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## Gene Therapy: Legal and Ethical Issues for Pregnant Women

Angela Liang

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# GENE THERAPY: LEGAL AND ETHICAL ISSUES FOR PREGNANT WOMEN

ANGELA LIANG<sup>1</sup>

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The possibility of eliminating birth defects, genetic diseases, and disabilities through gene therapy in utero seems incredible. Yet the Human Genome Project, a federally-funded project that will map and sequence all 50,000 to 100,000 genes in each human cell,<sup>2</sup> will undoubtedly increase our knowledge of human genetics and hopefully lead to the cure of many devastating diseases. Biotechnological advances in gene therapy have already treated thousands of patients.<sup>3</sup> By 1994, 2,000 to 3,000 genetic diseases that will likely respond to gene therapy had been identified.<sup>4</sup>

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<sup>2</sup>See Lori B. Andrews, *Past as Prologue: Sobering Thoughts on Genetic Enthusiasm*, 27 SETON HALL L. REV. 893, 898 (1997).

<sup>3</sup>Rick Weiss & Deborah Nelson, *Teen Dies Undergoing Experimental Gene Therapy*, WASH. POST at A1 (Sept. 29, 1999).

<sup>4</sup>See Julia Walsh, *Reproductive Rights and The Human Genome Project*, 4 S. CAL. REV. L. & WOMEN'S STUD. 145, 150 n.26 (1994) (quoting Office of Technology Assessment, U.S. Cong., Pub. No. OTA-BP-BA-32, Human Gene Therapy -- Background Paper 1 (1984)). "[G]ene therapy is available in conjunction with the [prenatal] diagnosis, as in the case of Rh incompatibility. . . . In some cases, blood transfusions were performed to treat Rh incompatibility." ROBERT BLANK & JANNA C. MERRICK, HUMAN REPRODUCTION, EMERGING TECHNOLOGIES, AND CONFLICTING RIGHTS 141 (1995). Furthermore, the Recombinant DNA Advisory Committee recently gave approval for experimental gene therapy of cystic fibrosis patients. Cystic fibrosis is an autosomal recessive genetic disorder which usually manifests

Although gene therapy remains in its infancy and gene therapy in utero remains in the distant future, legal commentators are already debating issues surrounding the obligation of a pregnant woman to her fetus.<sup>5</sup>

Most pregnant women will undoubtedly applaud the biotechnological advances that will allow prenatal genetic screening technology to properly diagnose and correct genetic defects such as sickle cell anemia in utero. Refusal of gene therapy in utero, will likely be rare in pregnancies carried to term once it is established as safe and effective.<sup>6</sup> In some cases, however, women with strong personal or religious beliefs may refuse gene therapy in utero.<sup>7</sup> The issues then becomes

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itself in the form of chronic lung disease. Although more traditional forms of treatment have extended the medical lifespan of patients to twenty-seven years, the disease remains serious and life-shortening. In addition, cystic fibrosis 'is the most common lethal genetic disease' among North American white children. The success of this treatment would affect the lives of an estimated eight million carriers in the United States, and will almost certainly change the way known carriers think about having children. Walsh, *supra*, at 150-51.

The gene responsible for sickle cell anemia, a serious blood disorder, was discovered in 1949, yet there is still no gene therapy for the syndrome. See Andrews, *supra* note 2, at 900. The gene that causes thalassemia, a disorder of adult hemoglobin production, has been identified as an excellent candidate for gene therapy and experimental trials are likely to begin soon. Walsh, *supra*, at 149.

<sup>5</sup>Compare Lois Shepherd, *Protecting Parents' Freedom to Have Children with Genetic Differences*, 1995 U. ILL. L. REV. 761, 803 (1995) (stating, "ordering a pregnant woman to undergo fetal surgery to correct a disabling genetic condition . . . would directly interfere with her conception of herself as parent to that child. . ."); with John A. Robertson, *Procreative Liberty and the Control of Conception, Pregnancy, and Childbirth*, 69 VA. L. REV. 405, 444-46 (1983) (arguing that when fetal therapy is established as safe and effective, then a mother's refusal may make her liable).

A more likely source of conflict with the fetus' mother would result from the mother's refusal of a fetal therapy established as safe and effective. Such a situation arises from time to time when a mother refuses an exchange transfusion for a fetus suffering from Rh incompatibility. . . . A mother's refusal of therapy in these situations could be the basis for civil suit or criminal prosecution if it resulted in death or injury to the fetus, just as a parent's refusal of necessary medical care for a child can now be the basis for civil or criminal liability. The fact that the mother must undergo surgery as part of the fetal therapy procedure would be no defense if the procedure did not present an undue risk to her life or health. [According to Robertson,] she waived her right to resist bodily intrusions made for the sake of the fetus when she chose to continue the pregnancy. . . . A mentally ill pregnant woman whose conduct threatened a viable fetus could probably be civilly committed to protect the unborn child. Perhaps a pregnant teenager who became anorectic could be force-fed if she were in the third trimester and the danger to the fetus were clearly established. In utero surgery performed through fetoscopy could also be ordered, once its safety and efficacy for the fetus is established, because fetoscopy does not carry high risks to the mother. . . . [M]andating fetal therapy and prenatal screening illustrate an important limit on a woman's freedom to control her body during pregnancy. She is free not to conceive, and free also to abort after conception and before viability. But once she chooses to carry the child to term, she acquires obligations to assure its well-being.

Robertson, *supra*, at 444-46, 450.

<sup>6</sup>See Robertson, *supra* note 5, at 444 n.120.

<sup>7</sup>See *id.*

whether a pregnant woman has a legal duty to undergo gene therapy for the sake of her fetus and whether a court could order a pregnant woman to undergo gene therapy in utero against her will.

The decision to undergo gene therapy in utero for the sake of a fetus should legally rest with the pregnant woman rather than the judiciary or the legislature.<sup>8</sup> Part I of this article provides an overview of the current scope of gene therapy. Part II discusses previous court decisions that either granted or denied petitions for involuntary prenatal intervention. Part III analyzes three reasons why the courts should not impose gene therapy on pregnant women as the technology becomes available. First, a policy that mandates gene therapy would place an undue burden on pregnant women and violate the Equal Protection Clause of the Fourteenth Amendment. Second, a policy that mandates gene therapy would disparately impact women based on race, gender, and socio-economic status. Finally, public policy demands resistance against a policy that mandates gene therapy because of the ethical dilemmas inherent in a judicial determination of which “abnormalities” should be “fixed.” Pregnant women should have the right to decide whether or not to undergo gene therapy in utero regardless of the seriousness of the disability, the effectiveness of the therapy, the intrusiveness of the procedure, or the reasons for resisting gene the therapy.

#### I. AN OVERVIEW OF GENE THERAPY

Gene therapy involves inserting genetic material into cells to correct specific genetic defects in these cells.<sup>9</sup> Gene therapy will likely revolutionize modern medicine by curing and preventing certain genetic diseases.<sup>10</sup> If a prenatal genetic

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<sup>8</sup>Although there may be a *moral* duty for the pregnant woman to undergo gene therapy, this paper addresses only whether there is a *legal* duty. I disagree with Deborah Mathieu’s statement that, “To assert that no fetal therapy should be mandated, or that all should be, would be unreasonable.” DEBORAH MATHIEU, PREVENTING PRENATAL HARM: SHOULD THE STATE INTERVENE 54 (1991). While it is true that “[d]ifferent therapies promise different outcomes,” in the case of gene therapy, I believe that even in those few instances in which a woman might refuse a non-invasive procedure that is guaranteed to correct a life-threatening condition, the woman’s decision should nonetheless be respected. *Id.* Mathieu lists six conditions that must be met in order to justify state intervention: 1) the harms to be prevented to the future person are grave and irreversible; 2) the physical harm of the intervention to the mother’s own health is relatively minor; 3) the intervention involves the least intrusive means available; 4) the intervention will be successful in preventing or at least ameliorating serious prenatal harms; 5) requirements of due process and equal protection of the law are met, and 6) the benefits of adopting this type of state intervention as social policy will greatly outweigh the benefits. *Id.* at 128. Mathieu concludes that “few, if any, coercive state interventions to prevent prenatal harms could meet the conditions stated above.” *Id.* However, I argue that even if all six conditions Mathieu lists are met, the pregnant woman still has the unilateral power to decline gene therapy in utero.

<sup>9</sup>See Walsh, *supra* note 4, at 150 (citations omitted).

<sup>10</sup>See Maha F. Munayyer, *Genetic Testing and Germ-Line Manipulation: Constructing a New Language for International Human Rights*, 12 AM. U. J. INT’L L. & POL’Y 687, 691-94 (1997).

test reveals that an embryo may have or be predisposed to a certain genetic defect, gene therapy could be utilized to correct that defect in utero.<sup>11</sup>

There are two categories of gene therapy: germ-line manipulation and somatic cell manipulation.<sup>12</sup> Germ-line manipulation targets specific germ cells such as sperm or egg cells.<sup>13</sup> Somatic cell manipulation targets all other cells in the human body.<sup>14</sup> Some people are particularly disconcerted with germ-line manipulation because any resulting genetic changes are passed on to future generations.<sup>15</sup> Some people are equally disconcerted by the fact that gene therapy may also change physical characteristics such as hair color, eye color, height, and athletic ability.<sup>16</sup> Gene therapy may also alter genetically-linked behavioral features such as personality, talent, intelligence, and even sexual orientation.<sup>17</sup>

Doctors performed the first authorized gene therapy procedure in 1990 on girls ages four and nine who suffered from a grave immune deficiency because they lacked the enzyme adenosine deaminase.<sup>18</sup> The doctors removed some white blood cells, altered them by inserting a gene to produce the missing enzyme, and returned the altered cells to the girls' bodies.<sup>19</sup>

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<sup>11</sup>*See id.*

<sup>12</sup>*See* Walsh, *supra* note 4, at 150; John R. Harding, Jr., *Beyond Abortion: Human Genetics and The New Eugenics*, 18 PEPP. L. REV. 471, 472-73 (1991). My analysis of mandated gene therapy is the same for both types of therapy, and thus, will be collectively referred to as gene therapy.

