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Do You Hear What I Hear?: The Right of Prospective Parents to Use PGD to Intentionally Implant an Embryo Containing the Gene for Deafness

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DO YOU HEAR WHAT I HEAR?: THE RIGHT OF PROSPECTIVE
PARENTS TO USE PGD TO INTENTIONALLY IMPLANT AN
EMBRYO CONTAINING THE GENE FOR DEAFNESS

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Had I a right, for my own benefit, to inflict this curse upon everlasting generations? . . . I shuddered to think that future ages might curse me as their pest, whose selfishness had not hesitated to buy its own peace at the price perhaps of the existence of the whole human race.¹

INTRODUCTION

In 2005, the *New York Times* interviewed Kelly Santos, a woman suffering from a genetic chromosomal defect that caused a ninety percent chance of miscarriage.² After enduring six miscarriages and undergoing six artificial inseminations and two in vitro fertilization (IVF) treatments, Mrs. Santos gave birth to a healthy baby girl.³ In 1999, a girl suffering from Fanconi's anemia received lifesaving stem cells from her newborn sibling's umbilical cord.⁴ In Chicago, Illinois,

1. MARY WOLLSTONECRAFT SHELLEY, *FRANKENSTEIN* 129–30 (Susan J. Wolfson ed., 2007).

2. Laurie Tarkan, *Screening for Abnormal Embryos Offers Couples Hope After Heartbreak*, N.Y. TIMES, Nov. 22, 2005, at F1.

3. *Id.*

4. Robert J. Boyle & Julian Savulescu, *Ethics of Using Preimplantation Genetic Diagnosis to Select a Stem Cell Donor for an Existing Person*, 323 BRIT. MED. J. 1240, 1240 (2001).

a little girl named Chloe Kingsbury was born; she will never suffer from the genetically inherited form of colon cancer that killed her grandmother, great-grandfather, and two uncles.⁵ All three of these happy endings are the product of more than mere chance—each of the babies involved had been purposely selected as an embryo using IVF and Preimplantation Genetic Diagnosis (PGD) treatments.⁶

In the early 1990s, doctors introduced the science of PGD, giving prospective parents a chance to avoid giving birth to a child crippled by a genetic disease.⁷ Today, however, PGD is used by parents who want the ultimate element of control: control over their child's genetic makeup.⁸ Even now, twenty years later, the scientific community has just begun to tap the potential of the science of creation.⁹ But as new discoveries arise, so too do new ethical and legal issues as governments, doctors, and parents debate over what qualifies as a “permissible” or “ethical” use of this technology.¹⁰ In each of the factual cases illustrated above, the choice of whether to use PGD was balanced against the probable pain and loss that would otherwise result.¹¹ The ethical dilemmas faced by each of these parents, though still troubling, were less burdensome and more easily overcome with the life or health of a child or the mother at stake.¹²

5. Amy Harmon, *Couples Cull Embryos to Halt Heritage of Cancer*, N.Y. TIMES, Sept. 3, 2006, at 1.

6. For Kelly Santos, the doctors used PGD to select and implant an embryo without the defective gene that caused the ninety percent rate of miscarriage. Tarkan, *supra* note 2, at F1. The parents of the girl suffering from Fanconi's anemia had IVF and PGD for the purpose of providing a stem cell donor for their daughter. Boyle & Savulescu, *supra* note 4, at 1240. Chloe was selected as an embryo using PGD to weed out embryos carrying the cancer causing gene. Harmon, *supra* note 5, at 1.

7. *Bergero v. Univ. S. Cal.*, 2009 Cal. App. LEXIS 2835, at *4–5 (Ct. App. 2009) (“[PGD] is intended to allow parents to avoid conceiving a child that will be born with a particular genetic disorder.”); Karen Sermon et al., *Preimplantation Genetic Diagnosis*, 363 LANCET 1633, 1633 (2004).

8. See, e.g., Darshak M. Sanghavi, M.D., *Wanting Babies Like Themselves, Some Parents Choose Genetic Defects*, N.Y. TIMES, Dec. 5, 2006, at F5 (“[S]ome parents had the painful and expensive fertility procedure for the express purpose of having children with a defective gene.”).

9. See, e.g., Michael D. Lemonick, *Designer Babies*, TIME, Jan. 11, 1999, at 64. Lemonick explains:

Within a decade or two, it may be possible to screen kids almost before conception for an enormous range of attributes, such as how tall they're likely to be, what body type they will have, their hair and eye color, what sorts of illnesses they will be naturally resistant to, and even, conceivably, their IQ and personality type.

Id.

10. See Boyce Rensberger, *NIH Panel Looks at Ethics, Standards for Human Embryo Research*, WASH. POST, Feb. 7, 1994, at A3.

11. See sources cited *supra* note 6 and accompanying text.

12. E.g., Harmon, *supra* note 5, at 20.

Research relating to the science of reproduction or the attempt to alter or control man's genetic makeup has always inspired fear of misuse, raising tricky ethical quandaries and religious fervor.¹³ The PGD technique is no different; it evokes ethical concerns ranging from the treatment of embryos as commodities, to its disquieting similarity to eugenic abortion.¹⁴ Like stem cell and cloning research, many of the fears about the use of PGD actually pertain to what the technology might be able to do in the future rather than to its current use.¹⁵ There is little outcry about the more common use of PGD to screen out fatal or crippling genetic diseases, disabilities, or aneuploidy.¹⁶ It seems few people object to preventing the birth of a child whose quality of life will be drastically impaired by a genetic disease.¹⁷

The real public outcry arises when a prospective parent considers using PGD to "design" a baby for reasons other than serious health issues.¹⁸ The most common of these uses include selecting an embryo with a genetic match to a sick sibling so that, at birth, the baby might provide stem cells or bone marrow to that sibling, or to select the gender of the child.¹⁹ Yet, despite the moral distaste or religious objections, neither of these uses of PGD will inherently result in physical harm to the unborn child.²⁰ Instead, the ethical quandaries arising from the use of PGD stem from the possible negative societal consequences, rather than because of any danger to the individual child.²¹

13. Scientists, specialists in the field, and other commentators question the moral ambiguity of using PGD to create a new child for the sole purpose of saving another existing child. Boyle & Savulescu, *supra* note 4, at 1241. In the realm of fiction, there is a plethora of cautionary tales about dystopias created through a misuse of genetic technology. See, e.g., ALDOUS HUXLEY, *BRAVE NEW WORLD* xviii (1946) (using literary fiction to caution the world about the danger of scientifically altered human beings); *GATTACA* (Columbia Pictures 1997) (painting a grim picture of a new class system resulting from gene selection technology).

14. John A. Robertson, *Extending Preimplantation Genetic Diagnosis: The Ethical Debate: Ethical Issues in New Uses of Preimplantation Genetic Diagnosis*, 18 *HUMAN REPROD.* 465, 466 (2003); see, e.g., Rensberger, *supra* note 10, at A3 (illustrating the new moral and ethical dilemmas arising from embryonic research and technology).

15. E.g., Lemonick, *supra* note 9, at 64 (discussing the fear that "parents may someday be able to go beyond weeding out undesirable traits and start actually inserting the genes they want—perhaps even genes that have been crafted in a lab.").

16. Robertson, *supra* note 14, at 465 ("[E]xcept for sex selection of the first child, most current extensions of PGD are ethically acceptable.").

17. See *id.* at 466.

18. *Id.*

19. *Id.* at 465.

20. But see Boyle & Savulescu, *supra* note 4, at 1241–42 (describing the emotional damage to a child that could occur when parents decide to have another baby for the sole purpose of saving an existing sibling).

