[23]

Currently, data for this surveillance study are being collected from newborn screening programs in 44 states, Puerto Rico, and the District of Columbia.[24] Michigan Department of Public Health (MDPH) staff claim this study "is particularly valuable because it provides a view of the HIV epidemic that cuts across the broad geographical, socioeconomic, ethnic, and age spectrum of the population of women giving birth in Michigan."[25] In Michigan, 299 (0.68 per 1,000 annual births) women tested HIV positive from July, 1988, through June, 1991.[26] "The majority (78 percent) are from the Detroit area and one-half are black. The rate is fairly evenly distributed across the range of age groups. No consistent upward or downward trend is apparent."[27] The results of the entire CDC study estimate that 6079 (1.5 per 1,000 births) HIV infected women gave birth nationwide in the two year period starting in mid-1988.[28] Assuming 30 percent transmission of the HIV to their newborns, this led to an estimated 1824 HIV-infected newborns.[29]

III. RECENT ACTIVITY ON MATERNAL HIV ANTIBODY TESTING BY NEW JERSEY AND MICHIGAN LEGISLATURES

New Jersey and Michigan are currently the only states to have introduced legislation concerning required non-anonymous HIV testing of newborns. On June 24, 1991, New Jersey State Senator Bassano, and other sponsors, introduced a Bill to the New Jersey Senate Committee on Institutions, Health and Welfare that requires HIV testing for hospital patients, health care professionals working in hospitals, pregnant women and newborn infants.[30]

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[23] *Guidelines for Foster Families, supra* note 16, at 681.

[24] *Perinatal HIV Testing, supra* note 18, at 791.

[25] Michigan Department of Public Health, *Policy Statement on HIV Testing of Newborns*, (Draft 1992) (on file at the Newborn Screening Office, Mich. Dep't. of Pub. Health) [hereinafter *MDPH Policy Statement*].

[26] *Id.*

[27] *Id.*

[28] *Gwinn, supra* note 15, at 1706.

[29] *Id.* at 1707 (Table 3).

[30] 1990 N.J. Senate Bill No. 3588 204th Legislature -- Second Regular Session (1991) [hereinafter 1991 N.J.S. 3588].

Sen. Bassano's office recently indicated that this Bill was not passed in 1991, nor was it reintroduced in 1992.[31]

In 1991, when the New Jersey Bill was introduced, the sponsors, concerned with the spread of AIDS,[32] reasoned that:

> The testing of pregnant women and newborn infants for HIV is a reasonable part of a rigorous epidemiological approach to the AIDS epidemic, given the accuracy of new confirmatory tests and the fact that perinatally transmitted HIV infection is now more common than congenital syphilis or phenylketonuria, both of which are tested for on a routine basis, as well as the need for HIV infected women to make informed choices about family planning, and the public health imperative to treat infected newborns as early as possible.[33]

An important feature of this Bill was that it also required the newborn's mother to receive pre-test and post-test counseling and give written informed consent prior to HIV testing of herself or her newborn.[34]

In Michigan, on April 28, 1992, House Bill 5863 was introduced by Rep. John Jamian, and other sponsors, to amend the Michigan Public Health Code. Applicable provisions of this Bill include, in part:[35]

Sec. 333.5133

> (1) Except as otherwise provided in this section, a physician who orders an HIV test or a health facility that performs an HIV test shall provide counseling appropriate to the test subject both before and after the test is administered.
>
> (2) Except as otherwise provided in this part, a physician, or an individual to whom the physician has delegated authority to perform a selected act, task, or function under section 16215, shall not order an HIV test for the purpose of diagnosing HIV infection without first receiving the written, informed consent of the test subject . . .

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[31] Telephone call to N.J. State Senator C. Louis Bassano's office (July 13, 1992).

[32] 1991 N.J.S. 3588, *supra* note 30:

1. The Legislature finds and declares that:
   a. New Jersey currently ranks fifth among all of the states, after New York, California, Florida and Texas, in the number of reported AIDS cases, with a reported cumulative total of almost 11,000 persons with AIDS, of whom more than 60% have died.
   b. The Department of Health has estimated that between 30,000 and 50,000 New Jerseyans are infected with HIV, and that by 1992, the cumulative total of diagnosed AIDS cases in the State may be approximately 17,500 persons.

[33] *Id.*

[34] *Id.* at §§ 5-6.