<sup>13</sup>*See* Walsh, *supra* note 4, at 150; Harding, *supra* note 12, at 472-73.

<sup>14</sup>*See* Walsh, *supra* note 4, at 150; Harding, *supra* note 12, at 472-73.

<sup>15</sup>However, the fear that gene therapy may have some impact on the genetic identity of the human species must be weighed against the benefit of treating diseases. *See* Walsh, *supra* note 4, at 149-50. J.M. Friedman rejects the fear that gene therapy may have permanent effects upon the germ line stating that “[w]hen viewed at the population level, . . . the effect of gene therapy of any type on gene frequencies is likely to be much smaller than that caused by changes that have already occurred because of environmental alteration and improved health care and sanitation.” J.M. Friedman, *Eugenics and the “New Genetics,”* 35 PERSP. BIOLOGY & MED. 145 (1991). Also, the Office of Technology Assessment notes that “altering the germ line is not unique to gene therapy because several other medical practices — such as vaccination, cancer chemotherapy, and radiation therapy — also carry this risk.” *Id.* at 150 n.26 (quoting Office of Technology Assessment, U.S. Cong., Pub. No. OTA-BP-BA-32, Human Gene Therapy Background Paper 7 (1984)). However, in other countries, “[b]ecause of the permanent nature of GLM [germ-line manipulation] and its potential cosmetic application, GLM is illegal in several countries.” *See* Munayyer, *supra* note 9, at 697.

<sup>16</sup>*See* Munayyer, *supra* note 10, at 691-94.

<sup>17</sup>*See id.*

<sup>18</sup>*See* BLANK & MERRICK, *supra* note 4, at 149; Barbara J. Culliton, *Gene Therapy Begins*, 249 SCI. 1372, 1372 (1990).

<sup>19</sup>*See* BLANK & MERRICK, *supra* note 4, at 149. Both girls are still alive and living normal lives nine years later. Paul Jacobs, Special Millenium Issue/Science & Technology Cutting Edge/Frontiers: Four Fields that Have Been Shaped by and Are Shaping, Southern California, Los Angeles Times Magazine 28 (July 25, 1999).

By 1997, over 550 Americans underwent gene therapy during approximately 100 different experiments.<sup>20</sup> By late 1999, thousands of patients have been treated with various kinds of gene therapy in the United States.<sup>21</sup> There is, however, little or no evidence of therapeutic benefit to patients who undergo gene therapy.<sup>22</sup> A federally-appointed committee that investigated gene therapy condemned most of the efforts as “pure hype.”<sup>23</sup> A similarly skeptical evaluation of the effectiveness of gene therapy was based on a study in which children with Severe Combined Immune Deficiency (SCID) improved after undergoing gene therapy.<sup>24</sup> That study did not conclusively show that gene therapy caused the improvements by itself because those children also received the standard medical treatment for SCID.<sup>25</sup>

No one knows exactly when the technology will allow pregnant women to undergo gene therapy in utero for the benefit of their fetuses. As gene therapy is likely to become more common,<sup>26</sup> legal scholars and bioethicists must not ignore the legal and policy implications of gene therapy on pregnant women.

## II. COURT ORDERED PRENATAL INTERVENTIONS

Courts generally consider four state interests when they determine whether to override competent medical treatment decisions: preserving life, preventing suicide, maintaining the ethical integrity of the medical profession, and protecting third parties.<sup>27</sup> All four factors weigh in favor of respecting the pregnant woman’s decision whether to undergo gene therapy in utero for the sake of her fetus.

First, the interest to preserve life is arguably irrelevant. “Although it might be argued that the State has an interest in the preservation of the potential life of the fetus, courts have traditionally examined the refusal of treatment as it impacts upon the preservation of the life of the [decision maker].”<sup>28</sup> Second, the interest to prevent suicide is inapplicable to gene therapy in utero. Third, the interest to maintain the ethical integrity of the medical profession weighs *in favor* of the pregnant woman’s decision because “the medical profession strongly supports upholding the pregnant woman’s autonomy in medical decision-making.”<sup>29</sup> Furthermore, the American

<sup>20</sup>See Andrews, *supra* note 2, at 901 (citation omitted).

<sup>21</sup>Rick Weiss & Deborah Nelson, *Teen Dies Undergoing Experimental Gene Therapy*, WASH. POST at A1 (Sept. 29, 1999).

<sup>22</sup>See Andrews, *supra* note 2, at 901 (citation omitted).

<sup>23</sup>See *id.*

<sup>24</sup>See *id.* at 901.

<sup>25</sup>See *id.*

<sup>26</sup>See, e.g., Robin Herman, *Gene Therapy is No Longer a Rarity: Applications for Experiments are Expected to Quadruple in the Next Two Years*, WASH. POST, Jan. 21, 1992, (Health), at 7.

<sup>27</sup>See *In re Fetus Brown*, 689 N.E.2d 397, 402 (Ill. App. Ct. 1997); *In re Baby Boy Doe*, 632 N.E.2d 326, 334 (Ill. App. Ct. 1994); *In re A.C.*, 573 A.2d 1235, 1246 (D.C. 1990).

<sup>28</sup>*In re Baby Boy Doe*, 632 N.E.2d at 334.

<sup>29</sup>*Id.* at 335 (discussing the American Medical Association’s recommendation that the physician’s duty is not to dictate the pregnant woman’s decision, but to ensure that she can make an informed decision).

Medical Association Board of Trustees recommends against judicial intervention when a pregnant woman has made an informed refusal of medical treatment designed to benefit her fetus.<sup>30</sup> Finally, the interest to protect third parties is not always considered by courts. For example, some courts consider this interest only in the context of whether a woman's refusal of medical treatment will cause her own death and orphan her already-born children.<sup>31</sup> Other courts, however, do not consider this interest to be determinative of a patient's right to refuse medical treatment.<sup>32</sup>

In addition to the foregoing state interests, courts may also consider the enforceability of a court order. In *In re Baby Boy Doe*, the court refused to override a pregnant woman's refusal of a Caesarean section because the State sought a court order to compel the surgery but at the same time specifically opposed the use of physical force against the pregnant woman.<sup>33</sup> The court determined that granting and enforcing such a court order would be repugnant.<sup>34</sup> In *In re A.C.*, the court noted that, "[e]nforcement could be accomplished only through physical force or its equivalent. A.C. would have to be fastened with restraints to the operating table, or perhaps involuntarily rendered unconscious by forcibly injecting her with an anesthetic, and then subjected to unwanted major surgery. Such actions would surely give one pause in a civilized society, especially when A.C. had done no wrong."<sup>35</sup> In *In re Fetus Brown*, the court considered the enforceability of a court order and declined to compel a pregnant woman to undergo a blood transfusion for the sake of her fetus.<sup>36</sup>

Most courts will not override a pregnant woman's refusal of medical treatment needed solely for the benefit of her fetus. In *Stallman v. Youngquist*, the court refused to recognize a tort action against a mother for infliction of prenatal injuries because such recognition would subject every act of a pregnant woman to state scrutiny and thereby intrude upon her rights to privacy, to bodily integrity, and to control over her own life.<sup>37</sup> The court strongly suggested that no consistent and

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<sup>30</sup>See *In re Fetus Brown*, 689 N.E.2d at 403 (citing H. Cole, *Legal Interventions During Pregnancy*, 264 J.A.M.A. 2603, 2670 (1990)).

<sup>31</sup>See *In re Baby Boy Doe*, 632 N.E.2d at 334 (citing *In re Brooks Estate*, 205 N.E.2d 435 (Ill. 1965)); *Winthrop University Hospital v. Hess*, 128 Misc.2d 804 (N.Y. Sup. Ct. 1985); *Wons v. Public Health Trust*, 500 So.2d 679 (Fla. App. 1987). See also *infra* text accompanying notes 64-65.

<sup>32</sup>See *Fosmire v. Nicoleau*, 551 N.E.2d 77 (N.Y. 1990); cf. *Norwood Hospital v. Munoz*, 564 N.E.2d 1017 (Mass. 1991) (holding that where there is no evidence of the abandonment of minor children, the state's interest in protecting third parties will not override a competent patient's refusal of medical treatment).

<sup>33</sup>See *In re Baby Boy Doe*, 632 N.E.2d at 335; see also *infra* text accompanying notes 46-51.

<sup>34</sup>*Id.* at 335.

<sup>35</sup>*In re A.C.*, 573 A.2d 1235, 1244 n.8 (D.C. 1990); see also *infra* text accompanying notes 37-45.

<sup>36</sup>See *In re Fetus Brown*, 689 N.E.2d 397, 405 (Ill. App. Ct. 1997); see also *infra* text accompanying notes 52-56.