21. See Harmon, *supra* note 5, at 20 (describing the fear that the expense of PGD could result in "the first significant step toward a genetic class divide in which the wealthy will become more genetically pure than the poor."); Lemonick, *supra* note 9, at 66

Today, advances in gene identification technology allow doctors to use PGD to determine whether a child will carry the gene for certain types of deafness.²² Most hearing parents would, and do, use this test to avoid having a deaf child.²³ Whether a purpose of avoiding a non-life-threatening condition is an ethical use of PGD is, in itself, a contentious ethical issue.²⁴ Yet, the real moral uncertainty arises when a Deaf parent uses PGD to choose to implant an embryo with the gene for deafness in order to intentionally give birth to a so-called “disabled” child.²⁵ This Note will argue that denying parents the right to use PGD to implant an embryo based on a desire for specific traits—particularly those commonly considered to be disabilities, such as deafness—is a violation of the Constitutional right to privacy, the right to refuse medical treatment, and the Fourteenth Amendment due process protection of property. The rights of parents and children and the limits of reproductive technology need to be enumerated in the United States legal system, lest these rights be trampled by individuals or lesser governments.

I. THE SCIENCE OF DESIGNING BABIES

PGD is currently inseparable from the increasingly popular IVF treatment.²⁶ IVF is a procedure by which female ova are removed from the womb through a process called ovarian hyperstimulation.²⁷ The ova are then fertilized with sperm in a test tube in a lab before being placed into the womb.²⁸ The procedure is both painful and

(foreseeing overuse of gender selection PGD technology and the resulting gender imbalance in countries that prize males over females); Robertson, *supra* note 14, at 469 (discussing the possibility of an expansion of sexism and gender discrimination due to PGD gender selection).

22. Steve Connor, *Deaf Parents Could Choose to Have Deaf Children*, INDEPENDENT, Sept. 21, 2000, <http://www.independent.co.uk/news/science/deaf-parents-could-choose-to-have-deaf-children-699096.html>. There are several types of inborn deafness; the type selected by PGD is a nonsyndromic form of deafness caused by a GJB2 or GJB6 gene mutation. Gheona Altarescu et al., *Preimplantation Genetic Diagnosis (PGD) for Nonsyndromic Deafness by Polar Body and Blastomere Biopsy*, 26 J. ASSIST. REPROD. GENET. 391, 392 (2009), available at http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2758950/pdf/10815_2009_Article_9335.pdf.

23. See Sanghavi, *supra* note 8, at F5.

24. See Harmon, *supra* note 5, at 1 (questioning the use of PGD to select for non-fatal diseases or conditions with uncertain effects, such as selecting an embryo to avoid the probability rather than an absolute certainty that a child will get cancer in later life); Lemonick, *supra* note 9, at 66 (illustrating the danger of overselecting or “designing” children).

25. See Sanghavi, *supra* note 8, at F5.

26. *Preimplantation Genetic Diagnosis (PGD)*, THE FERTILITY INSTITUTES, <http://www.fertility-docs.com/PGD.phtml> (last visited Nov. 6, 2012).

27. Sermon et al., *supra* note 7, at 1633.

28. Sanghavi, *supra* note 8, at F5.

expensive, resulting in costs that can reach tens of thousands of dollars.²⁹ The first successful birth from IVF occurred in England on July 26, 1978.³⁰ Although originally greeted with moral outrage and hesitation, the IVF procedure has since rapidly increased in popularity due to its use in countering infertility and aiding couples at risk of passing on genetic diseases.³¹ In 2009, for example, IVF treatment led to 45,870 live births and 60,190 infants in the United States alone.³²

Once the embryos are created in vitro, the doctor will use PGD, an “early form of prenatal diagnosis, in which embryos . . . are analysed for well-defined genetic defects.”³³ After the embryos’ genetic makeup has been analyzed, those embryos with the desired genetic makeup, or without a genetic defect, are then placed into the womb.³⁴ The initial goal of PGD is “to give prospective parents the ‘opportunity’ of giving birth to a healthy child.”³⁵ Doctors in London performed the first successful PGD procedure on humans in 1989.³⁶ The technology has been improved and refined over the past twenty years with doctors using PGD to screen for more and more types of genes.³⁷ Currently, PGD technology has the ability to determine the presence of one hundred different genetic conditions in all, including gender, hair and eye color, sex linked diseases, late onset diseases such as genetically linked cancers and Alzheimer’s Disease, tissue type for stem cell matching, dwarfism, and certain types of deafness.³⁸

29. Harmon, *supra* note 5, at 20.

30. The first babies born using IVF were nicknamed “test tube babies” and the procedure was titled in vitro, which literally means “in glass” due to the manner of their unique conception. Myra MacPherson, *The Doctor and the ‘Test Tube Baby,’* WASH. POST, Oct. 12, 1978, at D1.

31. See Lemonick, *supra* note 9, at 64, 66 (“‘When the world first learned about IVF two decades ago’ . . . ‘it was horrifying to most people, and most said that they wouldn’t use it even if they were infertile. But growing demand makes it socially acceptable’” (quoting biologist Lee Silver)); Sermon et al., *supra* note at 7, 1633.

32. *2009 Assisted Reproductive Technology Report*, CTRS. FOR DISEASE CONTROL & PREVENTION, <http://www.cdc.gov/ART/ART2009/> (last visited Nov. 6, 2012).

33. Sermon et al., *supra* note 7, at 1633; Boyle & Savulescu, *supra* note 4, at 1240 (PGD is the “genetic analysis of artificially fertilised embryos to select an embryo with a desired genotype before it is implanted.”). The actual process involves a biopsy of one to two cells in a six to eight cell embryo or the first and second polar bodies of an oocyte. The genetic material from these cells is then analyzed for the desired traits. Altarescu et al., *supra* note 22, at 391–92.

34. Sermon et al., *supra* note 7, at 1633.

35. Bartha M. Knoppers & Rosario M. Isasi, *Regulatory Approaches to Reproductive Genetic Testing*, 19 HUM. REPROD. 2695, 2696 (2004).

36. Tarkan, *supra* note 2, at F6.

37. *Id.*

38. TANIA M. SIMONCELLI, INT’L CTR. FOR TECH. ASSESSMENT, PRE-IMPLANTATION GENETIC DIAGNOSIS: ETHICAL GUIDELINES FOR RESPONSIBLE REGULATION 3–6 (2003); Sangavi *supra* note 8, at F5; Tarkan, *supra* note 2, at F6.

Without PGD and other *in vitro* processes, parents at risk of passing on genetic diseases to their unborn offspring would have to rely on Prenatal Diagnosis (PND).³⁹ PND involves testing an already developing fetus in the womb.⁴⁰ If the fetus is found to have a genetic condition, the parents are left with two terrible options: “to either . . . terminate the pregnancy . . . or continue with the pregnancy and prepare for the future knowing that the child will be born with a genetic condition.”⁴¹ For potential parents who might otherwise suffer the pain of losing a child to a severe and often fatal genetic disease or undergoing the psychological turmoil of terminating a pregnancy, PGD is “nothing short of miraculous.”⁴²

Aside from the moral implications, the only thing preventing a greater percentage of the population from “designing” their children using PGD is the expense and the taxing physical process of IVF.⁴³ Most uses of PGD, therefore, involve prospective parents at risk for serious genetic conditions.⁴⁴ Yet, as PGD and its fellow screening techniques increase in fame, more and more couples are opting to do IVF and PGD or similar techniques, including Florescence *in situ* Hybridization (FISH), to select the gender of their child or to avoid diseases that are merely likely instead of one hundred percent certain to occur.⁴⁵ In a survey of 190 United States PGD clinics, only three percent of those clinics reported using PGD “to select an embryo for the presence of a disability.”⁴⁶

II. LEGAL RESTRICTIONS ON THE USE OF PGD

Most developed countries, particularly those with a western society influence, have enacted regulations to control the use of, or research in, reproductive technology—particularly the permissibility or extent of the use of PGD.⁴⁷ These regulatory systems are difficult to generalize because each country regulates based on their own unique legal systems and the “cultural and socio-religious beliefs which inform and shape public policy on assisted reproductive

39. See Sermon et al., *supra* note 7, at 1633.

40. Knopper & Isasi, *supra* note 35, at 2696.

41. *Id.*

42. Tarkan, *supra* note 2, at F6.

43. Robertson, *supra* note 14, at 465–66; Harmon, *supra* note 5, at 20.

44. Robertson, *supra* note 14, at 465–66; Harmon, *supra* note 5, at 20.

45. See J.C. Harper & D. Wells, *Recent Advances and Future Developments in PGD*, 19 *PRENATAL DIAGNOSIS* 1193, 1193–98 (1999); see also Harmon, *supra* note 5, at 20 (detailing a couple’s decision to utilize PGD on discovering the husband’s genetic predisposition towards colon cancer).