[35] This is the 'as substituted' version and was mailed from Mich. Rep. John Jamian's (65th District) office on July 13, 1992 [hereinafter 1992 M.H.B. 5863].

(14) This section does not apply to an HIV test performed upon a newborn infant under section 5431.

Sec. 333.5431[36]

(1) A health professional in charge of the care of a newborn infant. . . shall administer . . . a test for . . . HIV or an antibody to HIV . . . . If the federal approval [for HIV tests] is denied or if no or insufficient federal funds are available for that purpose, then the department shall use state funds.[37]

On June 25, 1992, the House Committee on Public Health recommended Bill 5863, as substituted,[38] to the Michigan House of Representatives. Although the Bill was passed in the House (90 in favor; two opposed) on July 22, 1992, it was not enacted into law in 1992. A substantially similar bill has been introduced for 1993. Reading all these sections of the Bill together, HIV would be treated like the other seven newborn screens except that it would require "in person" notification of positive results. This Bill requires counseling and informed consent prior to most other types of HIV testing. However, subsection 14 makes an exception to informed consent and counseling requirements for newborn HIV screening. The practical effect of this exception would mean that all women who give birth in Michigan would be tested for HIV through their infants without counseling or informed consent requirements.

IV. ANALYSIS OF MANDATORY HIV TESTING AND REPORTING IN NEWBORN SCREENING

With few exceptions,[39] authors who have written on this topic are opposed to mandatory newborn testing for maternal HIV antibodies. The National Academy of Sciences' Institute of Medicine stated on January 16, 1991, that routine HIV screening of newborns was unjustified because the tests are inconclusive in newborns.[40] The American Academy of Pediatric's Task Force on Pediatric AIDS expressly opposes this "mandatory (involuntary) maternal and/or newborn testing."[41] Instead, they recommend HIV testing be routinely *offered* to all pregnant women and all women of childbearing age. The Academy particularly encourages testing for those women at increased risk for HIV

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[36] *Cf. supra* notes 13-14 and accompanying text for current text of what is currently tested under this section.

[37] 1992 M.H.B. 5863, *supra* note 35, at 12-13.

[38] *See* Michigan Bill Tracking-State Net (LEXIS).

[39] *See* Angell, *supra* note 3 and accompanying text; Ronald Bayer, *Should Newborns be Routinely Tested for HIV?*, 7 MED. ETHICS 1, 10 (Feb. 1992).

[40] Marlene Cimons, *AIDS Testing for Pregnant Women Urged*, L.A. TIMES, Jan. 16, 1991, at A19 [hereinafter *AIDS Testing Urged*].

[41] *Perinatal HIV Testing*, *supra* note 18, at 793.

infection because of engaging in high-risk behaviors and/or living in areas with high HIV-seroprevalence rates.[42]

The language of Michigan House Bill 5863 would have significant effects. It would, for the first time in Michigan and the United States, mandate non-anonymous HIV testing of newborns, without the informed consent of the mother.

Since newborn screening began in the mid-1960's, it has been standard practice to carefully review each type of screen before it is mandated. This type of review did not occur with Michigan House Bill 5863. Issues that should be reviewed prior to initiating newborn HIV screening include: the five guidelines for establishing a newborn screen (discussed *supra*); informed consent; confidentiality in newborn screening; and newborn screening refusals. These issues should then be balanced against the adequacy of identifying HIV positive newborns under current laws and practices relating to prenatal HIV testing.

A. Guidelines for Establishing a Newborn Screen

There are five general criteria used to determine if a disease is appropriate for newborn screening.[43] The two most debated criteria in newborn HIV screening are the availability of treatment and availability of an accurate testing method.

Various treatment protocols for HIV infection have been gaining acceptance in the medical community. The MDPH staff have stated that, "[a]lthough there is no cure for HIV infection, there are a number of early interventions that can prolong length and quality of life for newborns and children. These interventions are not without controversy but they can be useful."[44] Further, the American Academy of Pediatrics recommends that as part of treatment, "[s]ervices must be provided for the families as well as for individual HIV-infected women and should include psychosocial, behavioral, and clinical support."[45]

There remains some debate on the accuracy of the testing method and interpretation of newborn HIV test results. The current CDC study using dried newborn blood shows the presence of maternal HIV antibodies that were transmitted to the newborn. This test allows the CDC to monitor HIV seroprevalence of women giving birth.[46] Only about 30 percent of newborns who test positive will actually become infected with HIV.[47] Newborn HIV testing is essentially indirect maternal HIV testing. As discussed below, this

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42 *Id.* at 792.