<sup>37</sup>See *Stallman v. Youngquist*, 531 N.E.2d 355, 360 (Ill. App. Ct. 1988).

objective legal standard exists by which to judge a pregnant woman's actions because "[t]he circumstances in which each individual woman brings forth life are as varied as the circumstances of each woman's life."<sup>38</sup> The court reasoned that a fetus cannot have rights superior to those of its mother because the law will not treat a fetus as an entirely separate entity from its mother.<sup>39</sup>

Furthermore, the *A.C.* court held that a pregnant woman's decisions regarding medical treatment for herself and her fetus should be upheld.<sup>40</sup> Substituted judgement should only be considered where a patient is incompetent or cannot give informed consent.<sup>41</sup> In *A.C.*, a terminally ill woman near death was pregnant with a viable fetus.<sup>42</sup> The lower court ordered the woman to undergo a Caesarean section to save her unborn child.<sup>43</sup> Doctors performed the surgery yet both the mother and the child died.<sup>44</sup> The court reviewed the lower court ruling despite its mootness<sup>45</sup> and held that "in virtually all cases the question of what is to be done is to be decided by the patient—the pregnant woman—on behalf of herself and the fetus."<sup>46</sup> The court emphasized that competent persons have the right to make informed choices regarding medical treatment based on the doctrines of informed consent and bodily integrity.<sup>47</sup> The court determined that the lower court erred by applying a balancing test to weigh the rights of the pregnant woman against the interests of the state.<sup>48</sup>

In *Baby Boy Doe*, the Illinois Court of Appeals refused to compel a pregnant woman to undergo a Caesarean section when a problem with the placenta caused her fetus to receive insufficient oxygen.<sup>49</sup> Similar to the *A.C.* court, the *Baby Boy Doe* court reasoned that a balancing test should not be used because "a woman's competent choice to refuse medical treatment as invasive as a Caesarean section during pregnancy must be honored, even in circumstances where the choice may be harmful to her fetus."<sup>50</sup> The court further reasoned that, "a woman is under no duty to guarantee the mental and physical health of her child at birth, and thus cannot be compelled to do or not do anything merely for the benefit of her unborn child."<sup>51</sup>

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<sup>38</sup>*See id.* at 360.

<sup>39</sup>*See id.* at 359.

<sup>40</sup>*See In re A.C.*, 573 A.2d 1235 (D.C. 1990).

<sup>41</sup>*See id.* at 1237.

<sup>42</sup>*See id.*

<sup>43</sup>*See id.*

<sup>44</sup>*See id.*

<sup>45</sup>*See In re A.C.*, 573 A.2d at 1242 (stating that the case was one which is "capable of repetition, yet evading review").

<sup>46</sup>*See id.* At 1237.

<sup>47</sup>*See id.* at 1243.

<sup>48</sup>*See id.* at 1247.

<sup>49</sup>*See In re Baby Boy Doe*, 632 N.E.2d 326 (Ill. App. Ct. 1994).

<sup>50</sup>*Id.* at 326.

<sup>51</sup>*Id.* at 332.

The court emphasized that it knows of “no case that suggests that a mother or any other competent person has an obligation or responsibility to provide medically for a fetus . . . .”<sup>52</sup> The woman eventually delivered a healthy baby boy despite the physician’s prediction that her fetus had virtually no chance to survive natural childbirth.<sup>53</sup>

The *Baby Boy Doe* court left open the question whether a court could compel a pregnant woman to undergo a blood transfusion by characterizing it as non-invasive and relatively risk-free compared to a Caesarean section.<sup>54</sup> Three years later, however, the *Fetus Brown* court addressed the issue whether a court could compel a blood transfusion.<sup>55</sup> The court refused to compel a pregnant woman to undergo a blood transfusion for the benefit of her fetus.<sup>56</sup> Doctors estimated that the woman and her fetus had a five-percent chance of survival if she refused to undergo the transfusion.<sup>57</sup> The court rejected the characterization of blood transfusions as “relatively non-invasive and risk-free procedures” and determined that they are invasive procedures that interrupt a competent adult’s bodily integrity.<sup>58</sup> The court stated that, “without a determination by the Illinois legislature that a fetus is a minor . . . we cannot impose a legal obligation upon a pregnant woman to consent to an invasive medical procedure for the benefit of her viable fetus.”<sup>59</sup>

Conversely, some courts subject pregnant women to medical procedures against their will. In *Jefferson v. Griffin Spalding County Hospital Authority*, the court ordered a Caesarean section over religious objections of a pregnant woman.<sup>60</sup> Doctors estimated that there was a ninety-nine percent chance that the child would not survive natural childbirth and that there was a fifty percent chance that the mother would not survive natural childbirth.<sup>61</sup> Doctor’s further estimated that a Caesarean section would likely provide nearly a one-hundred percent chance to save the lives of *both* the child *and* the mother.<sup>62</sup> Contrary to the *A.C.* and *Baby Boy Doe*

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<sup>52</sup>*Id.* at 329. “Even though we may consider appellant’s beliefs unwise, foolish or ridiculous, in the absence of an overriding danger to society we may not permit interference therewith . . . for the sole purpose of compelling her to accept medical treatment forbidden by her religious principles and previously refused by her with full knowledge of the probable consequences.” *Id.* at 331 (citing *In re Estate of Brooks*, 205 N.E.2d 435 (Ill. App. Ct. 1965)).

<sup>53</sup>*Id.* at 328, 329 (stating the baby was “somewhat underweight” at birth). The fact that the physician’s prediction was wrong is another reason courts should decline granting petitions for involuntary prenatal interventions.

<sup>54</sup>*In re Baby Boy Doe*, 632 N.E.2d at 333.

<sup>55</sup>*See In re Fetus Brown*, 689 N.E.2d 397 (Ill. App. Ct. 1997).

<sup>56</sup>*Id.*

<sup>57</sup>*Id.* at 398.

<sup>58</sup>*Id.* at 405.

<sup>59</sup>*Id.* at 405-06.

<sup>60</sup>*Jefferson v. Griffin Spalding County Hosp. Auth.*, 274 S.E.2d 457 (Ga. 1981).

<sup>61</sup>*Id.* at 86.

<sup>62</sup>*Id.*

explicit rejections of balancing tests,<sup>63</sup> the *Jefferson* court balanced the rights of the mother to practice her religion and to refuse the surgery against the right to life of the fetus and the state interest to preserve the life of the mother.<sup>64</sup> The court determined that medical treatment can be compelled against a competent adult in narrow circumstances where a balancing test is properly used.<sup>65</sup> *Jefferson* can be distinguished from *A.C.* and *Baby Boy Doe* because the Caesarean section benefited *both* mother and fetus rather than the fetus alone and thereby triggered the court to use a balancing test.<sup>66</sup>

Similarly, in *In re Jamaica Hospital*, the court ordered a blood transfusion over the religious objections of a pregnant Jehovah's Witness.<sup>67</sup> The court determined that the state interest to protect third parties must be considered because the woman was a single mother of ten children whose only next of kin was a sister that was unable to care for children.<sup>68</sup> The *Jamaica Hospital* decision is distinguishable from court decisions to refuse to order medical treatment for pregnant women because it considered the welfare of already-born children rather than only the fetus.

Other court decisions that order medical treatment against the will of pregnant women are not so easily distinguishable. In *Raleigh Fitkin-Paul Morgan Memorial Hospital v. Anderson*, a pregnant Jehovah's Witness refused to undergo a blood transfusion for religious reasons.<sup>69</sup> The court held that a pregnant woman in her final weeks of pregnancy does not have the right to refuse necessary life saving treatment when the life of the fetus is also at stake.<sup>70</sup> In *Crouse Irving Memorial Hospital, Inc. v. Paddock*, the court ordered blood transfusions despite a pregnant woman's refusal.<sup>71</sup> The woman agreed to undergo a Caesarean section but refused any blood transfusions based on her deep religious beliefs.<sup>72</sup> The court emphasized that parents have the right to deny their children medical treatment unless they need *lifesaving* treatment.<sup>73</sup> The court ordered the blood transfusions to protect the health of the fetus and the mother.<sup>74</sup> Similarly, in *In re Madyun*, a pregnant Muslim woman whose water had broken for more than forty-eight hours refused a Caesarean section

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<sup>63</sup>See *supra* text accompanying notes 42-48.

<sup>64</sup>*Jefferson*, 274 S.E.2d at 460.

<sup>65</sup>*Id.*

<sup>66</sup>*Id.* at 86; see also *supra* text accompanying notes 40-53 (rejecting use of balancing test when an invasive procedure would benefit the fetus alone because a fetus cannot have rights superior to those of its mother).

<sup>67</sup>See *In re Jamaica Hosp.*, 491 N.Y.S.2d 898 (N.Y. Sup. Ct. 1985).

<sup>68</sup>*Id.*

<sup>69</sup>See *Raleigh Fitkin-Paul Morgan Mem'l Hosp. v. Anderson*, 201 A.2d 537 (N.J. 1964).

<sup>70</sup>*Id.*

<sup>71</sup>*Crouse Irving Mem'l Hosp., Inc. v. Paddock*, 485 N.Y.S.2d 443 (N.Y. Sup. Ct. 1985).

<sup>72</sup>*Id.* at 444.

<sup>73</sup>*Id.* at 444-45; cf. *Fosmire v. Nicoleau*, 551 N.E.2d 77 (N.Y. 1990).

