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# HIV TESTING OF PREGNANT WOMEN: WHY PRESENT APPROACHES FAIL TO REACH THE DESIRED OBJECTIVE & THE UNCONSIDERED OPTION

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## I. INTRODUCTION

The focus of HIV/AIDS campaigns and literature has shifted dramatically in recent years to Sub-Saharan Africa, where rates of HIV infection and AIDS-related deaths are undeniably staggering.<sup>1</sup> However, such concentrated attention upon the AIDS epidemic upon the African continent may inadvertently be causing the decay of HIV/AIDS awareness and prevention in the United States. In fact, the most recent epidemiological study of HIV/AIDS rates in the United States found that more people than ever before were living with HIV in 2005, a shocking 1.2 million people.<sup>2</sup> The increase has been noted as a reflection of mixed results in the United State's efforts to combat the AIDS epidemic.<sup>3</sup> More people with HIV are living longer due to antiretroviral treatment,<sup>4</sup> however, the "early gains made on the prevention front have not been sustained."<sup>5</sup> A thorough discussion of HIV/AIDS prevention at large in the United States would be an impossible endeavor under the constraints of a journal Note; therefore this Note seeks to focus specifically upon a highly debated sub-issue which arises from the HIV/AIDS discussion—mother-to-

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\* J.D. Candidate 2008, Benjamin N. Cardozo School of Law, Annotations Editor, *Cardozo Journal of Law and Gender*; B.A., New York University, 2005. I would like to dedicate this note to my loving sister in recognition of her unwavering support, guidance, and encouragement throughout the years. I would also like to thank my parents for instilling in me the importance of higher education and the courage to stop at nothing less than my greatest aspirations.

<sup>1</sup> See Avert.org, Worldwide HIV & AIDS Statistics, <http://www.avert.org/worldstats.htm> (last visited Nov. 1, 2006) [hereinafter Avert, Worldwide Statistics]. At the end of 2006, an estimated 24.7 million adults and children were living with HIV/AIDS in Sub-Saharan Africa.

<sup>2</sup> U.N. Econ. & Soc. Council [ECOSOC], UNAIDS/WHO, *2006 Report on the Global AIDS Epidemic*, at 44 (May 2006), available at [http://www.unaids.org/en/HIV\\_data/2006GlobalReport/default.asp](http://www.unaids.org/en/HIV_data/2006GlobalReport/default.asp) (last visited Nov. 1, 2006). [hereinafter *2006 Report on the Global AIDS Epidemic*]. The United Nations report provides the latest statistics on world epidemics of AIDS and HIV, referring only to the end of 2005.

<sup>3</sup> *Id.* at 45.

<sup>4</sup> See Avert.org, <http://www.avert.org/aidstreatment.htm> (last visited Nov. 1, 2006) [hereinafter Avert, Aids Treatment]. Antiretroviral drug treatment is the primary type of treatment for HIV and AIDS. It is not a cure, but it can deter illness for a number of years. Treatment consists of drugs that must be taken daily for the remainder of one's life.

<sup>5</sup> See *2006 Report on the Global AIDS Epidemic*, *supra* note 2, at 45.

child transmission prevention and consequently, mandatory HIV testing of pregnant women.

In 2005 alone, 700,000 children became infected with HIV primarily through mother-to-child transmission (MTCT).<sup>6</sup> Although the vast majority of such infections occur in Sub-Saharan Africa,<sup>7</sup> incidences of MTCT in the United States continue to occur in spite of available and oftentimes simple methods of prevention.<sup>8</sup> As of 2005, an estimated 6,726 children under the age of 13 were living with HIV/AIDS in only thirty-three states with confidential name-based reporting.<sup>9</sup> At the root of the issue is a woman's ignorance of her HIV status. None of the possible methods of MTCT prevention can or will be employed unless an expectant mother knows of her HIV status. This fact, as a result, has prompted endless debate and legislation surrounding the proper and justifiable measures of HIV testing of pregnant women and their newborns.

This Note seeks to evaluate present legislation of states to combat the issue of MTCT, to reconsider mandatory HIV testing of pregnant women, and to introduce a new approach of mandatory testing that endeavors to consider both the constitutional barriers that previously proposed mandatory testing procedures faced, as well as the benefits of early HIV detection in the prevention of MTCT. In this discussion's development, the Note will explore: (1) current pediatric HIV/AIDS statistics, (2) mother-to-child transmission of HIV, prevention methods, and the mandatory testing debate, (3) federal and state legislation passed to effectuate universal HIV testing of pregnant women, (4) mandatory HIV testing and its Constitutional implications and barriers, and (5) a new mandatory testing approach and its implementation.

## II. PEDIATRIC HIV/AIDS STATISTICS

Although the prevalence of HIV infection rates worldwide is still greatest among adults,<sup>10</sup> the number of pediatric AIDS cases is far from negligible. At the end of 2006, 2.3 million children were living with HIV/AIDS worldwide,<sup>11</sup> and in 2006 alone, five hundred thirty thousand children of the age of fourteen or younger

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<sup>6</sup> See Avert, *Worldwide Statistics*, *supra* note 1.

<sup>7</sup> *Id.*

<sup>8</sup> See CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC), *Mother-to-Child (Perinatal) HIV Transmission and Prevention* (May 2006), <http://www.cdc.gov/hiv/resources/factsheets/perinat1.htm> (last visited Sept. 21, 2007); CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC), *Cases of HIV Infection and AIDS in the United States* (2004), <http://www.cdc.gov/hiv/topics/surveillance/resources/reports/2004report/commentary.htm> (last visited Nov. 1, 2006) [hereinafter CDC: *Cases of HIV Infection and AIDS in the United States*].

<sup>9</sup> Cases of HIV/AIDS in children 13 and below are primarily the result of mother-to-child transmission (MTCT), with the exception of cases which occur as a result of hemophilia, blood transfusion, and risk not reported or identified. See CDC, *Basic Statistics* (2007), <http://www.cdc.gov/hiv/topics/surveillance/basic.htm#hivaidsage> (last visited March 7, 2007).

<sup>10</sup> At the end of 2006, an estimated 39.5 million adults were living with HIV/AIDS worldwide. See Avert, *Worldwide Statistics*, *supra* note 1.

<sup>11</sup> *Id.*

became infected with the virus.<sup>12</sup> Over 90% of newly infected children are babies born to HIV-positive women, who acquire the virus during pregnancy at birth or through their mother's breast milk.<sup>13</sup>

At the end of 2004, the Center for Disease Control (CDC) estimated that 462,792 persons were diagnosed and living with HIV/AIDS in the United States, a number thought to represent only 61% of the population affected by the epidemic.<sup>14</sup> Like world statistics, the number of adults living with the virus far exceeded that of children.<sup>15</sup> Nevertheless, of the 6,804 children living with HIV/AIDS in the United States, 90% had been exposed to the virus perinatally.<sup>16</sup> The CDC reports that through 2004, there have been a cumulative 8,779 cases of AIDS in children under the age of thirteen that resulted from HIV infection during pregnancy, birth, or breastfeeding.<sup>17</sup>

In the State of New York,<sup>18</sup> 111,597 persons were reported as living with HIV/AIDS at the end of 2005.<sup>19</sup> Of the 111,597 infected persons, 2,593 were under the age of thirteen.<sup>20</sup> New York state statistics show that New York City is the state's highest HIV/AIDS region.<sup>21</sup> In New York City, an estimated 85,588 persons were living with HIV/AIDS.<sup>22</sup> Of the total number of infected persons, 2,212 were under the age of thirteen.<sup>23</sup> For the children under the age of thirteen currently living with HIV/AIDS, perinatal transmission accounts for 91% of the cases.<sup>24</sup> In addition, in 2005 alone, 28 newly diagnosed cases of HIV/AIDS in New York State occurred among children under the age of 13.<sup>25</sup>

<sup>12</sup> *Id.*

<sup>13</sup> *Id.*

<sup>14</sup> The number of HIV+ people living in the United States varies between 900,000 and 1.2 million according to different estimates. See CDC: *Cases of HIV Infection and AIDS in the United States*, *supra* note 8.

<sup>15</sup> Only 6,804 of the estimated 462,792 persons living with HIV/AIDS were reported as children. *Id.*

<sup>16</sup> *Id.*

<sup>17</sup> See Avert.org, HIV & AIDS in America, <http://avert.org/america.htm> (last visited Nov. 1, 2006) [hereinafter Avert, USA Statistics].

<sup>18</sup> New York State has the highest reported percentage of cumulative national AIDS cases. This fact, in conjunction with the relevancy of New York legislation to the Cardozo Journal of Law & Gender, forms the basis of this note's focus on New York State statistics to the exclusion of others. See CDC: *Cases of HIV Infection and Aids in the United States*, *supra* note 8.

<sup>19</sup> BUREAU OF HIV/AIDS EPIDEMIOLOGY, N.Y. DEP'T OF HEALTH, *New York State HIV/AIDS Surveillance Semiannual Report* (2006), available at [http://www.health.state.ny.us/diseases/aids/statistics/semiannual/2005/surveillance\\_semiannual\\_report\\_2005-12.pdf](http://www.health.state.ny.us/diseases/aids/statistics/semiannual/2005/surveillance_semiannual_report_2005-12.pdf) (last visited Sept. 21, 2007) [hereinafter *NYS Semiannual Report*] (All statistics are current as of December 2005.).