46. Sanghavi, *supra* note 8, at F5.

47. SIMONCELLI, *supra* note 38, at 2.

technologies and genetic testing.”⁴⁸ Certain leading countries, including Australia, Germany, Austria, and Ireland, issued a blanket prohibition on all uses of the procedure when PGD initially developed.⁴⁹ Only recently have some of these countries loosened their laws on PGD, if only slightly.⁵⁰ Neighboring countries, including France, Italy, Belgium, Greece, the Netherlands, and the United Kingdom have chosen “to limit the use of PGD to a narrow range of applications, and in some cases, . . . establish a process for considering future application of the technology.”⁵¹

The United Kingdom, for example, created the Human Fertilisation and Embryology Authority Regulatory Committee to control and oversee the research and use of reproductive technology.⁵² This committee evolved after the enactment of the Human Fertilisation and Embryology Act of 1990, a comprehensive set of rules and regulations regarding the use of IVF, PGD, and related technology.⁵³ Due to the nationalization of the health care systems in countries like Canada and Britain, restricting and dictating the permissible uses of genetic enhancement or selection is easier.⁵⁴ Because the majority of the health care system in the United States is not managed by the government, there will always be “people with enough money . . . to pay for what they want.”⁵⁵

A. Regulation of PGD in the United States

The United States has no regulation or oversight control over much of the fertility industry, particularly the private use of PGD.⁵⁶ Decisions regarding which embryos may be implanted and which diseases a doctor may screen for are left almost entirely to a doctor’s discretion.⁵⁷ The United States government seems to be hesitant to

48. Knopper & Isasi, *supra* note 35, at 2695.

49. SIMONCELLI, *supra* note 38, at 2.

50. For example, Germany passed a law in July 2011 creating an exception to the Embryo Protection Act 1990, which banned PGD completely. Nishat Hyder, *Germany Allows PGD for Life-Threatening Genetic Defects*, BIONEWS (July 11, 2011), http://www.bionews.org.uk/page_101402.asp. The exception only narrowly passed in the legislature and still allows PGD only if parents have a predisposition to a serious genetic illness, whereupon the parents must still undergo counseling and be approved by an ethics panel. *Id.*

51. SIMONCELLI, *supra* note 38, at 2.

52. Human Fertilisation and Embryology Act, 1990, c. 37, §§ 5, 8 (Eng.).

53. Knoppers & Isasi, *supra* note 35, at 2700.

54. Lemonick, *supra* note 9, at 66.

55. *Id.*

56. SIMONCELLI, *supra* note 38, at 2.

57. *See also, e.g.*, Harmon, *supra* note 5, at 20 (discussing the expense and currently limited popularity of PGD).

enact restricting legislation.⁵⁸ This is perhaps because of issues with the status of embryos.⁵⁹ Another possibility is that because current use of PGD is rare, the inevitably contentious debate would seem to be a waste of time.⁶⁰ This means that, currently, parents can choose to implant an embryo that they know possesses the genetic mutation causing nonsyndromic deafness.⁶¹

The danger is that without any federal enumerated law in the United States, the individual states could step up to fill the gap, choosing to follow a similarly restrictive legislative path as countries like the United Kingdom.⁶² Clause 14 of the United Kingdom's Human Fertilisation and Embryology Bill of 2007–2008 prohibits preferring embryos at risk of developing “serious physical or mental disability” or “serious illness” to embryos where there is no such risk.⁶³ Although not specifically enumerated in the bill, in the Official Explanatory Notes and during proceedings in the House of Lords, deafness has been specified as one of the prohibited selected-for disabilities in the Act.⁶⁴ If the views of the majority in the United States are any indication, state law, particularly in conservative states, could become more restrictive on permissive uses of PGD and how much control a parent has over their embryos, particularly banning the selection of embryos with a gene for deafness.⁶⁵

The closest the United States government has come to regulating the use of PGD and similar treatments is in its regulation of federal funding for embryonic research and experimentation.⁶⁶ The National Institutes of Health (NIH) guidelines for funding, also called the Dickey-Wicker Amendment, bars funding for human embryonic research or experimentation “in which a human embryo or

58. SIMONCELLI, *supra* note 38, at 2.

59. *See, e.g., Doe v. Obama*, 631 F.3d 157, 160–61 (4th Cir. 2011) (analyzing the difficult concept of what status an embryo holds in our society for the purposes of legal rights).

60. *See* SIMONCELLI, *supra* note 38, at 2–4.

61. *See also id.* at 2 (“[A] virtually unregulated fertility industry has been left to offer any and all available PGD applications to its clients.”).

62. Knoppers & Isasi, *supra* note 35, at 2695, 2698.

63. Human Fertilisation and Embryology Bill, 2007–08, H.L. Bill [6] cl. 14 (U.K.).

64. Ailsa Stevens, *Debating Deafness and Embryo Selection: Are We Undermining Reproductive Confidence in the Deaf Community?*, BIONEWS (Apr. 21, 2008), http://www.bionews.org.uk/page_37988.asp.

65. *See also, e.g., Marie Arana-Ward, As Technology Advances, a Bitter Debate Divides the Deaf*, WASH. POST, May 11, 1997, at A1 (citing the conflict between the Deaf community's views on deafness and those of the hearing world); Harmon, *supra* note 5, at 20 (citing the distaste of PGD felt by anti-abortion groups and those who support embryo rights); Lemonick, *supra* note 9, at 64 (discussing the negative views most of the public feel towards genetic engineering).

66. Consolidated Appropriations Act of 2010, Pub. L. No. 111-117, §509, 123 Stat 3034, 3280–81 (2009); *see* *Sherley v. Sebelius*, 776 F. Supp. 2d 1 (D.D.C. 2011).

embryos are destroyed, discarded, or knowingly subjected to risk of injury or death.”⁶⁷

At first glance, the effect of this amendment on the use of PGD seems minimal. After all, the purpose of PGD seems to match up with the permitted experimentation in the Dickey-Wicker Amendment: to “meet the health needs of the fetus or enhance the probability of its survival to viability” by selecting healthy embryos.⁶⁸ Despite this argument, the court in *Sherley v. Sebelius* used PGD as an example of a type of research that would be prohibited from receiving federal funding.⁶⁹ The court reasoned that although the purpose of PGD is not to destroy a human embryo, there is a risk of injury or death which springs naturally from such treatment.⁷⁰ Part of the logic behind this conclusion may be based on the likely termination of the embryos not selected using PGD because they contain a genetic defect.⁷¹ Unlike couples who use IVF for infertility and who may store several embryos for a later, additional child,⁷² parents who use PGD to avoid a genetic defect or disease are unlikely to request storage for affected embryos.⁷³

The conclusion reached in *Sherley* does not affect the ability of parents or researchers to utilize PGD;⁷⁴ it just forbids the use of federal funds to do so.⁷⁵ The harm resulting from *Sherley* and the Dickey-Wicker Amendment stems from the implied government disapproval of embryonic research and treatments, including PGD. This disapproval could be used by states to limit not just government funding, but the actual application of PGD. On a positive front, President Obama recently expanded the approved types of embryonic research.⁷⁶

67. Consolidated Appropriations Act § 509(2).

68. 42 U.S.C. § 289g (2006).