<sup>74</sup>*Paddock*, 485 N.Y.S.2d at 445.

based on her strong religious beliefs.<sup>75</sup> The court balanced the significant risks to the fetus against the minimal risks to the mother and concluded that there was a compelling interest for court-ordered medical intervention.<sup>76</sup>

The *Anderson*, *Paddock*, and *Madyun* decisions involved life-threatening situations.<sup>77</sup> These decisions also involved fetuses that were gestationally well-advanced and approached “a moral status that is close to, but slightly less strong than, normative personhood.”<sup>78</sup> Gene therapy would likely almost never involve a life-threatening situation. Gene therapy instead would likely involve attempts to prevent disabilities. Moreover, gene therapy in utero would most likely occur early in a pregnancy to introduce normal genes into the chromosomes of the cells of defective genes.<sup>79</sup> Therefore, the *Roe v. Wade* trimester approach to abortion based on the “viability” of the fetus<sup>80</sup> will not likely be implicated by gene therapy in utero. Gene therapy would likely occur *before* the fetus becomes viable. A woman should not be forced to undergo gene therapy in utero when she has the legal right to abort the fetus. If gene therapy does occur after viability, however, the *Anderson*, *Paddock*, and *Madyun* courts would only order gene therapy in utero during life-threatening situations.

Courts should respect the decision of a pregnant woman regardless of the viability of her fetus in future cases that involve gene therapy in utero. A pregnant woman who refuses gene therapy in utero that would only benefit her fetus is distinguishable from parents who refuse medical treatment for their already-born children. Illinois courts consistently hold that the state can intervene under *life-threatening* circumstances and provide medical procedures over parental objections once a child is born; however, the state cannot override a competent patient’s decision for the benefit of a fetus alone.<sup>81</sup> Perhaps gene therapy should follow this distinction. Doctors should not conduct gene therapy in utero without consent. The performance of gene therapy in utero over the objections of a pregnant woman would arguably violate her rights to equal protection, privacy, bodily integrity, religious freedom, and due process. *After birth*, courts should order risk-free procedures that prove effective to cure life-threatening diseases over parental objections. At the same time, courts should never order *in utero* procedures on pregnant women over their competent refusal.

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<sup>75</sup>See *In re Madyun*, 573 A.2d 1235 (1990) (appendix to *In re A.C.*).

<sup>76</sup>*Id.* at 1264.

<sup>77</sup>See *supra* text accompanying notes 69-76.

<sup>78</sup>CARSON STRONG, *ETHICS IN REPRODUCTIVE AND PERINATAL MEDICINE* 179 (1997).

<sup>79</sup>See BLANK & MERRICK, *supra* note 4, at 149 (describing the science of gene therapy).

<sup>80</sup>*Roe v. Wade*, 410 U.S. 113 (1973).

<sup>81</sup>*Compare* *Wallace v. Labrenz*, 104 N.E.2d 769 (Ill. 1952) (ordering a blood transfusion for an eight day old infant over the parents’ religious objections) *with* *In re Fetus Brown*, 689 N.E.2d 397 (Ill. App. Ct. 1997) (declining to order a pregnant woman to undergo a blood transfusion and stating that the legislature must declare that a fetus is a minor before a pregnant woman’s consent could be overridden) *and* *In re Baby Boy Doe*, 632 N.E.2d 326 (Ill. App. Ct. 1994) (declining to order a pregnant woman to undergo a Caesarean section).

### III. REASONS NOT TO MANDATE GENE THERAPY IN UTERO

#### A. An Unconstitutional Burden on Women

The coercion of pregnant women to undergo gene therapy in utero would place an undue burden on women in violation of the Equal Protection Clause of the Fourteenth Amendment.<sup>82</sup> Before the enactment of the Pregnancy Discrimination Act,<sup>83</sup> courts held that pregnancy did not violate the Equal Protection Clause as an illegal sex-based classification.<sup>84</sup> In *Cohen v. Chesterfield County School Board*, the court stated:

Only women become pregnant; only women become mothers. But Mrs. Cohen's leap from those physical facts to the conclusion that any regulation of pregnancy and maternity is an invidious classification by sex is merely simplistic . . . . Pregnancy and motherhood do have a great impact on the lives of women, and, if that impact be reasonably noticed by a governmental regulation, it is not to be condemned as an invidious classification.<sup>85</sup>

In 1974, the U.S. Supreme Court held in *Geduldig v. Aiello* that a state disability insurance system that failed to include pregnancy within its coverage did not unconstitutionally discriminate on the basis of sex.<sup>86</sup> The Court stated:

While it is true that only women can become pregnant, it does not follow that every legislative classification concerning pregnancy is sex based classification . . . . Absent a showing that distinctions involving pregnancy are mere pretexts designed to effect an invidious discrimination against members of one sex or the other, lawmakers are constitutionally free to include or exclude pregnancy from the coverage of legislation such

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<sup>82</sup>U.S. CONST. amend. XIV ("No State shall . . . deny to any person within its jurisdiction the equal protection of the laws.").

<sup>83</sup>See *infra* text accompanying notes 88-91.

<sup>84</sup>See *General Elec. Co. v. Gilbert*, 429 U.S. 125 (1976); *Geduldig v. Aiello*, 417 U.S. 484 (1974); *Cohen v. Chesterfield Co. Sch. Bd.*, 474 F.2d 395, 397 (4th Cir. 1973).

<sup>85</sup>*Cohen v. Chesterfield Co. Sch. Bd.*, 474 F.2d 395, 397 (4th Cir. 1973). In *Cohen*, the court gave examples of legal government regulations that do not apply equally to men and women, such as regulations requiring all personnel to be clean shaven and laws that prohibit adult women from sunbathing topless. *Id.* at 397. The dissenting judge would have found the *Cohen* regulation unconstitutional and stated:

The majority concludes that the regulation does not discriminate against women as such; it only discriminates between pregnant teachers and other teachers. The distinguishing factor seems to be motherhood versus fatherhood. The simple question then arises: Is this sex related? To the simple query the answer is just as simple: Nobody . . . has yet seen a male mother. A mother, to oversimplify the simplest biology, must then be a woman." *Id.* at 400-01 (Winter, J., dissenting).

<sup>86</sup>See *Geduldig v. Aiello*, 417 U.S. 484 (1974).

as this on any reasonable basis, just as with respect to any other physical condition.<sup>87</sup>

Congress responded to the Court's decisions in *Geduldig* and *General Electric Co. v. Gilbert*<sup>88</sup> by enacting the Pregnancy Discrimination Act (the "PDA"), as an amendment to Title VII of the Civil Rights Act of 1964.<sup>89</sup> The PDA declared that discrimination based on pregnancy is facially discriminatory.<sup>90</sup> In *Newport News Shipbuilding & Dry Dock Co. v. EEOC*, the Court interpreted the PDA and held that "discrimination based on a woman's pregnancy is, on its face, discrimination because of her sex."<sup>91</sup>

Subsequently, in *International Union v. Johnson Controls*, the Court held that a company policy that prohibited women of childbearing age from performing occupations that might expose them to lead and cause birth defects violated both the PDA and the Fourteenth Amendment.<sup>92</sup> The Court reasoned that male reproductive capacities were also vulnerable to lead exposure but the policy prohibited only women from performing such occupations.<sup>93</sup> The Court concluded that the policy explicitly discriminated against women on the basis of sex.<sup>94</sup> The Court relied on the PDA determination that Title VII discrimination on the basis of sex included discrimination "because of or on the basis of pregnancy, childbirth, or related medical conditions."<sup>95</sup> The Court held the policy to be facially discriminatory "because it does not apply to the reproductive capacity of the company's male employees in the same way as it applied to that of the females."<sup>96</sup>

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<sup>87</sup>*Id.* at 496 n.20.

<sup>88</sup>*General Elec. Co. v. Gilbert*, 429 U.S. 125 (1976). In *Gilbert*, the company's policy of compensating for all disabilities except pregnancy was not shown to favor men over women. *Id.* "Pregnancy is, of course, confined to women, but it is in other ways significantly different from the typical covered disease or disability." *Id.* at 136.

<sup>89</sup>Title VII states an employer may not "limit, segregate, or classify his employees or applicants for employment in any way which would deprive or tend to deprive any individual of employment opportunities or otherwise adversely affect his status as an employee because of such individual's . . . sex . . ." 42 U.S.C. § 2003-2(a)(2) (1998).

<sup>90</sup>*See* 42 U.S.C.A. § 2000e *et seq.*

<sup>91</sup>*Newport News Shipbuilding & Dry Dock Co. v. EEOC*, 462 U.S. 669, 684 (1983). There was no challenge to the constitutionality of the PDA.

<sup>92</sup>*International Union v. Johnson Controls, Inc.*, 499 U.S. 187 (1991).

<sup>93</sup>*Id.* at 196-98 ("Fertile men, but not fertile women, are given a choice as to whether they wish to risk their reproductive health for a particular job. . . . Johnson Controls' policy is facially discriminatory because it requires only a female employee to produce proof that she is not capable of reproducing.").

<sup>94</sup>*Id.* at 197.

<sup>95</sup>*Id.* at 198-99.

<sup>96</sup>*Id.* at 199.