<sup>20</sup> *Id.*

<sup>21</sup> *Id.*

<sup>22</sup> *Id.*

<sup>23</sup> *Id.*

<sup>24</sup> See The Body, *Infants, Children and HIV: Just the Facts*. <http://www.thebody.com/content/art5973.html#pediatric> (last visited Sept. 21, 2007)

<sup>25</sup> See *NYS Semiannual Report*, *supra* note 19.

Statistics demonstrate that cases of pediatric HIV/AIDS are far from negligible. Although worldwide statistics indicate that the incidence of pediatric infection is greatest outside of the United States, a substantial number occur within the United States. It is true that the number of perinatal transmissions in the United States appears disproportionately small in comparison to global statistics; however, a more focused evaluation of the raw number of persons infected perinatally in New York State alone demonstrates that the issue within our borders cannot and should not be trivialized.

### III. PERINATAL TRANSMISSION (MOTHER-TO-CHILD TRANSMISSION) PREVENTION METHODS & THE MANDATORY TESTING DEBATE

Perinatal transmission or mother-to-child transmission (MTCT) refers to the vertical transmission of HIV from an HIV-positive pregnant mother to her unborn fetus or infant.<sup>26</sup> Perinatal transmission is the primary cause of pediatric HIV infection.<sup>27</sup> Such transmission occurs either during pregnancy, labor and delivery, or breastfeeding.<sup>28</sup> “But, many researchers believe that most of the transmission during this time occurs in late pregnancy and during the birth process.”<sup>29</sup> The most effective methods of eliminating perinatal transmission are preventing HIV infection among prospective parents and avoiding unwanted pregnancies among HIV-positive women.<sup>30</sup> Nevertheless, such methods are clearly not always possible and HIV-positive women often become pregnant, either knowingly or inadvertently.<sup>31</sup> In such circumstances, mothers who know of their HIV status may increase the probability of preventing transmission to their infants through the use of antiretroviral drugs, the choice to have a caesarian section at time of delivery, and the employment of safer feeding practices.<sup>32</sup>

If an HIV-positive mother employs MTCT prevention methods, the rate of perinatal transmission may be decreased dramatically. Without treatment, an estimated 15-30% of infants born to HIV-positive women will become infected with HIV during pregnancy and delivery, and approximately 15% further will become infected through breastfeeding.<sup>33</sup> With the use of antiretroviral drugs,

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<sup>26</sup> Lawrence O. Gostin & James G. Hodge, Jr., *The “Names Debate”: The Case for National HIV Reporting in the United States*, 61 ALB. L. REV. 679, 701 (1998).

<sup>27</sup> *Id.*

<sup>28</sup> See Avert.org, Preventing Mother-to-Child Transmission of HIV, <http://www.avert.org/motherchild.htm> (last visited, Nov. 1, 2006) [hereinafter Avert, Preventing MTCT].

<sup>29</sup> See NATIONAL INSTITUTE OF CHILD HEALTH & HUMAN DEVELOPMENT (NICHD), *Sexually Transmitted Diseases and Infections (STDs and STIs) and HIV/AIDS Research*, available at <http://www.nichd.nih.gov/womenshealth/research/disorders/STDHIV.cfm> (last visited Jan, 28, 2007) [hereinafter NICHD: *STDs and STIs*].

<sup>30</sup> *Id.*

<sup>31</sup> *Id.*

<sup>32</sup> *Id.*

<sup>33</sup> See Avert, Preventing MTCT, *supra* note 27.

breast-milk substitutes, and other interventions, the risk of transmission to an infant can be effectively reduced from 25% to 2%,<sup>34</sup> a fortunate possibility.

Studies have also shown that medical treatment with antiretroviral drugs allows HIV-positive women to reduce the risk of vertically transmitting the virus to their infants dramatically.<sup>35</sup> Scientists from the AIDS Clinical Trial Group Protocol 076 (ACTG 076) study reported in 1994 that pregnant women who received a course of the antiretroviral drug zidovudine (AZT) treatment reduced the risk of fetal transmission to 8%.<sup>36</sup> As a result, AZT treatment has become the primary, and is regarded as the most effective, form of treatment for HIV-positive pregnant mothers.<sup>37</sup> According to the U.S. Department of Health, the most common treatment for pregnant HIV-positive mothers is a three-part AZT regimen.<sup>38</sup> With this regimen, HIV-positive pregnant women begin AZT treatment at 14 to 34 weeks of pregnancy, an intravenous AZT treatment is administered during labor and delivery, and the newborn is given AZT in liquid form every six hours for six weeks after birth.<sup>39</sup> Although AZT treatment cannot ensure that an infant will be born uninfected, the three-part AZT regimen has been shown to reduce the risk of perinatally transmitting the virus by almost 70%.<sup>40</sup> As an alternative to the extensive three-part regime treatment, a CDC study determined that a significantly less expensive and shorter course of AZT treatment that is administered to pregnant women in only the last four weeks of pregnancy could still reduce perinatal transmission by up to 50%.<sup>41</sup> Studies have found no short-term side effects in mothers or their infants,<sup>42</sup> and the use of AZT during pregnancy is not associated with an increase in birth complications, such as premature delivery.<sup>43</sup> However the benefits of AZT treatment cannot be discussed without due recognition of the fact that long-term consequences of babies' exposure to anti-HIV medications *in utero* are at the present time unknown.<sup>44</sup>

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<sup>34</sup> See Avert.org, HIV Testing in Pregnancy, [http://www.avert.org/HIV\\_testing-pregnancy.htm](http://www.avert.org/HIV_testing-pregnancy.htm) (last visited Nov. 1, 2006) [hereinafter Avert, HIV Testing in Pregnancy].

<sup>35</sup> See Avert, Preventing MTCT, *supra* note 27.

<sup>36</sup> *Id.*

<sup>37</sup> See NATIONAL INSTITUTES OF HEALTH, *Shorter AZT Treatment Reduces Mother to Child HIV Transmission as Well as Longer Treatment but for Less Cost*, October 4, 2000. <http://www.nichd.nih.gov/news/releases/azt.cfm> (Last visited Sept. 21, 2007) [hereinafter NIH: *Shorter AZT Treatment*].

<sup>38</sup> U.S. DEP'T OF HEALTH AND HUMAN SERVICES, *HIV During Pregnancy, Labor and Delivery, and After Birth: Health Information for HIV-positive Pregnant Women at 5* (August 2006), available at [http://aidsinfo.nih.gov/ContentFiles/Perinatal\\_FS\\_en.pdf](http://aidsinfo.nih.gov/ContentFiles/Perinatal_FS_en.pdf) (last visited Nov. 1, 2006) [hereinafter DOH, *HIV During Pregnancy, Labor and Delivery, and After Birth*].

<sup>39</sup> *Id.*

<sup>40</sup> U.S. DEP'T OF HEALTH AND HUMAN SERVICES, *HIV and Pregnancy* (August 2006), available at [http://www.aidsinfo.nih.gov/ContentFiles/HIVandPregnancy\\_FS\\_en.pdf](http://www.aidsinfo.nih.gov/ContentFiles/HIVandPregnancy_FS_en.pdf) (last visited Nov. 1, 2006) [hereinafter DOH, *HIV and Pregnancy*].

<sup>41</sup> See Gostin, *supra* note 26, at 703.

<sup>42</sup> See Avert, Preventing MTCT, *supra* note 27.

<sup>43</sup> See NICHD: *STDs and STIs*, *supra* note 28.

<sup>44</sup> DOH, *HIV During Pregnancy, Labor and Delivery, and After Birth*, *supra* note 38, at 6. The most reassuring findings were released in 1999 by the National Institute of Health (NIH), stating that

In addition, a discussion of the benefits of AZT treatment would not be complete without evaluating the costs of such procedures and the availability of healthcare coverage. The average cost of standard treatment that begins during the second trimester of pregnancy, and continues until delivery, during labor and delivery, and to the baby for six weeks after birth is approximately \$1000.<sup>45</sup> The average cost of a shorter regimen of AZT treatment, which generally begins at the 28<sup>th</sup> week of pregnancy until labor, and for three days after birth, costs approximately \$200.<sup>46</sup> HIV-positive persons, including mothers and infants, are provided HIV care and treatment coverage by both public and private initiatives.<sup>47</sup> Public initiatives which focus upon providing healthcare to low-income individuals include both insurance programs, such as Medicaid and Medicare, and funding provided by the Ryan White C.A.R.E Act (CARE Act).<sup>48</sup> Private coverage is provided by private insurance companies and drug company programs, such as patient assistance programs and clinical trials.<sup>49</sup> In addition, AIDS Drug Assistance Programs (ADAPs), which operate in all 50 states and all United States territories, are authorized under Title II of the CARE Act to provide HIV-related prescription drugs to underinsured and uninsured individuals to cover costs of continual treatment and testing.<sup>50</sup>

Attaining either public or private coverage for treatment and care costs is not without its challenges, however, such issues can only be resolved by improving bureaucratic efficiency and public awareness, questions beyond the scope of this Note. Nevertheless, HIV-positive pregnant mothers and their families should be comforted by the fact that coverage is available through insurance programs, initiatives taken by drug companies in recognition of the importance of treatment and continued research, and the federal government through the CARE Act's Title

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children who were exposed to AZT during the ACTG 076 *in utero* and as newborns and did not acquire HIV from their infected mothers showed no adverse health effects. Investigators plan on following these children until the age of twenty-one. See NATIONAL INSTITUTE OF ALLERGY AND INFECTIOUS DISEASES (NIAD), *Reassuring Findings About Infants Exposed to Zidovudine*, available at <http://www3.niaid.nih.gov/news/newsreleases/1999/pactg219.htm> (last visited Jan 6, 2007) [hereinafter NIAD, *Reassuring Findings*].