69. *Sherley*, 776 F. Supp. 2d at 18.

70. *Id.*

71. See Rebecca Knox, Note, *Preimplantation Genetic Diagnosis: Disease Control or Child Objectification?*, 22 ST. LOUIS U. PUB. L. REV. 435, 441 (2003).

72. Helene S. Shapo, *Assisted Reproduction and the Law: Disharmony on a Divisive Social Issue*, 100 NW. U. L. REV. 465, 465 (2006).

73. See also Knox, *supra* note 71, at 436 (stating that only those embryos determined to be unaffected by the genetic disease or defect in question are to be used and implanted).

74. *Sherley*, 776 F. Supp. 2d at 19 (holding only that the Dickey-Wicker Amendment forbids the federal funding of PGD research without mentioning the legality of the research itself).

75. *Id.* at 18.

76. President Obama ordered:

Research involving human embryonic stem cells and human non-embryonic stem cells has the potential to lead to better understanding and treatment of many disabling diseases and conditions. Advances over the past decade in this promising scientific field have been encouraging, leading to broad agreement in the scientific community that the research should be supported by Federal funds.

Exec. Order No. 13,505, 3 C.F.R. 229 (2009).

Although not directly applicable to PGD, this marks a step towards further exploration and openness to new treatments.⁷⁷

B. Wrongful Life

Under New York law “a child does not have a fundamental right to be born free of genetic defects, regardless of how the child was conceived.”⁷⁸ This holding has been applied most frequently to determine “wrongful life” suits.⁷⁹ Wrongful life refers to a case in which a parent is suing the doctor or hospital for negligent use of PGD or for the failure of PGD to prevent a genetic disease.⁸⁰ For example, in *Paretta v. Medical Offices for Human Reproduction*, the plaintiff, the parents of a child born with cystic fibrosis, sued the doctors who had “manipulated the embryonic material [that] was implanted” into her womb through IVF and PGD.⁸¹ The plaintiff’s argument was that the doctor defendants were “negligent in failing to test the egg, sperm and embryo before implantation,” specifically, failing to test the donor egg using PGD or to screen the plaintiff father for a genetic risk of cystic fibrosis.⁸² The plaintiffs also argued that the doctors failed to obtain the “proper informed consent . . . about the potential for cystic fibrosis.”⁸³ Despite these claims, the court held for the defendant doctors under the theory that the doctor’s responsibility did not extend so far as to prevent a child from being born with any one of a myriad of disabilities.⁸⁴

Similarly, the court in *Paretta* also refused to allow the plaintiffs to recover for emotional distress caused by the birth of a child with a genetic disease.⁸⁵ On this matter, the court does not differentiate between a birth via IVF and PGD and a natural birth: “[t]his Court cannot treat the emotional distress and psychic pain suffered by parents who give birth to a sick child after in-vitro fertilization any differently from that sustained by other parents.”⁸⁶ The implications of *Paretta* on the use of PGD to purposely select for deafness are clear. If a child has no fundamental right to be born without a

77. *Id.*

78. *Paretta v. Med. Offices for Human Reprod.*, 760 N.Y.S.2d 639, 644 (Sup. Ct. 2003).

79. *See, e.g.*, *D. D. v. Idant Labs.*, 374 F. App’x 319, 324 (3d Cir. 2010); *Andrews v. Keltz*, 838 N.Y.S.2d 363, 368 (Sup. Ct. 2007).

80. Kate Wevers, Note, *Prenatal Torts and Pre-Implantation Genetic Diagnosis*, 24 HARV. J.L. & TECH. 257, 265 (2010).

81. *Paretta*, 760 N.Y.S.2d at 643.

82. *Id.*

83. *Id.*

84. *Id.* at 645–46.

85. *Id.* at 645.

86. *Id.*

disability,⁸⁷ parents and their doctor are not violating any inherent right of a child by using PGD to choose deafness prior to birth. By treating PGD and natural birth equally,⁸⁸ the court is eliminating the difference between an embryo with the gene for deafness that was naturally implanted, and the embryo with the gene for deafness that was chosen purposely for implantation out of other healthy embryos which would have had an equal chance of being born otherwise.

III. RIGHT TO PRIVACY

Similar to stem cell research debates, much of the argument about legal uses of PGD and other fertility treatments result from the need to interpret the Constitution to deal with issues that were well beyond the scope of the Framers' imaginations. Whether a parent could choose their child's genetic makeup was not even considered an issue existing outside of science fiction until very recently.⁸⁹ For the purposes of PGD and the rights of parents, looking to the right to privacy as enumerated in case law spanning from the early twentieth century to abortion law is more pertinent.⁹⁰

The Supreme Court solidified the right to privacy in the 1973 abortion case, *Roe v. Wade*.⁹¹ *Roe* is famous for its stance on abortion rights, holding that a Texas law which criminalized abortion at any stage, except to preserve the life of the mother, was unconstitutional.⁹² Yet, the ramifications for the Constitutional right of privacy spread far beyond the right to an abortion.⁹³ The Court held that although "[t]he Constitution does not explicitly mention any right of privacy . . . the Court has recognized that a right of personal privacy, or a guarantee of certain areas or zones of privacy, does exist under the Constitution."⁹⁴ The liberties protected under the right of privacy include: the right to procreation, upheld in *Skinner v. Oklahoma*,⁹⁵ the right to contraception, guaranteed in *Eisenstadt v. Baird*,⁹⁶ and the right to "child rearing and education" from *Pierce v. Society of Sisters*.⁹⁷ The Court draws this right from the First

87. *Paretta*, N.Y.S.2d at 644.

88. *Id.* at 646.

89. Sanghavi, *supra* note 8, at F5.

90. *See, e.g.*, *Roe v. Wade*, 410 U.S. 113, 153 (1973); *Pierce v. Soc'y of Sisters*, 268 U.S. 510, 530 (1925); *Meyer v. Nebraska*, 262 U.S. 390, 390 (1923).

91. *Roe*, 410 U.S. at 114.

92. *Id.*

93. *Id.* at 152–53.

94. *Id.* at 152 (citation omitted).

95. *Id.* (citing *Skinner v. Oklahoma*, 316 U.S. 535, 541–42 (1942)).

96. *Id.* (citing *Eisenstadt v. Baird*, 405 U.S. 438, 453–54 (1972)).

97. *Roe*, 410 U.S. at 153 (citing *Pierce v. Soc'y of Sisters*, 268 U.S. 510, 535 (1925)).

Amendment,⁹⁸ the Fourth and Fifth Amendments,⁹⁹ the penumbras of the Bill of Rights,¹⁰⁰ the Ninth Amendment,¹⁰¹ and the “concept of liberty guaranteed by the first section of the Fourteenth Amendment.”¹⁰² The result in *Roe* being that a mother has the Constitutional right to terminate a pregnancy during the first trimester.¹⁰³

The right to select which embryo to implant in one’s own womb must be implied from the right to decide whether or not to *have* an embryo in one’s womb: i.e., whether to abort a fetus. If the State has no right to demand that a woman abort a disabled child,¹⁰⁴ the State should have no right to interfere with a woman choosing to initiate a pregnancy with the knowledge and intent that the child will be born with a disorder.¹⁰⁵

Meyer v. Nebraska enumerates the right to establish a home and to raise children.¹⁰⁶ The practice at issue in *Meyer* was merely whether a parent has a right to educate their children as they see fit: namely, whether a law banning the teaching of a foreign language in schools was unconstitutional.¹⁰⁷ The Court held that:

“[L]iberty” denotes[] not merely freedom from bodily restraint, but also the right of the individual . . . to marry, establish a home, and bring up children, to worship God according to the dictates of his own conscience, and generally to enjoy those privileges long recognized at common law as essential to the orderly pursuit of happiness by free men.¹⁰⁸

Similarly, in *Pierce v. Society of the Sisters*, two private schools sued the Governor of Oregon to invalidate the Compulsory Education Act of 1922 which required all parents or guardians to enroll their children in public schools instead of private school.¹⁰⁹ The Court extended the right to privacy to include the right to raise children as a parent or guardian sees fit.¹¹⁰

98. *Id.* (citing *Stanley v. Georgia*, 394 U.S. 557, 564 (1969)).