43 *See* Cuckle, *supra* note 12 and accompanying text.

44 *MDPH Policy Statement*, *supra* note 25.

45 *Perinatal HIV Testing*, *supra* note 18, at 791.

46 *See supra* notes 24-27 and accompanying text; *AIDS Testing Urged*, *supra* note 40.

47 *See supra* note 20 and accompanying text.

raises informed consent problems. Further, although the testing method may be accurate for the maternal HIV antibody, its false positive rate has not been established.

Currently, physicians are reluctant to treat newborns who merely show the presence of their mother's HIV antibody because of the serious side effects of anti-AIDS drugs. Several different tests are being developed which may address this concern by determining the infection status of the infant. These tests include culture, polymerase chain reaction, and detection of infant-produced, HIV-specific antibodies of the IgA and/or IgM classes.[48] These tests may allow physicians to treat only those newborns actually infected with HIV, rather than all newborns who have maternal HIV antibodies.

B. Informed Consent

Traditionally, if a physician treats a patient without informed consent, he has committed the tort of assault and battery.[49] Informed consent is distinct from general consent in that it involves the:

> duty of a physician to make reasonable disclosures to his or her patient regarding the potential risks of the proposed treatment, expected benefits, and alternative treatments. A physician who fails to inform his or her patient of the potential results of the treatment or alternative methods of treatment may be held liable for negligence.[50]

These concepts of consent typically relate to implications of invasive procedures to the patient. A simple blood test traditionally does not involve informed consent. However, "due to the early hysteria regarding AIDS . . . special informed consent practices developed concerning HIV testing. Clearly this represents an expansion of the legal 'informed consent' requirement."[51]

Currently, there is a consensus among public health professionals that informed consent should be obtained prior to HIV testing.[52] The National Academy of Sciences' Institute of Medicine reported on January 15, 1991, that routine HIV screening of newborns was not only unjustified because the tests are inconclusive in newborns,[53] but also, "'[u]sing newborn HIV screening to identify HIV-infected mothers would . . . mean that post-partum women currently would be the only civilian, non-institutionalized adult population not given the opportunity to consent to or refuse HIV testing, an outcome that

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48 *Perinatal HIV Testing*, *supra* note 18, at 791 (citations omitted).

49 Salwa G. Spong, *AIDS and the Health Care Provider: Burgeoning Legal Issues*, 67 MICH. B.J. 610, 614 (1988) (citing Franklin v. Peabody, 288 N.W.2d 681 (Mich. 1930); Banks v. Wittenberg, 266 N.W.2d 788 (Mich. App. 1978)).

50 *Id.* (citations omitted).

51 *Id.* at 615-16.

52 *Id.* at 616.

53 Cimons, *supra* note 40, at A19 col. 1.

is ethically unacceptable."[54] The American Academy of Pediatrics Task Force on Pediatric AIDS also recommends that "[t]esting in the perinatal period should occur under specified polices which ensure retesting, education, informed consent, counseling, and follow-up criteria."[55]

Another compelling argument in favor of informed consent prior to HIV testing is found in the Ryan White Comprehensive AIDS Resources Emergency Act (CARE) which Congress enacted in 1990 to direct AIDS relief.[56] The specific purpose of the CARE Act is to provide:

> emergency assistance to localities that are disproportionately affected by the Human Immunodeficiency Virus epidemic and to make financial assistance available to States and other public or private nonprofit entities to provide for the development, organization, coordination and operation of more effective and cost efficient systems for the delivery of essential services to individuals and families with HIV disease.[57]

There are three major entitlements in the CARE Act.[58] To receive Title III funds, certain restrictions apply. All Title III grants must provide pre-test and post-test counseling.[59] The statute states:

> 300ff-61. Confidentiality and informed consent
> (b) Informed consent
> (1) In general
>
> The Secretary may not make a grant under this part unless the applicant for the grant agrees that, in testing an individual for HIV disease, the applicant will test an individual only after obtaining from the individual a statement, made in writing and signed by the individual, declaring that the individual has undergone the counseling described in section 300ff-62(a) of this title and that the decision of the

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[54] *Id.* citing *Institute of Medicine Report* (Jan. 15, 1992).

[55] *Perinatal HIV Testing, supra* note 18, at 793.