<sup>45</sup> See NICHD, *Shorter AZT Treatment Reduces Mother to Child HIV Transmission as Well as Longer Treatment but for Less Cost*, <http://www.nichd.nih.gov/news/releases/azt.cfm> (last visited Jan. 28, 2007) [hereinafter NICHD, *Shorter AZT Treatment*].

<sup>46</sup> *Id.*

<sup>47</sup> See Project Inform: Access to Treatment, available at <http://www.projinf.org/fs/access.pdf> at \*1 (last visited Jan. 27, 2007) [hereinafter Project Inform].

<sup>48</sup> *Id.* The Ryan White Comprehensive AIDS Resources Emergency (CARE) Act, passed by Congress in 1990, provides health and support services for people living with HIV in the United States and its territories. The CARE Act is the third-largest federal source of funding for HIV care and covers both uninsured and underinsured individuals and families living with HIV/AIDS. In addition, Title IV of the Act specifically addresses care for families and children with provisions for AZT treatment and both prenatal and postnatal care of HIV-positive pregnant mothers. Ryan White CARE Act, 42 U.S.C.S. § 300ff-33 (2000).

<sup>49</sup> *Id.* at 6.

<sup>50</sup> See Drug Company Patient Assistance Programs, <http://www.atdn.org/access/states/index.html> (last visited Jan. 27, 2007).

IV programs, which provide perinatal and pediatric specialty care services to HIV-positive mothers and infants.<sup>51</sup>

In addition to AZT treatment, it is important to emphasize that an HIV-positive mother can prevent risks of infant infection by other means, namely the election to undergo a caesarian section at time of delivery and the use of breast-milk substitutes after birth. A caesarian section protects the baby from direct contact with an HIV-positive mother's blood and other bodily fluids, thereby diminishing the rate of transmission to uninfected infants.<sup>52</sup> Researchers found that an elective caesarian section performed before a woman's water breaks and before she enters labor reduces transmission rates by 50%.<sup>53</sup> The use of breast milk substitutes further reduces the probability of transmission, since HIV transmission through breast milk accounts for one-third of perinatal HIV transmission.<sup>54</sup> Therefore, an HIV-positive mother has at her disposal options other than AZT treatment to prevent perinatal transmission.

The preventive measures discussed above are promising, but all such methods require knowledge of a mother's HIV infection in advance.<sup>55</sup> Moreover, the effectiveness of AZT treatment has been shown to increase incrementally, meaning that the earlier the treatment is administered the more effective the method is in preventing transmission.<sup>56</sup> Therefore, HIV testing during pregnancy has become the focal point of much heated debate, as well as federal and state legislation, on the prevention of perinatal transmission. The means and efficacy of approaches employed by states to attain universal HIV testing of pregnant women vary, and it is the deficiency of these methods that has acted as an impetus for this Note's discussion suggesting the development of an approach that has not yet been considered.

#### IV. FEDERAL AND STATE LEGISLATION & THE EFFECTUATION OF UNIVERSAL HIV TESTING OF PREGNANT WOMEN

The primary purpose of testing a woman for HIV during pregnancy is to prevent any possible infection from being passed to her unborn child, but it also serves to protect the health of the mother through identification of infection and

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<sup>51</sup> See U.S. DEP'T OF HEALTH AND HUMAN SERVICES, *Pediatric HIV/AIDS in the United States*, <http://hab.hrsa.gov/history/Pediatric/> (last visited Jan. 27, 2007) [hereinafter DOH: *Pediatric HIV/AIDS*].

<sup>52</sup> See Avert, Preventing MTCT, *supra* note 28.

<sup>53</sup> See Jennifer S. Read, *Cesarean Section Delivery to Prevent Vertical Transmission of Human Immunodeficiency Virus Type 1 Associated Risks and Other Considerations*, in 918 ANN. N.Y. ACAD. SCI. 115 (2000), available at <http://www.annalsnyas.org/cgi/content/full/918/1/115?ck=nck> (last visited Sept. 21, 2007).

<sup>54</sup> See CENTER FOR DISEASE CONTROL AND PREVENTION, *Perinatal Prevention*, <http://www.cdc.gov/hiv/topics/perinatal/index.htm> (last visited Nov. 1, 2006) [hereinafter CDC: *Perinatal Prevention*].

<sup>55</sup> See Gostin, *supra* note 26, at 703.

<sup>56</sup> See NIH: Shorter AZT Treatment, *supra* note 37.

treatment.<sup>57</sup> Therefore, it is no surprise that both federal and state legislation have taken initiatives to increase HIV testing during pregnancy.

#### *A. Federal HIV Testing Initiatives*

As a result of the success of ACTG 076 and statewide clinical experiences, Congress amended the CARE Act to directly address the issue of perinatal transmission of HIV.<sup>58</sup> The CARE Act was originally enacted in 1990 to provide for emergency funding for cities that are disproportionately affected by the AIDS epidemic in order to increase the access of poor persons infected with the virus to healthcare.<sup>59</sup> However, the 1996 amendments were enacted to focus more specifically upon combating perinatal transmission by requiring that states adopt the CDC guidelines concerning recommendations for HIV counseling and voluntary testing of pregnant women in order to receive Ryan White funding.<sup>60</sup> For the 2005 fiscal year, all fifty states, the District of Columbia, as well as Puerto Rico, the Virgin Islands, and Guam received Ryan White funding.<sup>61</sup>

Congress appropriated funds in the amount of \$30,000,000 for each of the fiscal years between 2001 and 2005, with the explicit goal of implementing comprehensive programs to provide counseling on HIV, voluntary testing of pregnant women, mandatory testing of newborns, and treatment services for pregnant HIV-positive women and their infants.<sup>62</sup> However, such funding is contingent upon a state proving that women are either routinely consenting to testing or showing that there has been a substantial reduction in the rate of perinatal transmission.<sup>63</sup> Therefore, although the amendments do not obligate states to implement mandatory testing measures, they have created strong incentives to do so. In addition, the language of the amendments explicitly states that nothing in the amendments shall be construed to disqualify a state from receiving grants if the state at any time establishes a program of mandatory HIV testing,<sup>64</sup> and nowhere in the statute are limitations upon the types of mandatory testing which may be implemented. As a result, some have described the 1996 amendments as Congress'

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<sup>57</sup> See Avert, *HIV Testing in Pregnancy*, *supra* note 34.

<sup>58</sup> Ryan White CARE Act, *supra* note 48.

<sup>59</sup> Jennifer Brown, *A Troublesome Maternal-Fetal Conflict: Legal, Ethical, and Social Issues Surrounding Mandatory AZT Treatment of HIV-positive Pregnant Women*, 18 *BUFF. PUB. INT. L.J.* 67, 73 (1999).

<sup>60</sup> See Ryan White CARE Act, *supra* note 48.

<sup>61</sup> Kaiser State Health Facts, *50 State Comparisons: Total Ryan White CARE Act Funding, FY2005*, <http://www.statehealthfacts.org/comparemaptable.jsp?ind=534&cut=11> (last visited March 1, 2007).

<sup>62</sup> Ryan White CARE Act, *supra* note 48.

<sup>63</sup> *Id.*

<sup>64</sup> Section 300ff-37 explicitly states, "Nothing in this subpart [42 USCS §§ 300ff-33 et seq.] shall be construed to disqualify a State from receiving grants under this subpart [42 USCS §§ 300ff et seq.] if such State has established at any time prior to or after May 20, 1996 a program of mandatory HIV testing. See Ryan White CARE Act, *supra* note 48.

invitation to the states “to impose mandatory testing measures or lose all of their Ryan White funding.”<sup>65</sup>

### *B. State HIV Testing Initiatives & Mandatory Newborn Testing*

States have adopted various methods to increase the number of women who are tested for HIV during pregnancy.<sup>66</sup> Such approaches include the “opt-out” approach, “opt-in” approach, mandatory testing of newborns, and rapid testing during labor.<sup>67</sup> For a number of reasons discussed below, the adoption of certain approaches have been favored over others and the effectiveness of each approach in attaining widespread HIV testing of pregnant women varies. Nevertheless, the present is an appropriate time to revisit mandatory testing of newborns, chosen by New York and Connecticut legislatures,<sup>68</sup> which was hotly contested and challenged prior to and immediately after its adoption, but since its implementation has been notably successful in attaining high rates of testing among pregnant women.<sup>69</sup>

It is important to note that the above list of approaches is not exhaustive. In fact, as will be discussed below, the most heavily debated approach is the implementation of universal mandatory testing of pregnant women. Although this approach has not been adopted by any of the states, an analysis of the constitutional and ethical issues which surround it is necessary in the discussion of present state HIV testing initiatives and possible future approaches.