99. *Id.* (citing *Terry v. Ohio*, 392 U.S. 1, 8–9 (1968); *Katz v. United States*, 389 U.S. 347, 350 (1967); *Boyd v. United States*, 116 U.S. 616 (1886)).

100. *Id.* at 152 (citing *Griswold v. Connecticut*, 381 U.S. 479, 484–85 (1965)).

101. *Id.* at 129 (citing *Griswold*, 381 U.S. at 486).

102. *Id.* (citing *Meyer v. Nebraska*, 262 U.S. 390, 399 (1923)).

103. *See Roe*, 410 U.S. at 153.

104. *See id.*

105. Connor, *supra* note 22.

106. *Meyer*, 262 U.S. at 399.

107. *Id.*

108. *Id.*

109. *Pierce v. Soc’y of Sisters*, 268 U.S. 510, 530 (1925).

110. *Id.* at 532.

Government control over which embryo a parent may choose to implant “unreasonably interferes with the liberty of parents and guardians to direct the upbringing . . . of children under their control.”¹¹¹ If a deaf parent chooses to have a deaf child, that is their choice and right as a parent, making a decision that they feel is best for their future child.¹¹² The right to choose whether to have children, how many children to have, and how to raise those children are all within the rights of the parent or guardian.¹¹³ Why then would the right to determine which embryos a parent may or may not choose to raise fall under the State’s purview, rather than the rights of the parents?

States are not allowed to interfere with the right to privacy “under the guise of protecting the public interest, by legislative action which is arbitrary or without reasonable relation to some purpose within the competency of the state to effect.”¹¹⁴ States do have the compelling state interest in protecting a child’s health and well-being.¹¹⁵ Child abuse, for example, is a classic instance when the state may interfere in a person’s parenting.¹¹⁶ Selecting a naturally occurring embryo for certain genetic makeup for a child does not fall within the parameters of child abuse.¹¹⁷ The simplest defense being that an embryo is not a child.¹¹⁸

According to *Roe v. Wade*, “the word ‘person,’ as used in the Fourteenth Amendment, does not include the unborn.”¹¹⁹ Therefore, an embryo has no rights under the Constitution.¹²⁰ Instead, it is the parents who have the right to determine what happens to those embryos; they can choose to implant them, dispose of them, sell them, donate them, or store them.¹²¹ Current debates about embryo disposal

111. *Id.* at 534–35.

112. *See also id.* at 535 (“The child is not the mere creature of the state; those who nurture him and direct his destiny have the right, coupled with the high duty, to recognize and prepare him for additional obligations.”).

113. *See id.*

114. *Meyer v. Nebraska*, 262 U.S. 390, 400 (1923); *see Pierce*, 268 U.S. at 535 (“[R]ights guaranteed by the Constitution may not be abridged by legislation which has no reasonable relation to some purpose within the competency of the state.”).

115. *See Washington v. Glucksberg*, 521 U.S. 702, 726 (1997); *Roe v. Wade*, 410 U.S. 113, 158 (1973).

116. 18 U.S.C. § 2251 (2006) (prohibiting sexual abuse or exploitation of children); 42 U.S.C. § 5106a (2006) (dictating when the federal government may make a monetary grant to a State for programs to prevent or investigate incidents of child abuse and neglect).

117. *See, e.g., Meyer*, 262 U.S. at 399 (upholding the right of parents to raise their child as they see fit).

118. *Roe*, 410 U.S. at 158.

119. *Id.*

120. *Id.*

121. *Doe v. Obama*, 631 F.3d 157, 162 (4th Cir. 2011).

and ownership have been relegated to the realm of property law rather than human rights.¹²² In determining that there is no consideration for the health of a first trimester fetus,¹²³ abortion case law has therefore determined that there is no consideration for the lesser status of an embryo.¹²⁴ The issue is that these embryos, unlike those in abortion cases, *are* intended to develop into babies with rights who will suffer the consequences of any misuse or unethical treatment.

A. *Compelling State Interest: The Child's Best Interests*

Because an embryo chosen by PGD is intended to be carried to term and born to the rights under the Constitution, the issue of whether a parent may purposely choose to “disable” their child may stretch beyond ordinary abortion law. The issue would then turn on whether the state has a compelling interest to protect the health of a future child.¹²⁵

The intentional selection of an embryo because it possesses the gene for a disability like deafness has been met with disgust and moral outrage.¹²⁶ Most people view purposely choosing a deaf child as a “very real conflict between parental desires and the welfare of the child.”¹²⁷ An online magazine called this practice akin to “the deliberate crippling of children.”¹²⁸ Yet, it is not child abuse to raise a child in the Deaf culture.¹²⁹ Nor is it child abuse to deny a deaf child a cochlear implant or hearing aids, both of which would result in, essentially, “creating” a deaf child.¹³⁰ To understand why a parent would purposely choose to inflict a condition that is normally considered a disability on a child, one must first understand the Deaf culture.

122. *Roe*, 410 U.S. at 163.

123. *Id.*

124. *Id.* at 158.

125. *See, e.g., id.* at 114 (citing the compelling state interest of preserving human life and health).

126. Connor, *supra* note 22 (“[W]ide-scale introduction of pre-implantation genetic diagnosis (PGD) will raise the prospect of disadvantaged babies being born who will be deliberately chosen to be disabled for the benefit of their parents.”).

127. *Id.* (quoting Professor Allan Templeton).

128. Sanghavi, *supra* note 8, at F5 (quoting *Slate Magazine*).

129. The right to raise a child in the Deaf culture is a choice that falls clearly within the right to raise one’s children as one sees fit as established by *Pierce*. *See, e.g., Pierce v. Soc’y of Sisters*, 268 U.S. 510, 534–35 (1925).

130. *See, e.g., Cruzan v. Dir., Mo. Dept. of Health*, 497 U.S. 261, 268 (1990) (citing the right to refuse unwanted medical treatment).

B. *Understanding Deaf Culture*

Deaf with a capital “D” describes the culture of hearing impaired people who communicate with sign language.¹³¹ This culture is defined by its own language, history, and the “shared sense of isolation from the hearing world.”¹³² In the United States, Deaf people generally communicate using American Sign Language (ASL) which uses visual cues, such as “hand shape, position and movement, plus posture, [and] facial expressions” in order to communicate.¹³³ Though many deaf people learn to speak and to read lips—particularly those with only slight hearing loss or those who lost their hearing at an advanced age—Deaf people view sign language as their “native” language, which they utilize to create their own poetry, art, and expression.¹³⁴

Several members of the Deaf community, along with certain sociologists, psychologists, and doctors, would argue that it is in the child’s best interest to allow deaf parents to choose to have deaf children.¹³⁵ The arguments used by the Supreme Court to justify their holding in *Roe v. Wade* are the same used to justify the right of Deaf parents to choose to implant an embryo carrying the gene for deafness.¹³⁶ For example, *Roe* justifies its holding by referring to the psychological and social damage involved in raising an unwanted child:

The detriment that the State would impose upon the pregnant woman by denying this choice altogether is apparent Maternity, or additional offspring, may force upon the woman a distressful life and future. Psychological harm may be imminent. Mental and physical health may be taxed by child care. There is also the distress, for all concerned, associated with the unwanted child, and there is the problem of bringing a child into a family already unable, psychologically and otherwise, to care for it.¹³⁷

This reasoning mirrors the distress that could occur in families where the child is excluded from his parent’s culture because of his genetic makeup.¹³⁸ Deaf parents, particularly those imbued in the

131. Arana-Ward, *supra* note 65, at A1.

132. Carina Dennis, *Genetics: Deaf by Design*, CTR. FOR GENETICS & SOC’Y (Oct. 20, 2004), <http://www.geneticsandsociety.org/article.php?id=1516>.