[56] 42 U.S.C. § 300ff (Supp. III 1989-1992).

[57] Raymond C. O'Brien, *A Legislative Initiative: The Ryan White Comprehensive AIDS Resources Emergency Act of 1990*, 7 J. CONTEMP. HEALTH L. & POLICY 183, 188 (1991) (quoting Pub. L. No. 101-381, § 2, 104 Stat. 576).

[58] They include:
Title I--HIV Emergency Relief Grant Program (creating and amending Title XXVI--HIV Health Care Services Program of the Public Health Service Act) directed towards metropolitan areas;
Title II--HIV Care Grants (amending Title XXVI) directed towards the states; and
Title III--Early Intervention Services (amending Title XXVI) directed towards the states and efforts to test, educate, and counsel.
O'Brien, *supra* note 57, at n.22.

[59] *Id.* at 199. *See also*, 42 U.S.C.A. § 300ff-61(a) (Pub. L. No. 101-381, 104 Stat. 576, 609).

> individual with respect to undergoing such testing is voluntarily made.[60]

Clearly Congress finds counseling and informed consent an important aspect of any HIV testing program.[61] In contrast, the proposed Michigan Bill mandating HIV testing does not require any counseling and informed consent for newborn results.[62] Additionally, the MDPH staff state that adding HIV testing to the newborn screening program would jeopardize continued CDC funding of Michigan's maternal HIV seroprevalence survey.[63]

C. Confidentiality in Newborn Screening

The United States Supreme Court has "recognized a 'zone of privacy,' encompassed in the Constitution [that] protects against unwarranted governmental intrusions into personal matters."[64] In *Whalen v. Roe*,[65] the Court extended this right to an "individual['s] interest in avoiding disclosure of personal matters."[66] "Nevertheless, 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."[67]

Newborn screening programs in this country often retain data, including test results, on all infants screened. (All Michigan newborn screening results have been maintained in a computerized database since October 1, 1987). One author has warned,

> [i]f mass screening programs collect and retain data about persons screened, other persons may seek access to some of the data for a variety of purposes, such as seeking compatible bone marrow or other organ donors or attempting to locate biological parents (or offspring)

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60 42 U.S.C. § 300ff-61(b)(1) (Supp. III 1989-1992).

61 The state of Michigan and its municipalities are therefore obligated to use of informed consent process by accepting funds under this Act. As of July 20, 1992, the MDPH receives approximately $1,207,302 annually under Title II of this Act. Further, programs within the cities of Detroit and Grand Rapids combined receive approximately $1,275,000 annually under Title III.

62 1992 M.H.B. 5863, *supra* note 35 and accompanying text at § 5133(14).

63 *MDPH Policy Statement*, *supra* note 25.

64 Spong, *supra* note 49, at 616 (citing Roe v. Wade, 410 U.S. 113 (1973); Eisenstadt v. Baird, 405 U.S. 438 (1972); Griswold v. Connecticut, 381 U.S. 479 (1965).

65 429 U.S. 589 (1977).

66 *Id.* at 599 (footnote omitted). *See also* Spong, *supra* note 49, at 616.

67 Whalen, 429 U.S. at 602 (footnote omitted).

> after an adoption. . . . Making such information available without a court order may well expose screening programs to liability.[68]

Concerns for confidentiality and resulting liability are particularly important with HIV results due to the stigma associated with being designated HIV positive. "Persons with AIDS or HIV infection have a very strong interest in maintaining the confidentiality of their health status, particularly given the close association of HIV infection with sexual practice and drug use, and the ensuing social ostracism and discrimination potential that may accompany a positive HIV test result."[69] Physicians routinely contact newborn screening programs for the status of their patient's newborn screen.[70] Additional procedures for safeguarding HIV data would be needed if the proposed Michigan bill became law.

D. Newborn Screening Refusals

The MDPH staff are also concerned about how the addition of newborn HIV testing would affect screening refusals. It is estimated that each year there are only about ten families that refuse newborn screening.[71] That is extremely low considering there are 150,000 Michigan births each year. If HIV testing is mandated, it is expected that this number of refusals would significantly increase. This is based on

> experience that shows . . . when HIV testing is perceived to be forced on an individual, or when testing is done without the proper consent, people react negatively due to the stigma associated with HIV, concern about how the test results will be used, lack of understanding about the meaning of the test results, . . .[72]

This increased refusal rate would not only impact HIV testing but also would adversely affect the entire newborn screening program.[73]

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[68] *Legal Liability and Quality Assurance in Newborn Screening*, AMERICAN BAR FOUNDATION at 134 (Lori B. Andrews, ed. 1985) (citing Roger B. Dworkin, *Legal Issues Posed by Newborn Screening Program*).