#### 1. State Options: Approaches Adopted by the States

States have responded to the push for increasing HIV testing among pregnant women through a number of approaches, each with their own methodology and

<sup>65</sup> Brown, *supra* note 59, at 74 (citing Theresa M. McGovern, *Mandatory HIV Testing and Treating of Child-Bearing Women: An Unnatural, Illegal, and Unsound Approach*, 28 COLUM. HUM. RTS. L. REV. 469, 477 (1997))

<sup>66</sup> See Avert, *HIV Testing in Pregnancy*, *supra* note 34.

<sup>67</sup> *Id.*

<sup>68</sup> See N.Y. PUB. HEALTH LAW § 2500-f (1996). Effective June 26, 1996, the New York legislature enacted a public health law addressing the problem of perinatal transmission by mandating the testing of all newborns. Section 2500-f states in pertinent part that: “[T]he commissioner shall establish a comprehensive program for the testing of newborns for the presence of human immunodeficiency virus and/or the presence of antibodies to such virus.” Connecticut soon followed New York’s lead by enacting Con. Gen. Stat. §19a-593 in June of 1999, stating in pertinent part that

if an HIV-related test has not been documented in the patient's medical record at admission for delivery of the baby, then the health care provider responsible for the patient's care shall inform the pregnant woman . . . of the health benefits to herself and her newborn of being tested for HIV infection either before delivery or within twenty-four hours after delivery and, in the absence of specific written objection, shall cause such test to be administered.

<sup>69</sup> *Id.* See also Melinda Tuhus, *Groups Challenge New HIV Testing Law*, N.Y. Times, Dec. 12 1999.

results. However, “of the fifty states and the District of Columbia, only seventeen have specific prenatal HIV testing statutes.”<sup>70</sup>

The “opt-out” approach has been adopted by six states, where all women receive an HIV test, unless they specifically state that they do not want one.<sup>71</sup> Prior to testing, all women are given information about HIV/AIDS, the purpose of the test, and the procedure.<sup>72</sup> Any woman who subsequently receives a positive result will then be counseled and given the appropriate treatment if necessary.<sup>73</sup> Studies show that 85-95% of pregnant women who are offered HIV testing under this approach agree to have one.<sup>74</sup> As a result, most commentators and academics have concentrated their support upon the “opt out” approach.<sup>75</sup>

The “opt-in” approach, which has been adopted by eleven states, provides that a woman may be informed that a test is available, but will only be given one if she specifically requests it.<sup>76</sup> Therefore, only women who are concerned about possible HIV infection will be tested and the approach fails to reach the objective of widespread testing.<sup>77</sup> A study conducted by the CDC demonstrates that critics of this approach are likely correct; the study concluded that in states employing the “opt-in” approach, prenatal HIV testing rates ranged from only 25-69%.<sup>78</sup> Such an approach exacerbates the common misconceptions among women that they simply do not need an HIV test, and that doctors and other medical professionals will judge them if they do choose to get tested.<sup>79</sup> As a result, the “opt-in” approach has been disfavored by both policymakers and state legislatures.

Some states have chosen to experiment with rapid testing during labor. The rapid test uses an HIV antibody test that provides results within twenty to forty-five minutes, therefore a positive result allows for safer delivery practices to be adopted and for AZT to be administered during labor and delivery.<sup>80</sup> In addition, such timely knowledge of the mother’s HIV status provides opportunities for other

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<sup>70</sup> Z. Lazzarini and L. Rosales, *Legal Issues Concerning Public Health Efforts to Reduce Perinatal HIV Transmission*, 3 YALE J. HEALTH POL’Y L. & ETHICS 67, 81 (Winter 2002).

<sup>71</sup> See Avert, *HIV Testing in Pregnancy*, *supra* note 33. See also Lazzarini, *supra* note 70, at 82.

<sup>72</sup> *Id.*

<sup>73</sup> *Id.*

<sup>74</sup> *Id.* Schuman, Paula et. al., *Voluntary HIV Counseling and Testing of Pregnant Women -- An Assessment of Compliance With Michigan Public Health Statutes*, MEDSCAPE GENERAL MEDICINE, Vol. 6 No. 2, June 16, 2004.

<sup>75</sup> See Avert, *HIV Testing in Pregnancy*, *supra* note 33. See also Center for Disease Control and Prevention: *Routine Perinatal Testing: The Opt-Out Approach Questions and Answers*, <http://www.cdc.gov/hiv/topics/perinatal/resources/qa/opt-out.htm> (last visited Sept. 21, 2007).

<sup>76</sup> See Avert, *HIV Testing in Pregnancy*, *supra* note 34. See also Lazzarini, *supra* note 70, at 78.

<sup>77</sup> *Id.*

<sup>78</sup> See CENTERS FOR DISEASE CONTROL AND PREVENTION, *HIV Testing Among Pregnant Women—United States and Canada, 1998-2001*, <http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5145a1.htm> (last visited Jan. 27, 2007) [hereinafter CDC: *HIV Testing Among Pregnant Women*].

<sup>79</sup> *Id.*

<sup>80</sup> See CENTERS FOR DISEASE CONTROL AND PREVENTION, *Rapid HIV-1 Antibody Testing During Labor and Delivery for Women of Unknown HIV Status: A Practical Guide and Model Protocol*, [http://www.cdc.gov/hiv/topics/testing/resources/guidelines/rt-labor&delivery\\_introduction.htm#intro](http://www.cdc.gov/hiv/topics/testing/resources/guidelines/rt-labor&delivery_introduction.htm#intro) (last visited Nov. 1, 2006) [hereinafter CDC: *Rapid HIV Testing*].

interventions that reduce transmission, such as elective cesarean section, avoiding artificial rupture of membranes, and avoiding breastfeeding.<sup>81</sup> Although studies have shown that rapid testing during labor has been effective in identifying unknown cases of HIV, the voluntariness of the consent given during labor has been questioned by critics who believe that the method is ethically undesirable.<sup>82</sup> In addition, such late knowledge of the mother's HIV status does not take advantage of the benefits of early HIV detection for treatment planning and delivery options.<sup>83</sup>

Lastly, only two states, New York and Connecticut, have adopted laws that require mandatory testing of newborns, where every newborn baby has a mandatory HIV test if the mother has not had a test during her pregnancy.<sup>84</sup> As a result of such programs, New York and Connecticut have substantially increased the number of women being tested during pregnancy and a number of infants at risk of HIV have been effectively identified.<sup>85</sup> However, mandatory newborn testing of newborns has been the focus of much consternation, criticism and debate as a result of the legal and ethical implications of such testing.<sup>86</sup> In addition, because women can still choose not to test during pregnancy, such an approach fails to detect the virus at the most critical stages of HIV prevention, namely during pregnancy and delivery. Therefore mandatory testing of newborns has been generally disfavored as well.<sup>87</sup>

## 2. Mandatory Newborn Testing, Criticism and Its Effectiveness

Prior to and immediately after the adoption of mandatory newborn testing laws in New York and Connecticut, the only two states with such legislation, a substantial amount of debate and literature criticized the constitutionality, ethicalness, and effectiveness of such laws. Nevertheless, in the decade since New York's adoption of the "Baby AIDS Bill," which requires mandatory HIV testing of newborns, the state which has historically had the highest rate of pediatric AIDS has undergone dramatic progress in decreasing the number of infants born with HIV and increasing the number of mothers who elect to get tested prior to their child's birth.<sup>88</sup> Similar results have occurred in Connecticut after the passing of

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<sup>81</sup> *Id.*

<sup>82</sup> Topic of numerous law journal notes and debate, sources to be lifted from argument below.

<sup>83</sup> See CDC: *Rapid HIV Testing*, *supra* note 80.

<sup>84</sup> *Id.*

<sup>85</sup> *Id.*

<sup>86</sup> See American Civil Liberties Union, *HIV Testing of Pregnant Women and Newborns*, Jan. 1, 2001, <http://www.aclu.org/hiv/testing/11535pub20010101.html> [hereinafter American Civil Liberties Union: *HIV Testing*]. A more through discussion of the ethical and legal implication will follow in Section IV.B.2.

<sup>87</sup> *Id.*

<sup>88</sup> NewsMax.com, *Mandatory AIDS Test 'Law Does Work'* (May 3, 2001), available at <http://www.newsmax.com/archives/articles/2001/5/2/213417.shtml> (last visited March 1, 2007). See also Roland R. Foster, *Baby AIDS*, <http://www.childrensaidsfund.org/resources/babyaids.pdf> (last

Bill 1252, which like its New York counterpart, requires newborns to undergo mandatory HIV testing during their post-natal screening process.<sup>89</sup>

Those who oppose legislation like that of New York and Connecticut argue that mandatory testing of newborns raises both ethical and constitutional issues, many of which are echoed in the debate on mandatory testing of pregnant women and will be discussed thoroughly in the subsequent section.<sup>90</sup> Nonetheless, challenges to such legislation have been scant and, when challenged, proven unsuccessful.<sup>91</sup>

Opponents urge that mandatory newborn testing clearly violates the mother's right to privacy and equal protection.<sup>92</sup> Nevertheless, perinatal HIV testing statutes in general have not been widely challenged, and in the one instance where a plaintiff sought to challenge the legality of the Connecticut law, the claim was dismissed.<sup>93</sup> In the previously mentioned action, Connecticut Hospital Association ("Association") filed a complaint against the Governor, seeking pre-enforcement injunctive relief from the state's newborn HIV testing statute.<sup>94</sup> The Association claimed that the provision violates the Fourth and Fourteenth Amendment rights of pregnant women and newborns, but the district court denied immediate injunctive relief.<sup>95</sup> After the law's implementation, hospitals in Connecticut soon became accustomed to the changes, the Association did not further pursue the challenge which led to the stipulation's dismissal. No further actions were brought.<sup>96</sup> Perhaps the lack of legal challenges to newborn testing is evidence of moral acceptance of these practices by society and a lack of the offensiveness to privacy and equal protection that many critics feared.