133. *Id.*

134. *Id.*

135. Connor, *supra* note 22.

136. *See Roe v. Wade*, 410 U.S. 113, 170–71 (1973).

137. *Id.*

138. Connor, *supra* note 22.

Deaf culture, believe that a hearing child would be alienated from his home environment.¹³⁹ Such alienation could result in harmful effects to both the child and his parents.¹⁴⁰

Members and supporters of the Deaf community argue that deafness is so mild a disability that being deaf is “in the long-term interests of the child . . . so that they will share the same experiences as their affected parents.”¹⁴¹ A hearing person, even family members of deaf people, are often unable to breach the barriers between them and their deaf relative despite knowing sign language.¹⁴² A deaf child born into a deaf family would share his or her parents’ culture, language, and their “birthright of silence”—connections that a hearing child could never share.¹⁴³

A fitting comparison often made by Deaf activists is that “[t]rying to ‘fix’ a deaf child . . . is like trying to fix someone because he or she speaks Japanese.”¹⁴⁴ Whether those outside the Deaf culture think it is a disadvantage or not, the right to teach a child a foreign language is inherent in the right to raise one’s children as one sees fit that is included in the right to privacy.¹⁴⁵ Culturally Deaf people do not believe they suffer from a disability.¹⁴⁶ They view themselves as a separate community, and many parents want to share that community with their children, just as other parents do their religious or ethnic backgrounds.¹⁴⁷ The State has no compelling state interest in denying parents the right to share their cultural background, traditions, and language with their child.

IV. RIGHT TO REFUSE MEDICAL TREATMENT

The Due Process Clause of the Fourteenth Amendment protects a variety of rights under the right to privacy as discussed in Part II of this Note.¹⁴⁸ The protection guaranteed under the Due Process Clause, however, extends to protect a vast number of individual liberties¹⁴⁹ from “certain government actions regardless of the fairness of the

139. *Id.*

140. *Id.*

141. *Id.*

142. Dennis, *supra* note 132.

143. Arana-Ward, *supra* note 65, at A20.

144. *Id.*

145. *Meyer v. Nebraska*, 262 U.S. 390, 398 (1923).

146. Arana-Ward, *supra* note 65, at A20.

147. *Id.*; see Natalie Angier, *Baby in a Box*, N.Y. TIMES, May 16, 1999, at SM86 (expressing the generally held truth that all parents want to see something of themselves in their children).

148. See *supra* Part II.

149. *Reno v. Flores*, 507 U.S. 292, 301–02 (1993).

procedures used to implement them.”¹⁵⁰ One of these protected liberties is the right to refuse lifesaving medical treatment.¹⁵¹ In *Cruzan v. Director, Missouri Department of Health*, the parents of an incompetent woman in a permanent vegetative state sought permission from the courts for the right to withdraw life-sustaining treatment from their daughter.¹⁵² While the Court held that the appellant parents could not withdraw treatment in this case, they did recognize the Constitutional right of competent persons to refuse any medical treatment, even to the extent of costing them their lives.¹⁵³

A. *The Right to Refuse Medical Treatment and PGD*

This right to refuse medical treatment extends to parents choosing to exclude their children from medical treatment under the right to raise one’s children as one sees fit.¹⁵⁴ This right only extends to non-life-sustaining treatments unless the parent refuses under the Constitutional right to freedom of religion.¹⁵⁵ Under this standard, it is likely that a court could refuse to uphold a parent’s choice to implant an embryo that suffered from a severe or fatal genetic disease. Nonsyndromic deafness, however, is not a fatal condition.¹⁵⁶ Many would further argue that deafness is not even a severe condition since a deaf child could live almost as ordinary a life as a hearing child.¹⁵⁷ If parents using IVF have the right to select healthy embryos to implant in the womb, the Deaf and other mildly disabled parents should expect the same right to select embryos carrying their own genetic disorder.¹⁵⁸

In many states the doctor who implements PGD treatment is required by law to “consider, prior to treatment, the welfare of any child that might be born.”¹⁵⁹ Many doctors, therefore, refuse to implant embryos affected by the gene for deafness or other slight disabilities, like dwarfism, despite the parent’s wishes.¹⁶⁰ The idea of

150. *Collins v. City of Harker Heights*, 503 U.S. 115, 125 (1992) (quoting *Daniels v. Williams*, 474 U.S. 327, 331 (1986)) (internal quotation marks omitted).

151. *See Cruzan v. Dir., Mo. Dept. of Health*, 497 U.S. 261, 279 (1990).

152. *Id.* at 265.

153. *Id.* at 279.

154. Emily Catalano, Comment, *Healing or Homicide?: When Parents Refuse Medical Treatment for Their Children on Religious Grounds*, 18 *BUFF. J. GENDER L. & SOC. POL’Y* 157, 169 (2009–2010).

155. *Id.* at 162.

156. *See Altarescu et al.*, *supra* note 22, at 394.

157. Arana-Ward, *supra* note 65, at A20.

158. Connor, *supra* note 22.

159. *Id.*

160. *See id.*; Solveig Magnus Reindal, *Disability, Gene Therapy and Eugenics—A Challenge to John Harris*, 26 *J. MED. ETHICS* 89, 90 (2000).

creating a child with a disability seems likely to inspire fear of future regret and lawsuits.¹⁶¹ Many doctors have suffered in the civil courts because their use of PGD to choose healthy children failed.¹⁶² This, at least, is a problem that is easily solved. For a doctor to protect himself or herself from liability in the absence of negligence, all that is necessary is for the doctor to give the patient “informed consent”¹⁶³ and to fulfill the doctor’s “fiduciary duty to disclose facts material to the patient’s consent.”¹⁶⁴ Yet, by requiring the doctor to take special, extra precautions when implanting an embryo, these state laws substantially affect a parent’s right to privacy and the right to refuse medical treatment and are therefore unconstitutional.¹⁶⁵

A legally competent adult also has the right, “in the exercise of control over his own body, to determine whether or not to submit to lawful medical treatment.”¹⁶⁶ This rule implies the right of a mother to have her embryos tested for genetic disabilities and then refuse to exclude the embryos with the disability. The result of a doctor choosing to go ahead with implanting only the embryos without the disabilities violates the right of the mother to choose whether to submit to lawful medical treatment.¹⁶⁷ Furthermore, certain states have held it against public policy to enforce prior decisions in the “highly personal area of reproductive choice” if one of the parents changes his or her mind.¹⁶⁸ The government has enumerated the right to control one’s own body in *Roe*, *Cruzan*, and *Moore*;¹⁶⁹ there is no more personal decision regarding one’s body than whether to bear a certain child.

B. Cochlear Implants

Most Deaf people take advantage of the right to refuse medical treatment by refusing to make use of the recent technological breakthrough in hearing repair: the cochlear implant.¹⁷⁰ In fact, when the cochlear implant was first developed, it was met with “hostility and

161. See *Paretta v. Med. Offices for Human Reprod.*, 760 N.Y.S.2d 639, 647–48 (Sup. Ct. 2003).

162. *Id.*

163. *Cobbs v. Grant*, 502 P.2d 1, 9 (Cal. 1972).

164. *Moore v. Regents of Univ. of Cal.*, 793 P.2d 479, 483 (Cal. 1990).

165. See, e.g., *Roe v. Wade*, 410 U.S. 113, 153–55, 162–65 (1973) (holding that any obstacles created by a state that substantially interfere with the right to an abortion—the right to privacy—are unconstitutional).