Despite the PDA, not every pregnancy-related discrimination complaint successfully proves illegal sex discrimination.<sup>97</sup> In *Dimino v. Staten Island Railway*, a police officer alleged that her employer prevented her from performing her job solely because of her pregnancy.<sup>98</sup> The officer requested to be placed on restricted duty but she was instead told to go home.<sup>99</sup> The court determined that *Johnson Controls* was distinguishable because there was no determinant policy that prevented pregnant police officers from performing certain jobs.<sup>100</sup> Rather, the officer requested to be placed on restricted duty.<sup>101</sup> The court held that absent a determinant policy, there could be no illegal pregnancy-based classification.<sup>102</sup>

Under the PDA, a gene therapy policy that applies to the reproductive capacity of men in the same way that it does to women would likely be upheld under Title VII and the Equal Protection Clause. Genetic alteration of male sperm whose male genetics hold the disability or disease could actually preempt the issues that arise from gene therapy in utero. Some suggest that gene therapy can be performed on males through the use of mice.<sup>103</sup> Male sperm could be genetically altered and produced inside mouse testes before being used to fertilize the female egg.<sup>104</sup> The issues surrounding compelled gene therapy *in utero*, however, only implicate women. The policy would therefore “apply to the reproductive capacity of . . .

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<sup>97</sup>See *Dimino v. Staten Island Railway*, No. Civ A. CV-97-5927DGT, 1998 WL 760341 (E.D.N.Y. Sept. 18, 1998); *Bray v. Alexandria Women’s Health Clinic*, 506 U.S. 263, 330-31 (1993) (upholding the right of anti-abortion activists to hold demonstrations at abortion clinics and holding that opposition to abortion does not discriminate against a class of women seeking abortion). Justice Stevens’ dissent in *Bray* argued that all pregnancy based classifications illegally discriminate based on sex and states, “[I]t seems commonsense, that since only women can become pregnant, discrimination against pregnant people is necessarily discrimination against women. . . .” *Bray*, 506 U.S. at 331 (Stevens, J., dissenting) (citing Rep. Hawkins’ statements in 123 Cong.Rec. 10581 (1977) (statement of Rep. Hawkins)).

<sup>98</sup>See *Dimino*, 1998 WL 760341 at \*1.

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

<sup>100</sup>*Id.* at \*4.

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

<sup>102</sup>*Id.* at \*5.

<sup>103</sup>See Rick Weiss, *Science on the Ethical Frontier: Engineering the Unborn*, THE WASH. POST, March 22, 1998, at A1.

One way germline therapy may be done to ensure a man with a genetic disease doesn’t pass it to his child:

1. Doctors remove the man’s sperm-producing cells, which contain a defective gene.
2. A healthy gene is added to each cell to replace the defective ones.
3. The cells are put into mouse testes.
4. They mature inside the mouse and start producing healthy human sperm.
5. Those sperm, once tested, are used to fertilize a woman’s eggs in a laboratory dish.
6. The resulting embryos are placed in a woman’s womb.
7. She gives birth to a child whose genes are free from the father’s disease.

*Id.*

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

male[s] in [a different] way as it applies to that of the females.”<sup>105</sup> Based on *Johnson Controls* and *Dimino*, any policy that compels women to undergo gene therapy in utero would likely be a sex-based classification.

In *Craig v. Boren*, the Court set forth a legal standard to evaluate the constitutionality of gender classifications.<sup>106</sup> The Court used an intermediate level of scrutiny to determine that gender-based classifications “must serve important governmental objectives and must be substantially related to the achievement of those objectives.”<sup>107</sup> The Court would likely uphold a sex-based classification regarding gene therapy in utero based on the legitimate governmental interest in public health.<sup>108</sup> Furthermore, gene therapy procedures performed in utero that successfully prevent birth defects and diseases are likely “substantially related” to such a governmental objective because those procedures directly cause the “successful” outcome. This is not, however, the end of the inquiry. Courts will also likely consider whether a policy has discriminatory effect<sup>109</sup> or whether it places an undue burden on specific individuals.<sup>110</sup>

For example, in *Cleveland Board of Education v. LaFleur*, the Court examined whether a school board policy that required pregnant teachers to take maternity leave five months before their due dates was sufficient means to achieve the legitimate objective of continuity of instruction.<sup>111</sup> The Court determined that the school board policy served important governmental objectives and was substantially related to the achievement of those objectives under *Craig* but examined “whether the particular means chosen to achieve those objectives unduly infringe[d] upon the [pregnant] teacher’s constitutional liberty.”<sup>112</sup> The Court “has long recognized that freedom of personal choice in matters of marriage and family is one of the liberties protected by the Due Process Clause of the Fourteenth Amendment.”<sup>113</sup>

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<sup>105</sup>See *Dimino*, 1998 WL 760341 at \*5 (quoting *International Union v. Johnson Controls, Inc.*, 499 U.S. 187, 199, 211 (1991)).

<sup>106</sup>See *Craig v. Boren*, 429 U.S. 190 (1976) (holding a statute prohibiting males under age 21 and females under age 18 from buying beer to be unconstitutional sex discrimination).

<sup>107</sup>*Id.* at 197. Chief Justice Burger’s dissenting opinion states that the majority’s intermediate level scrutiny standard “apparently comes out of thin air.” *Id.* at 220 (Burger, C.J., dissenting). The Chief Justice would have applied the rational basis test which would have upheld the statute as being rationally related to the governmental objective and “permits the States a wide scope of discretion in enacting laws which affect some groups of citizens differently than others.” *Id.* at 216-17, 221-22.

<sup>108</sup>*Id.* at 199-200.

<sup>109</sup>See *Nashville Gas Co. v. Satty*, 434 U.S. 136, 154 (1977) (“Even though a plan which frankly and unambiguously discriminates against pregnancy is ‘facially neutral,’ the Court will find it unlawful if it has a ‘discriminatory effect.’”) (Stevens, J., concurring); see also *supra* Part III B describing the likely discriminatory effect of gene therapy in utero.

<sup>110</sup>See *Cleveland Bd. of Educ. v. LaFleur*, 414 U.S. 632 (1974).

<sup>111</sup>*Id.* at 641-42.

<sup>112</sup>*Id.* at 647.

<sup>113</sup>*Id.* at 639 (citing *Roe v. Wade*, 410 U.S. 113 (1973); *Loving v. Virginia*, 388 U.S. 1, 12 (1967); *Griswold v. Connecticut*, 381 U.S. 479 (1965), and other cases). If the Supreme Court can constitutionally guarantee a right to abortion, forcing a pregnant woman to undergo gene

Similarly, in *Nashville Gas Company v. Satty*, the Court based its decision on the imposition of a substantial burden.<sup>114</sup> The Court stated that “petitioner has not merely refused to extend to women a benefit that men cannot and do not receive, but has imposed on women a substantial burden that men need not suffer.”<sup>115</sup> Under *Satty*, the substantial burden test might preclude courts from forcing pregnant women to undergo gene therapy in utero.

Court compulsion of gene therapy in utero forces a medical procedure upon women that no man would ever have to bear.<sup>116</sup> Those courts would place an undue burden on pregnant women by forcing them to undergo gene therapy *in utero* while at the same time refusing to force others to donate bone marrow or blood to their *living* relatives.<sup>117</sup>

Many courts uniformly decline to force medical procedures upon individuals, particularly minor children. In *Curran v. Bosze*, the court declined to order three-year-old twins to undergo blood tests to determine bone marrow compatibility with their leukemia-stricken half-brother.<sup>118</sup> The mother of the twins resisted the father’s compulsion and refused to consent to the procedure.<sup>119</sup> The court determined that previous cases of court-ordered medical procedures involved benefits to the potential donors based on their close relationships with the recipients and the consent of both parents of the donors.<sup>120</sup> Based on *Curran*, mandated gene therapy in utero would

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therapy to prevent a child with a disability or disease should also remain a woman’s choice. However, even though the right to an abortion disappears at the point of a fetus’ viability, I argue gene therapy, even for viable fetuses, should not be performed over a pregnant woman’s objections.

<sup>114</sup>See *Nashville Gas Co. v. Satty*, 434 U.S. 136, 141-42 (1977).

<sup>115</sup>*Id.* at 142. On the other hand, Justice Stevens stated, “Differences between benefits and burdens cannot provide a meaningful test of discrimination since, by hypothesis, the favored class is always benefited and the disfavored class is equally burdened.” *Id.* at 155 n.4 (Stevens, J., concurring). In my analysis, however, imposing a burden on pregnant women does not benefit men or any “favored class.” I believe the discrimination is that there is no burden placed on men while there would be a heavy burden imposed on pregnant women.

<sup>116</sup>See Walsh, *supra* note 4, at 164.

<sup>117</sup>See *Curran v. Bosze*, 566 N.E.2d 1319 (Ill. 1990) (refusing to compel twin minors to donate bone marrow to a half sibling despite the little risk to the twins and the sibling’s life depended on the transplant; in fact, the court would not even compel the minors to undergo a blood test to determine whether they would be compatible donors); *McFall v. Shimp*, 10 Pa.D.3d 90 (Allegheny County Ct. 1978) (refusing to order Shimp to donate bone marrow to save cousin’s life); *Lausier v. Pescinski*, 226 N.W.2d 180 (Wis. 1975) (holding that an incompetent brother cannot be forced to donate a kidney to save the life of his dying sister); *Bonner v. Moran*, 126 F.2d 121, 122 (U.S. App. D.C. 1941) (requiring parental consent, despite the fifteen year old’s own consent, for removal of a skin patch to benefit severely burned cousin).

<sup>118</sup>See *Curran v. Bosze*, 566 N.E.2d 1319 (Ill. 1990).