As a secondary argument, opponents highlight that mandatory testing laws have caused women to experience breaches of confidentiality, lack of counseling, and failure to get test results in a timely manner, thereby defeating the benefits that such testing was implemented to achieve.<sup>97</sup> Such a claim was made by the plaintiffs in *R.Z. v. Pataki*, a class action suit brought against several New York hospitals, the State Department of Health, and the Governor.<sup>98</sup> It is important to note that such a suit was brought as a result of the error of practitioners who failed

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visited Sept. 21, 2007).

<sup>89</sup> See Kelly D. Bryce, *Mandatory Testing of Newborns: Is There a Better Way to Achieve the State's Goal of Preventing Transmission of HIV to Newborns and Ensuring Them Treatment*, 4 QUINNIPIAC. HEALTH. L.J. 69 (2000).

<sup>90</sup> Arguments concerning the ethical and constitutional issues in the mandatory testing of pregnant women shall be discussed in the subsequent section.

<sup>91</sup> Lazzarini, *supra* note 70, at 86.

<sup>92</sup> *Id.*

<sup>93</sup> *Id.* at 89.

<sup>94</sup> *Id.*

<sup>95</sup> Conn. Hosp. Ass'n v. Rowland, No. 3:99CV1923 (D.Conn. Oct. 16, 2000).

<sup>96</sup> Lazzarini, *supra* note 70, at 89.

<sup>97</sup> *Id.* at 90.

<sup>98</sup> See Bryce, *supra* note 89, at 76 (citing *R.Z. v. Pataki*, Index No. 97-112960 (Sup. Ct. NY County, Compl. filed July 18, 1997)).

to inform the mothers of the HIV-screening program or revealed the baby's status in a public setting.<sup>99</sup> The suit was not a challenge to the legality of the New York law itself. Therefore, although the negligent actions of the hospital employees were reprehensible, the grievances were the result of human inaction and not the unconstitutionality of the law.

Both New York and Connecticut have seen dramatic increases in the number of pregnant women who voluntarily test for HIV since the implementation of mandatory newborn testing laws.<sup>100</sup> In New York, the proportion of women who receive an HIV test during pregnancy has increased to 93% in 2001.<sup>101</sup> In Connecticut, the testing rate has increased from 31%, prior to the adoption of the mandatory newborn testing law, to 81% after its enactment in 1999.<sup>102</sup> As a result of the dramatic success of the mandatory newborn testing laws, former critics of the legislation are beginning to reevaluate their positions. For example, Dr. Urania Magriples of Yale University School of Medicine stated, "I was opposed to the law that requires testing... [b]ut the law does work."<sup>103</sup> Her study at Yale found that before the law went into effect, less than 40% of women underwent testing and after the law went into effect, more than 95% of women allowed themselves to get tested.<sup>104</sup>

The success of mandatory newborn testing laws in increasing the number of pregnant women who choose to become tested and the lack of legal challenges to such legislation do not make up for the inherent deficiencies of such legislation. For a number of pragmatic and legal reasons, mandatory newborn testing still faces scathing criticism and has provoked the American Civil Liberties Union (ACLU) to regard mandatory newborn testing as "the least effective program of mandatory testing that the legislature could have implemented" and to say that "a testing program for infants makes no sense."<sup>105</sup> However, in a study conducted by Dr. William Cusick of Columbia University between October 1999 and July 2000 alone, mandatory testing uncovered seven pregnant women who were apparently unaware that they had HIV.<sup>106</sup> Such success led Dr. Cusick to state, "[b]eing able to save one child in nine months is worth it, I think. There are few times in medicine you can prevent a lethal disease."<sup>107</sup>

First, testing of a newborn can show that the mother is HIV-infected and that her infant has been HIV-exposed, but HIV-exposure does not necessarily mean

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<sup>99</sup> *Id.*

<sup>100</sup> See CDC: *HIV Testing Among Pregnant Women*, *supra* note 78.

<sup>101</sup> *Id.*

<sup>102</sup> *Id.*

<sup>103</sup> See NewsMax.com, *supra* note 88.

<sup>104</sup> *Id.*

<sup>105</sup> See American Civil Liberties Union, *supra* note 82.

<sup>106</sup> See NewsMax.com, *supra* note 88.

<sup>107</sup> *Id.*

HIV-infection of the infant.<sup>108</sup> As a result, the mother's status is revealed although she opted to forgo testing during pregnancy. Faced with the possibility of HIV-infection of the child, the mother must make an immediate decision whether or not to treat her infant, although the mother cannot be sure that the child is infected. In addition, if test results are not made available within 48 hours of birth, the possible AZT treatments will have no impact in preventing infection.<sup>109</sup> Most importantly however, the advantages of early detection, which include preventative labor delivery practices and early administration of AZT, are lost.<sup>110</sup>

Second, sudden revelations of a child's HIV-exposure and a mother's own HIV-infection may threaten the emotional health of women.<sup>111</sup> The adverse psychological effect on the mother may be heightened if she is suffering from postpartum depression and because she is adapting to her new life as a mother.<sup>112</sup> In addition, a mother's refusal to get tested throughout the pregnancy can only serve to foster feelings of guilt, shame, and regret in not having gotten tested earlier.

Lastly, constitutional issues of privacy that arise with mandatory testing of pregnant women are also implicated with the implementation of mandatory testing of newborns. HIV testing of newborns "tells little about the infant and everything about the mother" because all babies born to HIV-positive mothers, regardless of their HIV status, will test positive for several months after birth.<sup>113</sup> As one commentator correctly stated, "the medical community cannot circumvent the privacy issue by substituting testing of the infant for testing of the mother."<sup>114</sup> In actuality, the real difference between testing a newborn rather than testing the mother during pregnancy is the elimination of an "opportunity for a two-thirds improvement in a child's chances to be born free from HIV infection."<sup>115</sup>

An evaluation of the aforementioned state approaches for effectuating universal HIV testing of pregnant women shows that their success in attaining this goal varies. However, all approaches share an overarching commonality, the inability to achieve universal HIV testing of pregnant women. This conclusion acts as the impetus for the remainder of this Note—a re-evaluation of the often criticized possibility of mandatory testing of pregnant women, its constitutional barriers to implementation, and the development of an integrative program tailored

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<sup>108</sup> See Jennifer Sinton, *Rights Disclosure and Mandatory HIV Testing of Pregnant Women and Newborns*, 6 J.L. & POL'Y 187, 205 (1997).

<sup>109</sup> See American Civil Liberties Union, *supra* note 82.

<sup>110</sup> *Id.*

<sup>111</sup> Sinton, *supra* note 108, at 208.

<sup>112</sup> *Id.*

<sup>113</sup> See R. Curtis McNeil, *Prenatal HIV Testing Under Ohio Revised Section 3701.242: The Doctors' Dilemma and the State's Shame*, 22 DAYTON L. REV. 301, 311 (1997).

<sup>114</sup> *Id.* at 310.

<sup>115</sup> *Id.* at 311.

to effectuate the state's compelling interests in preventing MTCT and the protection of public health, while reflecting developed constitutional precedent.

#### V. MANDATORY HIV TESTING OF PREGNANT WOMEN & ITS CONSTITUTIONAL IMPLICATIONS AND BARRIERS

The mandatory HIV testing debate is a multifaceted one that elicits contentious discourse that not only questions the legality of such legislation, but also raises difficult questions regarding the desirability and ethicalness of such a public health policy. A thorough analysis of the debate requires a discussion of the public policy concerns, constitutionality, and ethicalness of implementing a mandatory HIV testing scheme of pregnant women. The following sections seek to elucidate each of these critical areas of debate.

##### *A. Public Health Policy Concerns and Opposing Perspectives*

Advances in antiretroviral treatment and success in reducing perinatal transmission provides a strong public health justification for testing.<sup>116</sup> As a result, the general consensus of the CDC, medical professional organizations, and the medical community at large is the desirability of moving toward routine HIV testing of pregnant women.<sup>117</sup> The means by which this objective can be achieved, however, remains the cause of much debate and varying state programs. Public health policy concerns are often viewed apart from the legal implications of proffered programs. An analysis of the opposing perspectives to mandatory testing of pregnant women, in particular, follows.

Proponents have strong public health justifications for mandatory testing of pregnant women for HIV. First, many mothers choose not to be tested.<sup>118</sup> Second, knowledge of a mother's HIV status is a precondition to receiving counseling about her condition, the risk of transmission to her child, and the options she has available to her.<sup>119</sup> Third, without being aware of her status she and her child cannot receive treatment to reduce the risk of her child being born HIV-positive.<sup>120</sup> Fourth, failure to identify HIV-positive newborns puts them at higher risk for potentially fatal infections and may cause them to receive improper immunizations at the time of birth, a concern rarely discussed.<sup>121</sup>

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<sup>116</sup> Lazzarini, *supra* note 70, at 86.