[69] Spong, *supra* note 49, at 616.

[70] In Michigan there are approximately 20 such requests every day.

[71] *MDPH Policy Statement, supra* note 25. *See* Bayer, *supra* note 39 at 4 ("[V]ast majority of [HIV] infected women who are hospitalized during childbirth choose not to be tested when counseled about the importance of knowing their own HIV status.").

[72] *MDPH Policy Statement, supra* note 25.

[73] With increased refusals, some cases of currently screened disorders would be missed. For example, a five percent refusal rate in Michigan would result in approximately two missed cases each year of congenital hypothyroidism, a sporadic disorder leading to severe mental retardation if untreated.

V. CURRENT MICHIGAN LAW FOR PRENATAL HIV TESTING

Since 1988, Michigan has mandated, under M.C.L.A. § 333.5123, that pregnant women be offered prenatal testing for HIV (as well as for other venereal diseases and hepatitis B).[74] The test samples are obtained on the woman's initial prenatal visit. This law not only benefits the mother, but also her baby. Many believe this is the best time to test for HIV so long as there is counseling and informed consent.[75] This is also the best time to identify infants exposed to hepatitis B and venereal disease. When HIV results are available prenatally, the affected mother can be counseled and educated to prevent risk behaviors and transmission (such as avoiding breast feeding, which may transmit the virus).[76] These benefits are not achievable using the newborn screening method.[77]

A potential drawback of M.C.L.A. § 333.5123 is that it allows too much opportunity to opt out of the prenatal HIV test. The law states:

> This subsection shall not apply if, in the professional opinion of the physician or other person, the tests are medically inadvisable or the woman does not consent to be tested.

This language creates a path of least resistance for health care providers to avoid performing these prenatal tests. Although no statewide data are available, anecdotal accounts indicate that this prenatal testing is not being conducted comprehensively. Perhaps public health needs would be better served if Michigan Bill 5863 proponents sought to strengthen prenatal HIV testing legislation instead of mandating HIV testing of newborns.

VI. CONCLUSION

Only New Jersey and Michigan have introduced legislation concerning non-anonymous HIV testing of newborns. The New Jersey Bill was rejected;

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74 M.C.L.A. § 333.5123.

AIDS test for pregnant women

Sec. 5123. (1) A physician or an individual otherwise authorized by law to provide medical treatment to a pregnant woman shall take or cause to be taken, at the time of the woman's initial examination, test specimens of the woman and shall submit the specimens to a clinical laboratory approved by the department for the purpose of performing standard venereal disease tests approved by the department, a test for HIV or antibody to HIV, and a test for hepatitis B. This subsection shall not apply if, in the professional opinion of the physician or other person, the tests are medically inadvisable or the woman does not consent to be tested.

75 *Perinatal HIV Testing supra* note 16, at 792. *See also, MDPH Policy Statement, supra* note 25.

76 *MDPH Policy Statement, supra* note 25.

77 Other benefits of prenatal testing for these conditions are the ability to prepare for vaccination of the infant against hepatitis B immediately after birth and the ability to treat syphilis during pregnancy, thus preventing congenital syphilis.

Michigan House Bill 5863, as substituted, although overwhelmingly passed by the Michigan House of Representatives, died at the close of the State's 1991-1992 legislative session, only to be introduced again in 1993 in a substantially similar form.

The current consensus in the legal, scientific and public health community is that mandating newborn screening for HIV does not meet goals of identification and follow-up of HIV infected mothers or newborns. Testing newborns without parental informed consent or counseling would, in effect, result in the involuntary HIV screening of every woman giving birth. If forced to include non-anonymous HIV tests, state newborn screening programs would be adversely affected due to an increased number of refusals and inefficiencies created by the need to maintain stricter confidentiality of test results.

Considering issues of informed consent, confidentiality, possible newborn screening refusals, and the potential for identifying HIV-exposed neonates through prenatal testing, the addition of non-anonymous HIV testing to routine newborn screening appears to be neither efficient nor ethically defensible. Enhancing prenatal HIV testing with informed consent is a more preferable course for legislatures to follow.