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

<sup>120</sup>*Id.* at 1331. For example, in *Strunk v. Strunk*, the Kentucky Court of Appeals granted a petition for a kidney to be removed from a mentally incompetent ward of the State to be implanted in the ward’s brother because of the close relationship between the brothers. See *Strunk v. Strunk*, 445 S.W.2d 145, 146 (Ky. 1969). The ward was “greatly dependent upon

not pass muster without the consent of the pregnant woman to the procedure. A pregnant woman certainly has a close relationship to the recipient, i.e., the fetus. However, a policy that forces a competent pregnant woman to undergo medical treatment against her will provides no emotional, psychological, or medical benefit to that woman.

[O]ne human being is under no legal compulsion to give aid or to take action to save another human being or to rescue . . . . For our law to compel defendant to submit to an intrusion of his body would change every concept and principle upon which our society is founded. To do so would defeat the sanctity of the individual, and would impose a rule which would know no limits, and one could not imagine where the line would be drawn.<sup>121</sup>

A policy that mandates gene therapy in utero for the benefit of the fetus would likely place an unconstitutional undue burden on pregnant women. Donating blood takes only about an hour, causes only slight discomfort, has no permanent side effects, and is desperately necessary.<sup>122</sup> Yet, courts refuse to compel blood donations despite their simplicity and despite any arguments based on morality.<sup>123</sup> “Most people do not want to live in a society in which they can be compelled to undergo surgery or sacrifice body parts, even if it would be morally incumbent upon them to do so. Placing limits on what can be demanded of citizens, especially where bodily integrity is involved, is essential to a free society.”<sup>124</sup> “Surely . . . a fetus cannot have rights . . . superior to those of a person who has already been born.”<sup>125</sup>

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[his brother], emotionally and psychologically, and [the ward’s] well-being would be jeopardized more severely by the loss of his brother than by the removal of a kidney.” *Id.* Similarly, in *Hart v. Brown*, parents of identical seven year old twins sought to have a kidney removed from the healthy twin to be transplanted into the seriously ill twin. *See Hart v. Brown*, 289 A.2d 386 (Conn. Supp. 1972). The hospital sought a court declaration that the parents had the right to give their consent to the operation. *Id.* at 387. The court allowed the kidney transplant based on the “immense benefit to the donor in that the donor would be better off in a family that was happy than in a family that was distressed and in that it would be a very great loss to the donor if the donee were to die from her illness.” *Id.* at 389-90. Additionally, in *Little v. Little*, the court granted a mother’s petition to remove the kidney of her mentally incompetent daughter to be transplanted in her younger son based on the close relationship between the donor and donee and both parents’ consent. *See Hart v. Brown*, 289 A.2d 386 (Conn. Supp. 1972).

<sup>121</sup>*See* *McFall v. Shimp*, 10 Pa.D.3d 90, 91 (Allegheny County Ct. 1978).

<sup>122</sup>*See* Bonnie Steinbock, *Maternal-Fetal Conflict and In Utero Fetal Therapy*, 57 ALB. L. REV. 781, 790 (1994).

<sup>123</sup>*Id.* at 791.

<sup>124</sup>*Id.* at 790.

<sup>125</sup>*In re A.C.*, 573 A.2d 1235, 1244 (D.C. 1990).

B. *The Discriminatory Impact and Treatment of Involuntary Gene Therapy on Pregnant Women: Race, Gender, and Socio-economic Status*

1. Race

If courts order a pregnant women to undergo gene therapy, racial minorities may be treated discriminatorily. Historically, eugenics programs targeted both women,<sup>126</sup> and minorities. In 1912, the Public Health Service gave immigrants intelligence tests because the Service suspected that immigrants were a prime source of social decline.<sup>127</sup> “The inadequate genes of the people trying to gain entry to the United States was ‘demonstrated’ by H.H. Goddard . . . who administered pen and paper intelligence tests to exhausted, frightened individuals who had just landed on Ellis Island. The results — 87% of the Russians, 83% of the Jews, 80% of the Hungarians, and 79% of the Italians were found to be feebleminded.”<sup>128</sup> In 1924, Congress set quotas on the number of immigrants from various countries in response to such “social decline.”<sup>129</sup> By 1931, most states passed eugenic laws that authorized the involuntary sterilization of certain groups of people.<sup>130</sup>

Furthermore, poor women of color are more likely to be deemed “unfit” and subjected to sterilization abuse.<sup>131</sup> The sterilization rates of poor women and women of color are higher than those of white women.<sup>132</sup> An estimated 30% to 42% of all Native Americans have been sterilized and Hispanic women who neither spoke nor understood English were often subjected to sterilization in Los Angeles.<sup>133</sup>

Some commentators predict that similar discrimination against ethnic minorities will occur as gene therapy procedures continue to develop:

In the future, people thought to have genetic predisposition to crime might be subject to gene therapy if it becomes usable . . . . Any medical intervention to curtail the manifestation of alleged criminal genes would be applied in a discriminatory fashion. African-American individuals are more likely to be prosecuted than white individuals and African-American individuals receive harsher sentences than Whites for similar crimes.<sup>134</sup>

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<sup>126</sup>See *infra* text accompanying notes 138-152.

<sup>127</sup>See Harding, *supra* note 12, at 481.

<sup>128</sup>Andrews, *supra* note 2, at 908 (citations omitted).

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

<sup>130</sup>See Harding, *supra* note 12, at 481 (stating that thirty two states had passed discriminatory eugenic laws).

<sup>131</sup>See Lisa C. Ikemoto, *The Code of Perfect Pregnancy: At the Intersection of the Ideology of Motherhood, The Practice of Defaulting to Science, and the Interventionist Mindset of Law*, 53 OHIO ST. L.J. 1205, 1231 (1992).

<sup>132</sup>*Id.* at 1232 (listing ethnic elitism, classism, and racism as reasons for the increased sterilization rates among women of color and poor women).

<sup>133</sup>*Id.*

<sup>134</sup>Andrews, *supra* note 2, at 913-14.

Lori Andrews states that out of twenty-one cases where court orders were sought for prenatal interventions, 81% of the women were black.<sup>135</sup> Court-ordered Caesarean sections are disproportionately imposed on low-income women of color.<sup>136</sup> Furthermore, the majority of all court-ordered surgeries were performed on women of color, many of whom were immigrants and refugees.<sup>137</sup>

Unfortunately, there is no compelling reason to believe that a court system that discriminatorily applies criminal sentences would equally order gene therapy procedures. On the other hand, courts could mandate gene therapy only on those individuals thought to be “valuable” or “worthy” in our society. The expense that will likely accompany gene therapy procedures may actually *prohibit* many minorities from receiving gene therapy treatment in utero. Regardless, courts should neither mandate nor prohibit gene therapy in utero.

## 2. Gender

Gender, like race, will also likely play a large role in a court’s decision to order gene therapy. Historically, eugenics efforts disproportionately targeted women.<sup>138</sup> The first American eugenics efforts — the institutionalization of the ‘feebleminded’ — concentrated largely on women.<sup>139</sup> Some argue that geneticists and policy makers saw promiscuous women as a social problem and developed institutionalization and sterilization programs that forced women to behave in socially acceptable ways and forbade them from creating children outside of marriage.<sup>140</sup> For example, Carrie Buck, the woman who was involuntarily sterilized and about whom Justice Holmes stated that, “three generations of imbeciles is enough,”<sup>141</sup> was not an imbecile.<sup>142</sup> Ms. Buck and her daughter both did well in school.<sup>143</sup> Ms. Buck was institutionalized because she was ‘immoral’ for having a child out of wedlock rather than because she was ‘feebleminded.’<sup>144</sup>

The targeting of socially undesirable women continues today as “97% of obstetricians favor sterilizing unmarried welfare mothers.”<sup>145</sup> Although legislation

<sup>135</sup>See LORI B. ANDREWS, *MEDICAL GENETICS: A LEGAL FRONTIER* 236 (1987).

<sup>136</sup>See Deborah J. Krauss, *Regulating Women’s Bodies: The Adverse Effect of Fetal Rights Theory on Childbirth Decisions and Women of Color*, 26 HARV. C.R.-C.L. L. REV. 523 (1991).

<sup>137</sup>See Nancy K. Kubasek, *The Colonization of the Womb*, 43 DUKE L.J. 492, 517 (1993).

<sup>138</sup>See Andrews, *supra* note 2, at 906-07. “In the late 1800s, . . . [t]raits such as feeblemindedness, criminality, pauperism, [and] prostitution . . . were thought to be single gene defects.” *Id.* at 893-94.

<sup>139</sup>*Id.* at 906.

<sup>140</sup>*Id.* (citing Nicole H. Rafter, *Claims-Making and Socio-Cultural Context in the First U.S. Eugenics Campaign*, 39 SOC. PROBS. 17-34 (Feb. 1993)).

<sup>141</sup>See *Buck v. Bell*, 274 U.S. 200, 207 (1927).

<sup>142</sup>See Paul A. Lombardo, *Three Generations, No Imbeciles: New Light on Buck v. Bell*, 60 N.Y.U. L. REV. 30, 52 (1985).