166. *Moore*, 793 P.2d at 483 (citing *Cobbs v. Grant*, 8 Cal.3d 229, 242 (Cal. 1972)) (internal quotation marks omitted).

167. See *id.*

168. *In re Marriage of Witten*, 672 N.W.2d 768, 781 (Iowa 2003).

169. See *Roe v. Wade*, 410 U.S. 113, 153–54 (1973); *Cruzan v. Dir., Mo. Dept. of Health*, 497 U.S. 261, 279 (1990); *Moore*, 793 P.2d at 483.

170. Arana-Ward, *supra* note 65, at A20.

dismay” by a majority of Deaf individuals.¹⁷¹ The cochlear implant is “a surgically implanted device used by severe to profoundly deaf individuals who receive minimal benefit from hearing aids.”¹⁷² The implants repair the damage done to the inner ear and the cochlear.¹⁷³ At the minimum, a cochlear implant can give a deaf child access to the sounds of his or her environment, such as loud crashes, alarms, and car horns.¹⁷⁴ Particularly successful cases result in a deaf child who can successfully interact in the “mainstream oral world.”¹⁷⁵

Health care providers do not have to supplement cochlear implants, and many do not supplement them or pay for the operation.¹⁷⁶ No laws require parents to implant a cochlear implant in their deaf child’s brain despite the fact that some proponents claim that it “cures” deafness.¹⁷⁷ Parents can choose to keep their child deaf under the right to raise children, as enumerated in the right to privacy¹⁷⁸ and the right to refuse medical treatment.¹⁷⁹ The difference between the choice of parents to keep their child deaf and the choice to purposely make their child deaf through PGD is a negligible distinction. No matter which road a parent takes—refusing the cochlear implant or purposely implanting an embryo with the gene for deafness—the child will grow up deaf, which, as demonstrated, is not illegal.

V. THE RIGHT TO PROPERTY

The Court in *Roe v. Wade* determined that prior to birth an embryo or fetus does not qualify as a person for the purposes of the Constitution, particularly in regards to the rights and protections guaranteed in the Fourteenth Amendment.¹⁸⁰ Embryos have neither legally protected rights nor the standing to pursue a claim.¹⁸¹

171. Robert Sparrow, *Defending Deaf Culture: The Case of Cochlear Implants*, 13 J. POL. PHIL. 135, 135 (2005).

172. *A.U. ex rel. N.U. v. Roane Cnty. Bd. of Educ.*, 501 F. Supp. 2d 1134, 1137 (E.D. Tenn. 2007) (citation omitted) (internal quotation marks omitted).

173. *Id.*

174. Arana-Ward, *supra* note 65, at A1.

175. *Id.*

176. *See A.U.*, 501 F. Supp. 2d at 1143–44.

177. *But see* Arana-Ward, *supra* note 65, at A20.

178. *See Meyer v. Nebraska*, 262 U.S. 390, 399 (1923) (enumerating the right to raise children and establish a home).

179. *Cruzan v. Dir., Mo. Dept. of Health*, 497 U.S. 261, 279 (1990) (enumerating the right to refuse unwanted lifesaving medical treatment).

180. *Roe v. Wade*, 410 U.S. 113, 153 (1973); *see also Doe v. Irvine Scientific Sales Co.*, 7 F. Supp. 2d 737, 742 (E.D. Va. 1998).

181. *Doe v. Sebelius*, 676 F. Supp. 2d 423, 429 (D. Md. 2009), *aff’d sub nom. Doe v. Obama*, 631 F.3d 157 (4th Cir. 2011).

Following this reasoning, a logical conclusion is that the embryos are merely the property of their parents until viability under *Roe*.¹⁸²

The Fourteenth Amendment of the Constitution forbids any state from making a law that deprives citizens of “life, liberty, or property, without due process of law.”¹⁸³ If a court determines that embryos are property, states may make no law depriving citizens of the right to do with their property as they see fit.¹⁸⁴ In fact, embryos have a unique standing under the law, qualifying neither as “people” nor as “property.”¹⁸⁵ Yet, for the purpose of legal disputes, courts have often found it necessary to treat embryos like property while applying an almost meaningless “special respect” for the well-being of the embryo based on its potential for human life.¹⁸⁶ Biological parents of a fertilized embryo have an ownership interest in the embryo, similar to a property interest.¹⁸⁷ In cases involving the wrongful destruction or harm of an embryo, courts will base their findings on the “economic losses” suffered by the prospective parents rather than emotional distress that might occur from the loss of a child.¹⁸⁸ Because of this legal standing, parents are free to dispose of their unused embryos as they see fit, notwithstanding any state specific regulations.¹⁸⁹ If a parent is allowed to dispose of an embryo, that parent can also choose to implant that embryo, regardless of its genetic makeup.¹⁹⁰

VI. POSSIBLE EFFECTS OF THE CURRENT POLITICAL CLIMATE ON THE USE OF PGD

Today’s major political battles relating to reproduction technology and rights are almost entirely focused on proliferating or eliminating abortion rights.¹⁹¹ PGD barely generates the occasional news

182. *See Roe*, 410 U.S. at 158. *But see* *Davis v. Davis*, 842 S.W.2d 588, 597 (Tenn. 1992).

183. U.S. CONST. amend. XIV, § 1.

184. *See id.*

185. *Davis*, 842 S.W.2d at 597; *see also In re Marriage of Dahl*, 194 P.3d 834, 836, 840–41 (Or. App. 2008) (including a couple’s fertilized embryos in the pool of marital property to be distributed upon the dissolution of the marriage).

186. *Davis*, 842 S.W.2d at 597.

187. *Id.*

188. *Doe v. Irvine Scientific Sales Co.*, 7 F. Supp. 2d 737, 743 (E.D. Va. 1998).

189. *See In re Marriage of Dahl*, 194 P.3d at 836 (holding as valid a contract signed by the parents of six frozen embryos which allowed the clinic to dispose of the embryos upon request).

190. *See id.*; Reindal, *supra* note 160, at 90.

191. *See, e.g.*, Editorial, *The ‘Personhood’ Initiative*, N.Y. TIMES, Oct. 28, 2011, at A30; Jessica Valenti, *How an Anti-Abortion Push to Redefine ‘Person’ Could Hurt Women’s Rights*, WASH. POST, Oct. 28, 2011, http://www.washingtonpost.com/opinions/how-an-anti-abortion-push-to-redefine-person-could-wind-up-hurting-women/2011/10/26/gIQAQSwGQM_story.html.

article or minor protest because many people are still unaware of the variety of options in modern reproduction.¹⁹² Ten years ago, experts predicted a rise in the use of PGD to eliminate genetic diseases, chances of late onset cancers, to choose a child's gender, and much more as the technology was refined further.¹⁹³ Yet, although IVF has gained fame and popularity,¹⁹⁴ most people are still unaware that PGD technology and the options it provides to prospective parents are more than science fiction.¹⁹⁵

Ironically, without even intending the consequences,¹⁹⁶ the anti-abortion movement stands to limit or excise the right to implement PGD screening methods.¹⁹⁷ A recent change in tactics among anti-abortion movements has resulted in a proliferation of "Personhood" laws: state laws that define a person's life and rights as beginning at conception.¹⁹⁸ In Mississippi, a ballot asked voters to decide whether life begins at conception, i.e., in the embryonic stage.¹⁹⁹ In Wisconsin, Ohio, Florida, and Colorado similar bills or ballots have been brought to the public forum.²⁰⁰ Such laws are meant to criminalize abortions and most types of emergency birth control.²⁰¹ The resulting ripple effect goes much wider than the legislators or lobbyists probably considered.²⁰²

For "Personhood" supporters, i.e., those who believe that life begins at conception, PGD is nearly, if not equally, as unacceptable as abortion.²⁰³ By giving fertilized embryos the same rights as people, abortion rights won't be the only rights affected.²⁰⁴ Stem cell research, treatment for ectopic pregnancies, PGD, and IVF would all be prohibited.²⁰⁵ IVF treatment could be determined an illegal practice

192. Harmon, *supra* note 5, at 20.

193. Connor, *supra* note 22.

194. *Assisted Reproductive Technology (ART)*, CTRS. FOR DISEASE CONTROL & PREVENTION, <http://www.cdc.gov/art/> (last updated Aug. 1, 2012).