<sup>117</sup> Lazzarini, *supra* note 70, at 76.

<sup>118</sup> Many women do not get tested, either because they do not think they are at risk of being HIV-positive or do not wish to face the stigma associated with behaviors that put them at risk. Studies show that over 60% of the women diagnosed with AIDS first seek HIV testing because they become ill. See McNeil, *supra* note 113, at 302.

<sup>119</sup> *Id.*

<sup>120</sup> *Id.*

<sup>121</sup> *Id.*

A primary argument asserted by opponents of mandatory testing is the belief that mandatory testing will discourage women from seeking medical care.<sup>122</sup> They fear that pregnant women, feeling forced to get an HIV test, will turn away from the health care system and forego prenatal care altogether.<sup>123</sup> However, this argument is questionable as it relies on the unfounded assumption that a woman would forgo her own health and that of her unborn child for the sole purpose of avoiding HIV testing; experience with mandatory testing of newborns has shown contrary results.<sup>124</sup> Opponents have also criticized mandatory testing for constraining women's choices, forcing women to choose between availing themselves of medical assistance, which may involve unwanted testing, or receiving no care at all.<sup>125</sup> Opponents also fear that mandatory testing has the potential to undermine the trust between the physician and patient because improper disclosure could result in family violence, or discrimination in health care, insurance, employment, and housing.<sup>126</sup> It is important to note that such concerns have not been supported by studies, data, or history in related areas of medical practice.<sup>127</sup> Rather, they are the result of speculation and popular rhetoric surrounding the debate.

Both opponents and proponents of mandatory testing of pregnant women offer valid public policy concerns for their positions, but neither provide dispositive bases to end the debate. A discussion of present law governing the issue will offer a more definitive answer to the issues presented.

### *B. Existing Perinatal Testing Laws*

Mandatory testing of pregnant women for infectious diseases is not a novel idea. In fact, the mandatory testing of pregnant women for a number of sexually transmitted infectious diseases has been and continues to be standard procedure in many states.<sup>128</sup>

As of 2006, thirty-seven states require prenatal syphilis testing, with the remaining states "relying on good medical practice to include screening of a

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<sup>122</sup> Sinton, *supra* note 108, at 201. See also Bryce, *supra* note 87, at 76.

<sup>123</sup> Sinton, *supra* note 108, at 206.

<sup>124</sup> Studies have shown that women have not been deterred from HIV testing, but mandatory testing of newborn laws have caused a dramatic increase in the number of women who receive prenatal HIV tests. See generally NewsMax.com, *supra* note 88.

<sup>125</sup> Lazzarini, *supra* note 70, at 90.

<sup>126</sup> Bryce, *supra* note 89, at 78. See also Brown, *supra* note 59, at 76.

<sup>127</sup> The accuracy of the argument that mandatory HIV testing of women will drive women away from prenatal care is unclear. One study in Berlin, Germany "showed that compulsory HIV testing of pregnant women deterred women from going to clinics, [but] another study conducted at New York City's Bellevue Hospital found that pregnant women would not avoid prenatal treatment if mandatory testing were instituted." See Samantha Catherine Halem, *At What Cost: An Argument Against Mandatory AZT Treatment of HIV-Positive Pregnant Women*, 32 HARV. C.R.-C.L. L. REV. 491, 498 (Summer 1997).

<sup>128</sup> McNeil, *supra* note 113, at 310.

pregnant woman for syphilis.”<sup>129</sup> Other states mandate testing for disorders such as hepatitis B, phenylketonuria (PKU), and sickle cell disorder.<sup>130</sup> For example, in Ohio, physicians who attend a pregnant woman for conditions related to her pregnancy are required to take specimens, at or within ten days of the first examination, to be submitted to a laboratory for standard syphilis and gonorrhea tests.<sup>131</sup> Doctors also routinely perform rubella, measles, tetanus, hepatitis B, Chlamydia, and other blood disease tests on pregnant women without any special consent, as a standard procedure.<sup>132</sup>

Some commentators regard the history of mandatory syphilis testing as the most convincing argument for the plausibility of mandatory HIV testing.<sup>133</sup> In the early 1900’s, syphilis infection rates were growing rapidly and the disease often proved fatal.<sup>134</sup> “As with HIV, women with syphilis could infect their unborn children in utero, [with a transmission rate between] 70-100%.”<sup>135</sup> As a response to the epidemic, and in light of the high rates of fatality and perinatal transmission, hospitals began to mandate syphilis screening for all pregnant women seen at their clinics.<sup>136</sup> Nationwide syphilis screening soon followed and remains in effect today.<sup>137</sup> Such legislation, which began over fifty years ago, has never been challenged.<sup>138</sup>

Present mandatory perinatal testing laws serve as strong support for proponents of mandatory HIV testing of pregnant women. Some commentators “perceive the lack of legal challenges to prenatal and newborn testing as evidence in general of tacit moral acceptance of these practices.”<sup>139</sup> Economically, they note that since an additional test for HIV can be conducted on specimens already taken for mandatory testing of other infectious or genetic diseases, it will be relatively inexpensive.<sup>140</sup> Lastly, proponents suggest that “[t]he history of mandatory syphilis testing demonstrates that mandatory prenatal testing of perinatally transmitted diseases has been and is today an accepted reality in the United States.”<sup>141</sup>

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<sup>129</sup> *Id.* at 310.

<sup>130</sup> Lazzarini, *supra* note 70, at 89.

<sup>131</sup> McNeil, *supra* note 113, at 310.

<sup>132</sup> *Id.*

<sup>133</sup> Halem, *supra* note 127, at 497.

<sup>134</sup> *Id.*

<sup>135</sup> *Id.*

<sup>136</sup> *Id.*

<sup>137</sup> *Id.*

<sup>138</sup> McNeil, *supra* note 113, at 310.

<sup>139</sup> Lazzarini, *supra* note 70, at 90.

<sup>140</sup> Halem, *supra* note 127, at 496.

<sup>141</sup> *Id.* at 497.

*C. Case Law Challenging Medical Interventions*

Cases regarding medical interventions for the benefit of a fetus have resulted in seemingly incongruous decisions by courts. However, a more nuanced evaluation of the cases not only helps to reconcile the differences in decisions, but also lends support for mandatory testing of pregnant women.

Opponents of mandatory testing often point to cases involving the refusal by courts to order caesarian deliveries as support for their position. The leading case is that of *Angela C.*, a 1990 decision, where a woman diagnosed with terminal cancer faced death before her due date.<sup>142</sup> The lower court ordered a caesarian delivery despite the fact that her intent was never clearly ascertained.<sup>143</sup> Upon appeal, the court concluded that the trial court had erred in granting the order for surgery, upholding the right of a mother to refuse interventions that pose a risk to her merely for the benefit of her fetus.<sup>144</sup>

Those opposed to testing point to *Angela C.* as support for a pregnant woman's right to make choices about medical procedures during pregnancy. However, the decision in *Angela C.* must be understood in light of a critical fact – that the caesarian delivery might “very well hasten” the mother's death if performed.<sup>145</sup> An HIV test, however, does not pose a risk of fatality and can hardly be compared to a caesarian delivery. In addition, the case's focus is upon a mother's decision to elect treatment, which an HIV test is not. If the focus of this paper were upon mandatory AZT treatment, *Angela C.* would necessarily pose a harmful precedent to mandatory testing proponents. However, this paper's focus is upon mandatory HIV testing.

Unlike *Angela C.*, in another case involving a caesarian delivery, the court ordered such a procedure when it was to the benefit of both the mother and the fetus.<sup>146</sup> In *Jefferson*, despite a competent refusal by the mother to undergo the proposed surgery, evidence showed that performance of the caesarean was in the medical interests of both the mother and the fetus. Accordingly, the court ordered the caesarian, which was later upheld.<sup>147</sup> Analogizing to *Jefferson*, administering an HIV test to a pregnant woman will be to the benefit of both mother and child; therefore, the court's following precedent will likely uphold the performance of the procedure despite a mother's refusal. In addition, as mentioned above, an HIV test is far less invasive than a caesarian section, therefore lending support to the likelihood of upholding a mandatory HIV test.

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<sup>142</sup> *In re A.C.*, 573 A.2d 1235 (D.C. 1990) at 1238.

<sup>143</sup> *Id.* at 1240 - 41.

<sup>144</sup> *Id.* at 1247, 1252.

<sup>145</sup> *Id.* at 1240.

<sup>146</sup> See *Jefferson v. Griffin Spalding County Hosp. Auth.*, 274 S.E.2d 457, 459 (Ga. 1981).

<sup>147</sup> *Id.* In *Jefferson*, there was a ninety-nine-percent chance that her full-term fetus would perish and a fifty-percent chance that the mother would die as well, were vaginal delivery attempted.

Other cases suggest that more overt limitations on a woman's autonomy during pregnancy are permissible. In a recent case, a Massachusetts prosecutor succeeded in obtaining an order to confine a pregnant woman until delivery where a couple refused to seek any prenatal care, although an earlier child was believed to have died as a result of their refusal to seek medical care.<sup>148</sup> If such drastic measures can be taken by a state to protect the life of a fetus, a state's enforcement of mandatory HIV tests appears to pale in comparison when judged against the severity of the state action being upheld in the aforementioned case.