<sup>143</sup>*Id.*

<sup>144</sup>*Id.*

<sup>145</sup>Andrews, *supra* note 2, at 909.

that requires involuntary sterilization of welfare women has not been passed, several states have proposed legislation that provides financial incentives for welfare women who implant contraceptives or undergo sterilization.<sup>146</sup> Rosemarie Tong fears that pregnant women who decline gene therapy will be punished and wrote the following of individuals who are quick to punish women who do not have the perfect baby:

Currently, a relatively high number of citizens seem prepared to punish women for ‘negligently, recklessly, or intentionally’ engaging in lifestyle behaviors that result in serious, irreparable damage to their infants. Such behaviors are believed to encompass everything from engaging in unsafe sex with HIV-positive partners to not eating enough nutritious food, working in toxic environments, drinking too much caffeine, overexercising or underexercising, taking licit as well as illicit drugs that might imperil fetal well-being, or failing to follow physicians’ orders. Already, many pregnant women have been prosecuted and, in a few instances, imprisoned for giving birth to cocaine-exposed infants. What some feminists fear, then, is that if the concept of ‘fetal abuse’ or ‘fetal negligence’ captures the public’s imagination, the public might decide to punish not only pregnant women who do not ‘take care of themselves’ but also pregnant women who do not submit to gene therapy for their fetuses.<sup>147</sup>

Furthermore, women will likely fall further from social equality if gene therapy is used for cosmetic purposes such as thinness or athletic ability. “Given that all too many people will want their children to fit prevailing social norms, even when these norms happen to be sexist, racist, and classist in nature, gene therapy for enhancement purposes will only make the struggle for equity between men and women that much more difficult.”<sup>148</sup> The use of gene therapy for cosmetic purposes could actually lead to an *increase* in genetic diseases as unexpected side effects result from the alteration of the gene pool.<sup>149</sup> For example, blond hair and blue eyes have been linked to an increased susceptibility to skin cancer.<sup>150</sup> A narrow gene pool could also decrease the chances of human survival in the event of an epidemic. For example, while the United States may attempt to obliterate sickle cell anemia and cystic fibrosis, a recessive gene for sickle cell anemia or cystic fibrosis may be necessary to survive in other parts of the world.<sup>151</sup> The recessive sickle cell anemia gene protects against malaria and the recessive cystic fibrosis gene protects against cholera.<sup>152</sup>

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<sup>146</sup>*Id.*

<sup>147</sup>ROSEMARIE TONG, *FEMINIST APPROACHES TO BIOETHICS: THEORETICAL REFLECTIONS AND PRACTICAL APPLICATIONS* 239 (1997).

<sup>148</sup>*Id.* at 241.

<sup>149</sup>*See* Weiss, *supra* note 103, at A1.

<sup>150</sup>*Id.*

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

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

### 3. Socio-Economic Status

Since the 1800's, the policy argument in favor of sterilizing criminals and the feeble-minded was that those individuals cost money to the rest of society.<sup>153</sup> In 1907, Indiana enacted the first eugenics law that "provided for the involuntary sterilization of institutionalized, unimprovable individuals who were idiots, imbeciles, rapists, or habitual criminals."<sup>154</sup> Society could similarly support court-ordered gene therapy in utero because of the societal financial costs associated with the care of disabled children.<sup>155</sup> Furthermore, health care providers may coerce women to undergo gene therapy out of fear of liability for a child born with a genetic disorder. There are documented accounts of physicians who pressure pregnant women to abort genetically abnormal fetuses out of fear of liability.<sup>156</sup>

Any policy that mandates gene therapy in utero must realistically consider the costs involved. Economically disadvantaged women cannot afford the extreme expense that may be associated with gene therapy procedures.<sup>157</sup> Similar to poor women who must forego basic necessities and delay abortions until they can afford them,<sup>158</sup> mandated gene therapy in utero will likely deplete a pregnant woman of valuable financial resources that could be used to care for her upcoming baby. "[G]iven the absence of any national health insurance that would guarantee access of all pregnant women to [gene therapy,] it would be illogical and most unfair to hold a pregnant woman liable for failing to utilize a medical procedure that she was unable to afford."<sup>159</sup> "[F]eminists who favor gene therapy aimed at treating diseases and defects urge that it be provided to all women, rich or poor, on the grounds that all women should have equal procreative freedom."<sup>160</sup>

The combination of race, gender, and socio-economic status play a large role in the societal definitions of who is "socially undesirable." For example, obstetricians almost unanimously agree that women on welfare should not continue to have

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<sup>153</sup>See Andrews, *supra* note 2, at 894.

<sup>154</sup>*Id.* at 895 (stating further that the Nazis modeled their sterilization law after the American model).

<sup>155</sup>See Walsh, *supra* note 4, at 176 ("[S]ociety may reject children who are born with disabilities and the women who chose to have them. These attitudes may be driven by pure economics, since the public may fear the additional costs of caring for disabled children. . .").

<sup>156</sup>See Andrews, *supra* note 2, at 981.

<sup>157</sup>See TONG, *supra* note 147, at 240.

<sup>158</sup>See *Women of the State of Minn. v. Gomez*, 542 N.W.2d 17, 26 (Minn. 1995) (stating both parties conceded that Medicaid-eligible women who are denied funding delay abortion while seeking alternative funds and that women commonly cancel and reschedule appointments a number of times while seeking alternative funds); Laura M. Friedman, *Family Cap and the Unconstitutional Conditions Doctrine: Scrutinizing a Welfare Woman's Right to Bear Children*, 56 OHIO ST. L.J. 637, 660 (1995).

<sup>159</sup>TONG, *supra* note 147, at 141.

<sup>160</sup>*Id.* Although I agree that all women should have equal procreative freedom, I disagree with Rosemarie Tong's statement that women should be *provided* gene therapy. I would change Tong's statement from "provided to all women" to "available to all women."

children.<sup>161</sup> If society, the courts, or the legislature decide to force sterilization, contraception, or gene therapy on individuals deemed socially undesirable, a clear line cannot be drawn between those who are and are not worthy of bearing children. Involuntary sterilization or mandated gene therapy of certain groups of people may cross the line between preventing disease and serving clearly eugenic goals.<sup>162</sup> If all jailed criminals were sterilized, it would certainly be naïve for anyone to think that all crime would suddenly cease. Similarly, if pregnant women are forced to alter the genes of their fetuses, it would be naïve to think that all genetic “abnormalities” or “defects” would suddenly be eliminated.

*C. Public Policy: The Impossible Ethical Dilemmas Involved in Determining Which “Abnormalities” Should be “Fixed”*

Everyone has their own notion of what constitutes a “meaningful” life. Everyone most likely accepts that people should be free from pain at all times, should have love and happiness in their lives, and should be able to function as independent human beings. Quality of life issues arise when individuals pity or feel sorry for others, or when individuals judge the decisions of others, especially parents. It is difficult, if not impossible, to detach our own notions of a meaningful life. In *In re Sampson*, the court overrode a mother’s decision to not force her fifteen-year-old son to undergo several operations to correct a facial condition called neurofibromatosis.<sup>163</sup> Despite a lack of evidence that the teenager felt “abnormal” or unhappy, the judge stated that, “whatever chance he may have for a *normal, happy* existence . . . will unquestionably be impossible if the disfigurement is not corrected.”<sup>164</sup>

“The difficulty deciding which abnormalities should be fixed [i.e. by gene therapy] stems from our notions of quality of life. Using our own conceptions of what we think would not be worth living are imposed on whether we think other individuals would want to live.”<sup>165</sup> These “subjective assessments about the quality of life of the child to be born”<sup>166</sup> illustrate that it may be impossible to decide which illnesses, or disabilities, gene therapy should “fix.”

Some individuals would likely support the abortion of a fetus with a serious genetic defect or the correction of such a defect using gene therapy to prevent “suffering.” The concept of “suffering”, however, is just as subjective as individual views on “quality of life.” In fact, “health” and “disease” concepts and definitions

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<sup>161</sup>See *supra* text accompanying note 145.

<sup>162</sup>“Eugenics is generally defined as the ‘improvement of the human species by selective breeding.’ See Friedman, *supra* note 14, at 145. “Eugenics has been described as a social movement to improve the human species through the use of technology.” See Harding, *supra* note 12, at 477.

<sup>163</sup>See *In re Sampson*, 317 N.Y.S.2d 641 (N.Y. Fam. Ct. 1970), *aff’d*, 323 N.Y.S.2d 253 (N.Y. App. Div. 1971), *aff’d*, 278 N.E.2d 918 (N.Y. 1972).

<sup>164</sup>*Id.* at 646 (emphasis added).

<sup>165</sup>Shepherd, *supra* note 5, at 798-99.

<sup>166</sup>*Id.*

always involve judgment calls.<sup>167</sup> “Many well-meaning people who do not live with disabilities will assume that a fetus with disabilities will suffer if brought to term. Yet people living with disabilities and persons working and living with disabled people often say otherwise.”<sup>168</sup> Marsha Saxton, a disability rights activist who suffers from spina bifida, states that, “people with disabilities as a group do not suffer any more than any other group or category of humans.”<sup>169</sup> Every human being suffers at some time for some reason.<sup>170</sup> There is no way to objectively determine whether another person’s suffering is worth living with or if such a person would have been better off never being born. There are many historical examples of people who believe that suffering, no matter how severe, is acceptable and sometimes honorable when certain principles such as family, country, religion, or culture are at stake.<sup>171</sup> “Relieving a fetus [who has a genetic disease] of the burden of a life . . . might not be as kind-hearted as it initially appears, but rather may show a lack of human caring, acceptance, and respect.”<sup>172</sup>

In fact, defining the term “disability” remains challenging because of medical and technological advances and society’s changing perceptions of “disabled” persons. For example, the American deaf community generally considers deafness to be a “culture” rather than a “disability.”<sup>173</sup> “Rather than disabled, the deaf are a cultural, linguistic minority. . . . So strong is the feeling of cultural solidarity that many deaf parents cheer on discovering that their baby is deaf.”<sup>174</sup> The Deaf President Now revolution at Gallaudet University has drawn comparisons to the Stonewall Riot for gays and lesbians.<sup>175</sup> Roslyn Rose, president of the National Association of the Deaf, analogizes deafness with race by stating that, “[i]n our society everyone agrees that whites have an easier time than blacks. But do you think a black person would undergo operations to become white?”<sup>176</sup>

<sup>167</sup>See Weiss, *supra* note 103, at A1 (quoting LeRoy Walters, the Director of Georgetown University’s Kennedy Institute for Ethics, as saying, “There will be clear-cut cases where everyone in the world will agree, ‘this is a disease,’ but the concept of health and disease at the margin will always involve judgment calls.”).