195. Harmon, *supra* note 5, at 20.

196. Editorial, *supra* note 191.

197. *See, e.g., id.* (arguing that the debate over personhood statutes could severely limit or outlaw fertility treatments); Valenti, *supra* note 191 (discussing the negative impact a personhood statute would have on women's rights, including fertility treatment).

198. Valenti, *supra* note 191.

199. *Id.*

200. *Id.*

201. *Id.*

202. *The 'Personhood' Initiative*, *supra* note 191; *see also*, Harmon, *supra* note 5, at 20 ("P.G.D. is as unethical as abortion and perhaps more pernicious because it is psychologically less burdensome.").

203. Valenti, *supra* note 191.

204. Editorial, *supra* note 191.

205. *See* Laura Bassett, *'Personhood' Anti-Abortion Movement Gains National Momentum*, HUFFINGTON POST (Nov. 8, 2011, 3:23 PM), http://www.huffingtonpost.com/2011/11/08/personhood-abortion-bans_n_1082344.html ("You can't propose a ballot measure that encompasses more than a single subject In trying to ban abortion, ban

because more than half of those newly designated “people” would never even have the chance to be born and would face storage or disposal.²⁰⁶ The personhood bills would bridge the gap between PGD and eugenic abortion, requiring women to give birth to a child who may only live a few pain-filled months after birth due to a crippling genetic disease.²⁰⁷

Thus far, these personhood laws have been defeated in every state.²⁰⁸ Several key pro-life associations have even declined to support them.²⁰⁹ In 2011, the ACLU and Planned Parenthood preemptively filed lawsuits against the Personhood initiative in Nevada to send a message to try and halt the spread of this movement to other states.²¹⁰ Yet, as popularity for this pro-life strategy grows, the danger that such a law might pass increases.²¹¹ If passed, such a law would almost definitely be declared unconstitutional due to its direct opposition to the holding in *Roe v. Wade*.²¹² This political atmosphere makes enumeration of PGD and genetic screening rights more important than ever in order to preserve them from any collateral damage resulting from the abortion battle.

CONCLUSION

In 2002, a Deaf lesbian couple in the United States caused a stir by “designing” a deaf child.²¹³ Although the couple did not use PGD, the outrage over purposely seeking a sperm donor with a genetic history of deafness resounded internationally.²¹⁴ Yet no legal consequences arose from the birth of their deaf son.²¹⁵ While critics claim that the act of designing children “depersonalises human procreation and treats children as mere products,”²¹⁶ the search for further

treatment for ectopic pregnancies, ban stem cell research, ban IVF, these measures clearly encompass more than one subject.”) (quoting Alexa Kolbi-Molinas, an ACLU attorney working on the lawsuits challenging personhood initiatives in Nevada).

206. Editorial, *supra* note 191.

207. *See, e.g., id.* (citing the severe ramifications that a personhood law would have on all fertility and genetic screening treatments).

208. *See, e.g., id.*

209. *Id.* (pointing out that while many political leaders—both Democrats and Republicans—have supported these bills, pro-life organizations like the National Right to Life have withheld their support).

210. Bassett, *supra* note 205.

211. Editorial, *supra* note 191.

212. *Id.*

213. *Couple ‘Choose’ to Have Deaf Baby*, BBC NEWS (Apr. 8, 2002), <http://news.bbc.co.uk/2/hi/health/1916462.stm>.

214. *Id.*

215. *See id.*

216. *Deaf Designer Baby—The Issues*, BBC NEWS (Apr. 8, 2002), <http://news.bbc.co.uk/2/hi/health/1916812.stm> (quoting Julie du Plessis).

control over one's offspring does not originate with the development of PGD, as evidenced by the Deaf lesbian couple.²¹⁷

A vast majority of parents want their children to possess those genetic traits that they value most in themselves.²¹⁸ Parents want to look at their child and see something familiar—whether it be hair color, the shape of a face, race, or, in the case of certain disabled people, evidence of their own disability.²¹⁹ If Deaf people view their disability as a cultural distinction, almost a separate ethnicity, it is not unnatural for them to want to pass on that culture, that way of life, to their children. People have been exercising genetic choice over their children long before the advent of PGD in the selection of their partner simply by choosing a mate within the same religion, race, culture, or disability group.²²⁰ This freedom of choice is one of those “privileges long recognized at common law as essential to the orderly pursuit of happiness by free men.”²²¹ Why, then, should a line be drawn between a natural chance to have a disabled child and taking naturally occurring embryos and upping the odds of having a disabled child?

James Watson, co-discoverer of the DNA structure, was quoted as saying: “I don’t believe we can let the government start dictating the decisions people make about what sorts of families they’ll have.”²²² As demonstrated in the abortion rights issue and the “Personhood” movement, there has always been a struggle to determine whose right it is to control certain aspects of our bodies. Those personally affected—parents and friends—are likely to share James Watson’s views that the choice to select a certain embryo which will then be carried and raised by them is a deeply personal and private choice.²²³ Doctors and scientists often believe that the permissible uses of PGD are medical decisions that should be made by doctors qualified to know the likely outcomes of their decisions.²²⁴ And others feel that the government should step in to prevent those who can—those with money—from purposely selecting an embryo for unnecessary purposes: to select the gender of their child or to purposely cause their child to be disabled.²²⁵ Regardless of these personal views, under the

217. *Couple ‘Choose’ to Have Deaf Baby*, *supra* note 213.

218. Sanghavi, *supra* note 8, at F5.

219. *See* Angier, *supra* note 147, at SM86.

220. Sanghavi, *supra* note 8, at F5.

221. *Meyer v. Nebraska*, 262 U.S. 390, 399 (1923).

222. Lemonick, *supra* note 9, at 66.

223. *Id.*

224. *See* Knoppers & Isasi, *supra* note 35, at 2695, 2700.

225. Lemonick, *supra* note 9, at 64.

Constitution neither the government nor a woman's doctor can force her to implant an embryo that she does not wish to carry.²²⁶

This Note has explored the right to privacy, the right to refuse medical treatment, and the right to exercise control over one's property. All of these fundamental Constitutional rights support the rights of Deaf parents to use PGD to purposely implant an embryo carrying the gene for nonsyndromic deafness. Perhaps because our health care system is not as centralized as those in other countries, our government has not chosen to exercise much control over the private use of PGD.²²⁷ But, as the technology of PGD and similar techniques become more refined, less expensive, and more well-known, the government may have to step in to enumerate the rights of the parent. Without enumeration in United States federal law, movements like the "Personhood" movement and the anti-abortion movement could quickly infringe these Constitutional rights.

This Note is not necessarily arguing that a Constitutional Amendment shouldn't be made limiting the use of PGD. The purpose of this Note is not to argue the ethics or morality of using PGD to implant an embryo with the gene for deafness. Regardless of one's personal ethics or religious views, the issue discussed in this note—the issue of permissible uses of PGD—is a legal issue. Whether a disabled parent should choose to implant a child with a disability is a different question altogether. As it stands, the Constitution grants the right of the mother to control which embryos are implanted in her own womb.²²⁸ Barring an amendment to the Constitution, the United States Federal government and the State governments cannot prohibit the use of PGD to select an embryo with the gene for nonsyndromic deafness.

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226. *See supra* Part III.

227. *See supra* Part II.

228. *See supra* Part III.

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