#### *D. Constitutionality of Mandatory HIV Testing*

The Supreme Court has been virtually silent on issues dealing with maternal duties during pregnancy. With strong arguments available to both passionate proponents and opponents of such a scheme, a definitive answer as to the constitutionality of mandatory HIV testing is not easily found. A woman challenging a mandatory HIV testing regime could offer two main constitutional arguments. First, she could argue that mandatory testing violates her right to privacy, an interest protected by the Due Process Clause of the Fourteenth Amendment. Second, she could argue that mandatory testing violates the Equal Protection Clause by targeting only women.

##### 1. The Right to Privacy

At the core of the debate regarding mandatory HIV testing of pregnant women is the division between the perspectives of opponents and proponents concerning a mother's right to privacy. Opponents believe that mandatory testing is an unjustifiable violation of a mother's right to privacy.<sup>149</sup> On the other hand, proponents recognize that privacy rights are at stake, but believe that states have a "compelling interest in reducing the spread of sexually transmitted diseases and a compelling interest in the life of the child who will soon be born."<sup>150</sup> One proponent strongly wrote, "When the price paid for privacy is the slow and painful death of infants, privacy becomes a commodity society can no longer afford."<sup>151</sup> Participants in such heated discourse often lose sight of the legal underpinnings which give rise to the debate. Therefore, an analysis of case law is absolutely necessary to provide a thorough understanding of the right to privacy and the constitutional validity of a mandatory testing scheme for pregnant women. This analysis will demonstrate the constitutional difficulties that proponents of mandatory testing face and offer a strong reason why states have shied away from such legislation.

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<sup>148</sup> Lazzarini, *supra* note 70, at 92.

<sup>149</sup> Bryce, *supra* note 89, at 76.

<sup>150</sup> McNeil, *supra* note 113, at 310.

<sup>151</sup> *Id.* at 302.

A woman's right to reproductive privacy under the Federal Constitution was established by three leading cases: *Griswold v. Connecticut*, *Roe v. Wade*, and *Planned Parenthood v. Casey*.<sup>152</sup> These three leading decisions and their progeny have served to resolve cases involving a pregnant woman's rights if and when her interests conflict with those of her fetus.

"*Griswold v. Connecticut* was the first case to [clearly] establish a general right to reproductive privacy."<sup>153</sup> In *Griswold*, a Connecticut statute which criminalized the use of contraceptive devices was challenged.<sup>154</sup> The Supreme Court held the statute invalid as an unconstitutional invasion of the right to privacy of married persons.<sup>155</sup> The Court recognized that although the right to privacy is not explicitly enumerated in the Constitution, "specific guarantees in the Bill of Rights have penumbras, formed by emanations from those guarantees that help give them life and substance," creating "zones of privacy."<sup>156</sup> The marriage relationship "lies within the zone of privacy created by several fundamental constitutional guarantees."<sup>157</sup> These Amendments, namely the First, Third, Fourth, Fifth, and Ninth, were instituted to protect against various governmental invasions of a person's home and personal privacy.<sup>158</sup> In holding that the state could not intrude upon these rights, the Connecticut statute could not stand "in light of the familiar principle... that a governmental purpose to control or prevent activities constitutionally subject to state regulation may not be achieved by means which sweep unnecessarily broadly and thereby invade the area of protected freedoms."<sup>159</sup>

The landmark case of *Roe v. Wade* established a woman's fundamental right to have an abortion.<sup>160</sup> Echoing the words of *Griswold*, the Court stated that although the United States Constitution does not explicitly mention any right to privacy, a right to personal privacy or guarantee of certain areas or zones of privacy does exist.<sup>161</sup> Finding the right to privacy broad enough to encompass a woman's decision whether or not to terminate her pregnancy, the Court held the abortion decision to be a woman's right.<sup>162</sup> Nevertheless, the Court was explicit in saying that this right is not unqualified and not absolute.<sup>163</sup> The right must be considered against important state interest in regulation and "is subject to some limitations... at

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<sup>152</sup> See *Griswold v. Connecticut*, 381 U.S. 479 (1965); *Roe v. Wade*, 410 U.S. 113 (1973); and *Planned Parenthood v. Casey*, 505 U.S. 833 (1992).

<sup>153</sup> Bryce, *supra* note 89, at 80.

<sup>154</sup> See *Griswold*, 381 U.S. at 479.

<sup>155</sup> *Id.* at 485.

<sup>156</sup> *Id.* at 484.

<sup>157</sup> *Id.* at 485.

<sup>158</sup> *Id.* at 484.

<sup>159</sup> *Id.* at 485.

<sup>160</sup> See *Roe*, 410 U.S. at 164.

<sup>161</sup> *Id.* at 152.

<sup>162</sup> *Id.* at 153.

<sup>163</sup> *Id.* at 155.

some point the state interests as to protection of health, medical standards, and prenatal life, become dominant.”<sup>164</sup>

Offering guidance to their decision, the Court stated that a state’s interest in limiting such a fundamental right must be “compelling,” and legislative enactments must be “narrowly drawn to express only the legitimate state interest at stake.”<sup>165</sup> The court then went on to clarify that a state not only has an important and legitimate interest in preserving and protecting the health of the pregnant woman, but also in the potentiality of human life, with each becoming “compelling” at a point during the pregnancy.<sup>166</sup> Regarding the state’s important and legitimate interest in potential life, the “compelling” point is at viability, when the fetus has the capability to live outside the mother’s womb.<sup>167</sup> Viability is usually placed at approximately seven months or twenty-eight weeks, but may occur earlier at approximately twenty-four weeks.<sup>168</sup> The Court explicitly stated that if the state is interested in protecting fetal life after viability, it may go so far as to proscribe abortion during that period, except when it is necessary to preserve the life or health of the mother.<sup>169</sup> Therefore, after the second trimester of pregnancy, the Court observed that a State’s compelling interest in preserving potential life outweighs a mother’s fundamental right to have an abortion.

*Planned Parenthood v. Casey* explicitly reaffirmed *Roe v. Wade*’s essential holding, which the Court declared had three parts.<sup>170</sup> First, the Court recognized the right of a woman to choose to have an abortion before viability, and to obtain it without undue interference from the states.<sup>171</sup> Second, the Court confirmed the state’s power to restrict abortions after fetal viability.<sup>172</sup> Third, the Court restated that the state has “legitimate interests from the outset of the pregnancy in protecting the health of the woman and the life of the fetus that may become a child.”<sup>173</sup> The *Casey* decision further reaffirmed an individual right to privacy in matters concerning personal dignity and autonomy.<sup>174</sup> These “matters” are interpreted to include marriage, procreation, contraception, family relationships, child rearing, and education.<sup>175</sup>

Deviating from *Roe*, the *Casey* court rejected the rigid trimester framework and the finding of a fundamental right to an abortion necessitating strict scrutiny.

<sup>164</sup> *Id.*

<sup>165</sup> *Id.*

<sup>166</sup> *Id.* at 162–63.

<sup>167</sup> *Id.* at 163.

<sup>168</sup> *Id.* at 160.

<sup>169</sup> *Id.* at 163–64.

<sup>170</sup> *See Casey*, 505 U.S. at 846.

<sup>171</sup> “Before viability, the State’s interests are not strong enough to support a prohibition of abortion or the imposition of a substantial obstacle [to a woman’s choice to have an abortion].” *Id.*

<sup>172</sup> *Id.*

<sup>173</sup> *Id.*

<sup>174</sup> *Id.* at 851.

<sup>175</sup> *Id.*

The Court found that a lower level of scrutiny was applicable, holding that any regulation that does not place an “undue burden” on a woman’s right to choose is constitutional. The Court explained that it adopted the undue burden standard in order to protect the central right recognized by *Roe* while at the same time accommodating the state’s profound interest in potential life.<sup>176</sup> Commentators argue that *Casey* strengthened the *Roe* Court’s finding of a state interest in the fetus by holding that the state has an interest in the fetus from the moment of conception.<sup>177</sup>

The above cases clearly establish a right to privacy that encompasses the right of pregnant woman to choose to have an abortion without governmental interference until the time of viability. Although the Court recognized a state’s legitimate interest in protecting potential life, the Court has explicitly held that those interests are not compelling until the time of viability, therefore permitting a woman to choose to terminate her pregnancy until that time without undue interference by the State. If up until the point of viability, a mother has sole discretion over the life or death of her fetus, it would logically follow that a state should not be constitutionally justified in imposing a mandatory test upon a mother for the benefit of her fetus if she chooses not to have one. As a result, a regime that makes HIV testing of all pregnant women compulsory without distinction or limitation would likely be found unconstitutional as an undue burden upon a woman’s right to choose.

## 2. Equal Protection

A mandatory perinatal HIV testing law could also be challenged under the Equal Protection Clause by arguing that the regime constitutes pregnancy or sex discrimination.<sup>178</sup> However, the Supreme Court has only recognized the Equal Protection Clause to prohibit discrimination based upon pregnancy in the employment context, which offers little guidance in evaluating a universal mandatory testing scheme of all pregnant women.<sup>179</sup> Therefore, a court faced with such a regime must decide whether or not pregnancy discrimination is *per se* sex discrimination.<sup>180</sup>

If the Court decides that “pregnancy discrimination is *per se* sex discrimination, then the appropriate level of scrutiny is the intermediate level.”<sup>181</sup> The “policy or statute will be found constitutional if the state establishes that the regulation serves an important government objective and the regulation is

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<sup>176</sup> *Id.* at 870-71.