<sup>168</sup>Shepherd, *supra* note 5, at 782; see also Walsh, *supra* note 4, at 151-52, 168 (“Are programs aimed at the improvement of the overall genetic quality of the population or the elimination of genetic disease in complete conflict with the recognition of the rights and value of the disabled? Why do we reject the disabled under the guise of compassion for their suffering?”).

<sup>169</sup>Marsha Saxton, *Prenatal Screening and Discriminatory Attitudes About Disability*, 13 WOMEN & HEALTH 217, 222 (1988).

<sup>170</sup>See Shepherd, *supra* note 5, at 783-84 (1995).

<sup>171</sup>*Id.*

<sup>172</sup>*Id.* at 782.

<sup>173</sup>*Id.* at 761-62.

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

<sup>175</sup>See Dena S. Davis, *Genetic Dilemmas and the Child’s Right to an Open Future*, 28 RUTGERS L.J. 549, 570 (1997).

<sup>176</sup>*Id.* at 571. Another activist rhetorically asked, “When Gorbachev visited the U.S., he used an interpreter to talk to the President. Was Gorbachev disabled?” *Id.* at 572.

The U.S. Supreme Court recently addressed these difficulties and decided that individuals infected with HIV are “disabled” within the meaning of the Americans with Disabilities Act (the “ADA”).<sup>177</sup> Under *Bragdon v. Abbott*, asymptomatic individuals infected with HIV are disabled under the ADA and thereby protected from discrimination based on their disability.<sup>178</sup>

Another factor that makes it impossible to determine the genetic defects to which a court might order gene therapy is the wide spectrum of individual values and disabilities. Where do we draw the line between gene therapy and eugenics? In 1994, China passed legislation that required abortions of fetuses that carried hereditary diseases or were otherwise abnormal.<sup>179</sup> If gene therapy is permissible to relieve suffering, what level or threshold of suffering must be met?<sup>180</sup> “What about . . . Down’s syndrome, emotional instability, lack of artistic skill, athletic incompetence, shortness, or freckles? . . . If diabetes, sickle-cell anemia, and cancer are to be cured by altering the genetic makeup of an individual, why not proceed to other ‘disorders’: myopia, color blindness, left-handedness.”<sup>181</sup> This problem becomes even more complex when genetic predispositions to disease are considered. The concepts of “health” and “normality

” would become narrow, socially-determined standards.<sup>182</sup>

Furthermore, studies suggest that society will desire to alter or correct genes for reasons other than preventing disabilities or diseases, based on the wide range of attitudes regarding disabilities and diseases. One study evaluated the attitudes of parents of children with cystic fibrosis and found that the percentage of women who would abort fetuses with genetic disorders varied depending on the disorder.<sup>183</sup> Fifty-eight percent would abort a severely mentally retarded fetus during the first trimester.<sup>184</sup> Twenty percent would abort a fetus with cystic fibrosis and 17% would abort if the fetus would develop a painful and incurable disorder by age forty.<sup>185</sup> These attitudes toward abortion from those familiar with genetic diseases supports the inference that most women would choose to undergo gene therapy for serious diseases or disorders. An alarming outcome of that study was that 12% of those surveyed would abort a fetus that was predisposed to suffer from severe and

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<sup>177</sup>See *Bragdon v. Abbott*, 118 S.Ct. 2196 (1998).

<sup>178</sup>However, “[e]very agency to consider the issue under [§ 504 of] the Rehabilitation Act [which prohibits discrimination based on disability] found statutory coverage for persons with asymptomatic HIV.” *Id.* at 2207.

<sup>179</sup>See Shepherd, *supra* note 5, at 779 n.94. The law, titled the ‘Maternal and Infantile Health Care Law,’ was, in draft form, titled, ‘Eugenics and Health Protection,’ but was renamed following criticism from the West. *Id.*

<sup>180</sup>See Harding, *supra* note 12, at 511-12.

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

<sup>182</sup>See Munayyer, *supra* note 10, at 698-99.

<sup>183</sup>See Dorothy C. Wertz et al., *Attitudes Toward Abortion Among Parents of Children with Cystic Fibrosis*, 81 AM. J. PUBLIC HEALTH 992, 992 (1991). Severe mental retardation was the most crucial factor in deciding to abort. *Id.*

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

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

untreatable obesity.<sup>186</sup> Similarly, 3% would abort a fetus with a *treatable* physical defect such as cleft palate or nearsightedness, 2% would abort a fetus that was predisposed to alcoholism, and 0.4% would abort a fetus that was not the sex desired by the parents.<sup>187</sup> This study illustrates the extreme difficulties that face courts, legislatures, and society as a whole when deciding what “illnesses” must be “fixed” by gene therapy in utero.

Another study found that the percentage of women who would terminate their pregnancy varied based on the probability of the fetus being affected.<sup>188</sup> There was a “sharp increase in the number of women saying that they would have an abortion when the probability of the fetus being affected rose from 95 to 100 percent.”<sup>189</sup> However, thirty-nine women [out of almost five hundred surveyed] said they would not abort even if there was a 100% chance that the fetus had a neural tube defect.<sup>190</sup>

Another study shows that most Americans will take advantage of gene therapy when it becomes safe, effective, and somewhat routine.<sup>191</sup> However, those surveyed would use gene therapy for reasons other than prevention of disability or disease.<sup>192</sup> Forty-three percent approved the use of gene therapy to improve their childrens’ physical characteristics and 42% approved the use of gene therapy to improve their childrens’ intelligence level.<sup>193</sup>

It is impossible to objectively determine whether another person’s fetus should be aborted or genetically altered. Attitudes toward suffering and disability are so subjective that gene therapy for one woman’s fetus may be a good idea while gene therapy for another woman’s fetus with the same “disability” may not be. Courts should refrain from imposing their own notions of when life is or is not worth living or imposing gene therapy to alter another person’s quality of life.

## VI. CONCLUSION

Some predict that gene therapy issues will eventually swallow the abortion issue.<sup>194</sup> “With every step toward perfecting the control of genetics and procreation, abortion becomes a mere relic — a crude, draconian attempt from a bygone age to affect propagation.”<sup>195</sup> Regardless of whether this prediction has merit, issues surrounding gene therapy will certainly continue to be debated. Societal and individual conceptions of morality, suffering, health, and desirability of certain traits

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<sup>186</sup>*Id.* at 994 fig. 2.

<sup>187</sup>*Id.*

<sup>188</sup>See Ruth R. Faden et al., *Prenatal Screening and Pregnant Women’s Attitudes Toward the Abortion of Defective Fetuses*, 77 AM. J. PUBLIC HEALTH 288, 289 (1987).

<sup>189</sup>*Id.* at 290.

<sup>190</sup>*Id.* at 289.

<sup>191</sup>See Andrews, *supra* note 2, at 900 (citing Results of Public Survey on Human Genetics Released, Cancer Weekly, Dec. 21, 1992, at 9).

<sup>192</sup>*Id.*

<sup>193</sup>*Id.*

<sup>194</sup>See Harding, *supra* note 12, at 472.

<sup>195</sup>*Id.*

blur the line between gene therapy for the prevention of disease and gene therapy for purely eugenic purposes. If courts order pregnant women to undergo gene therapy in utero despite the undue burden on women and the lack of a rescue doctrine for those already living, “the social focus, whether scientifically realistic or not, shifts from encouraging tolerance of human diversity to developing methods to avoid it.”<sup>196</sup> Discrimination would expand from race, gender, and socio-economic status to include those who are genetically “inferior.” The decision to undergo gene therapy in utero should be the private decision solely for a pregnant woman.

[I]n a more ideal world where economic differences, if they exist, do not affect decisions of medical care or childbearing, where carrier screening and prenatal screening can accurately predict to the one-thousandth percent the likelihood and severity of expression of genetic traits, where prenatal screening and fetal therapies are, with perfect accuracy, medically recommended and performed without risk to mother or fetus, where in vitro fertilization to allow perfect gene replacement of the deleterious gene is widely available, safe, and effective, still, in that world, I maintain, a woman should be allowed to have a child with genetic differences. . . . If two deaf adults, or two adult dwarfs, wish to have a child and are comfortable with the possibility that they may pass on genes for deafness or dwarfism to their offspring . . . we [should] respect the prospective parents’ decision to ‘let nature take its course.’<sup>197</sup>

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<sup>196</sup>See Munayyer, *supra* note 10, at 699.

<sup>197</sup>Shepherd, *supra* note 5, at 796, 798-99.