<sup>177</sup> *Halem, supra* note 127, at 516.

<sup>178</sup> *Brown, supra* note 59, at 85.

<sup>179</sup> *Id.* at 85-86.

<sup>180</sup> *Id.*

<sup>181</sup> *Id.* at 86.

substantially related to that end.”<sup>182</sup> A state seeking to compel pregnant women to undergo HIV testing would have to demonstrate that testing would serve the important government objective of preventing perinatal transmission of HIV and “is substantially related to this objective.”<sup>183</sup> A state would certainly meet this standard. As discussed earlier, HIV testing is not only minimally intrusive, but a precondition to any discussion, planning, or employing of methods or treatment to prevent perinatal transmission.

“On the other hand, if the court finds that singling out pregnant women for [HIV testing] is not per se sex discrimination, then the rational basis standard of review” applies.<sup>184</sup> The rational basis standard requires “only that the regulation have a rational relationship to the state’s purpose.”<sup>185</sup> Traditionally, this standard has generally been an easy obstacle for the state to overcome. However, more recent cases such as *UAW v. Johnson Controls, Inc.* and *Nashville Gas Co. v. Satty* appear to have raised the level of scrutiny to intermediate by holding employment discrimination on the basis of pregnancy or the ability to become pregnant as sex discrimination.<sup>186</sup> Nevertheless, in light of the analysis above, the state will meet the standard of intermediate scrutiny. The state’s objective of reducing the risk that children being born with HIV can be achieved by a minimally intrusive HIV-test and the program of mandatory testing is sufficiently tailored to fulfill the state’s goals. Therefore, Equal Protection challenges to a mandatory testing scheme are weak and will likely fail.

#### *E. Conclusions Concerning Mandatory HIV Testing*

An analysis of the legality and ethicalness of mandatory HIV testing of pregnant women demonstrates that an implementation of such program faces a serious constitutional barrier, the reproductive privacy rights of pregnant women. Arguments presented by proponents of a mandatory testing regime are not without merit. In fact, they possess strong public health policy arguments and can look to the presence of mandatory prenatal tests for support. Precedent which has allowed the courts to order medical treatment for the benefit of mother and fetus also serve to lend proponents support. Lastly, although many commentators suggest that a mandatory testing program violates the Equal Protection clause, analysis of such an argument reveals its weaknesses and its likelihood of failure. Nonetheless, the right to privacy and the right of a woman to choose to have an abortion raises a serious barrier to its implementation. If a woman may choose to end the life of her fetus at any time before viability, it would logically follow that she may choose to refuse any medical procedure for the benefit of her fetus before viability.

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<sup>182</sup> *Id.*

<sup>183</sup> *Id.*

<sup>184</sup> *Id.*

<sup>185</sup> *Id.*

<sup>186</sup> *Id.* at 86-87.

The strength of the privacy argument is most clearly demonstrated by the failure of states to enact such legislation. Unfortunately, present laws that seek to attain the goal of routine HIV testing of pregnant women fall short of this goal and many women will continue to refuse testing. Remaining ignorant of their HIV status will only serve to foreclose HIV-positive women and their fetuses from possible life saving practices and treatment, while proliferating social stigma and ignorance concerning HIV/AIDS. As a result, the following section proposes a hybrid program of mandatory testing that will attain the universal goal of routine HIV testing of pregnant women, while doing so constitutionally.

## VI. NEW MANDATORY TESTING APPROACH AND ITS IMPLEMENTATION

In the debate over prenatal testing of pregnant women, commentators have simply argued for the validity or invalidity of a mandatory HIV testing regime. This paper proposes a more nuanced approach to mandatory testing that seeks to integrate established constitutional law with regard to a woman's right to reproductive privacy, namely *Roe v. Wade* and its progeny, with the implementation of a mandatory HIV testing only after the time of viability.

### *A. Proposing The New Approach – Voluntary/Mandatory Hybrid*

In the seminal cases of *Roe v. Wade* and *Casey v. Planned Parenthood*, the Court made clear that the state has an "important and legitimate interest in protecting the potentiality of human life" and that the state's interest in protecting potential life becomes compelling at the time of viability.<sup>187</sup> The *Casey* court in reaffirming *Roe* concluded that the line should be drawn at viability, so that before that time the woman has a right to choose to terminate her pregnancy.<sup>188</sup> The court reasoned that the concept of viability, as noted in *Roe*, "is the time at which there is a realistic possibility of maintaining... a life outside the [mother's] womb, so that the independent existence of the second life," the life of the child, "can in reason and all fairness be the object of state protection that now overrides the rights of the woman."<sup>189</sup> Therefore, subsequent to viability, the state in promoting its interest in potentiality of human life may, if it chooses, regulate, and even proscribe, abortion except where it is necessary for the preservation of the life or health of the mother.<sup>190</sup> The *Casey* court reasoned further that in some broad sense it might be said that a woman who fails to act before viability has consented to the state's intervention on behalf of the developing child.<sup>191</sup> It is with this constitutional

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<sup>187</sup> See *Roe*, 410 U.S. at 162; *Casey*, 505 U.S. at 871.

<sup>188</sup> *Casey*, 505 U.S. at 870.

<sup>189</sup> *Id.* (quoting *Roe v. Wade*, 410 U.S. at 163). See also *Coleman v. Dewitt*, 282 F.3d 908, 912 (6th Cir. 2002) and *Nat'l Abortion Fed'n v. Gonzales*, 437 F.3d 278, 287 (2d Cir. 2006), which reaffirmed the notion that viability is the point where the State's interest in protecting the child may override the mother's right to abortion.

<sup>190</sup> See *Casey*, 505 U.S. at 879.

<sup>191</sup> *Id.*

precedent in mind that this paper proposes the following mandatory testing approach.

The “new approach” would make HIV testing of pregnant women compulsory at the time of viability. Before the time of viability, HIV testing should be completely voluntary. Medical professionals in educating their patients will be required to inform pregnant women of the availability of HIV testing, the benefits of early testing, and the probability of HIV transmission to their fetus. In addition, medical professionals must inform mothers that at the beginning of their third trimester of pregnancy, the time of viability, if she has not yet chosen to take an HIV test, one will be administered as mandated by the state for her benefit and that of her fetus. This “new approach” would also be coupled with strict confidentiality laws to limit knowledge of the mother’s HIV status to herself and her physician.<sup>192</sup>

### *B. Benefits of the New Approach*

The “new approach” achieves a number of notable goals. First, this testing regime will accomplish the primary goal of routine HIV testing of all pregnant women. Second, since the approach requires medical professionals to inform patients about HIV testing, its benefits, and the possible risks associated with perinatal transmission, women will be more informed. Third, women who test positive for HIV at the time of viability will still be capable of taking advantage of AZT treatment, electing a caesarian delivery, abstaining from breastfeeding, and delaying immunizations to the newborn until the baby’s HIV status is known.

The “new approach” also preserves important legal precedent. By postponing HIV testing until the time of viability, the essential holding of *Roe* and its progeny is left undisturbed while preserving the state’s interest in protecting potential life. In addition, strict confidentiality laws will safeguard the doctor-patient relationship and the mother’s right to keep her status private.

### *C. Congress’ Role in Implementing the New Approach*

Congress has an important role in facilitating the passage of such legislation by creating incentives to states. Congress should consider amending the Ryan Care Act to explicitly provide funding for states who adopt the “new approach” as they did for states choosing to pass mandatory newborn testing laws. Such an amendment will create the appropriate incentive for states to legislate in this area.

## VII. CONCLUSION

HIV/AIDS in the United States is a fatal epidemic that can only be curbed through education, social acceptance, and prevention. For women who choose to

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<sup>192</sup> See N.Y. PUB. HEALTH LAW § 2780 (2007)

have children, they should do so responsibly and with knowledge of HIV risk to their innocent child. Protecting a woman's right to choose to have an abortion is of fundamental importance, but protecting the life and health of unborn children is of great significance as well. Implementing a program like the "new approach" will serve innumerable social benefits—widespread education, safeguarding of public health, and the preservation of life—and should be seriously considered.

Opponents will continue to assert the argument that HIV/AIDS is a socially stigmatizing disease, leading to discrimination and loss.<sup>193</sup> However, the continued coddling of ignorance in our society can only serve to encumber the progress that has made in the fight against AIDS. An HIV-positive woman does not have the option of forever avoiding her status. Inevitably, whether it is when she becomes ill or her child becomes ill, both she and her doctor will know.<sup>194</sup> Mandatory prenatal testing will only serve to accelerate the knowledge of her status to a point where she and her doctor can develop a plan for treating both mother and child intelligently. As one commentator movingly wrote, "The time has come to look beyond shame, and fear, by allowing doctors to provide these infants and their mothers with appropriate medical care."<sup>195</sup> Therefore, this paper asks that legislators consider implementing a thoughtful and educating program that will safeguard the rights of pregnant women and the life of unborn children, while moving society in the direction of social acceptance and awareness.

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<sup>193</sup> Halem, *supra* note 127, at 498.

<sup>194</sup> Children born HIV-positive who go without treatment will likely develop an illness related to HIV within the first year. *See* Bryce, *supra* note 89, at 79.

<sup>195</sup> McNeil, *supra* note 113, at 302.