Genetic Material Girl: Embryonic Screening, the Donor Child, and the Need for Statutory Reform

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Scientific breakthroughs have changed the lives of Americans and forced ethical debates throughout the centuries.¹ Reproductive technologies are among the most controversial of these breakthroughs.² Once again, doctors, lawmakers, and laypeople are compelled to take positions on ancient, difficult, and perhaps even unanswerable questions.³ When does life begin?⁴ What constitutes the destruction of life?⁵ Who has the right to create an embryo and in what circumstances?⁶ This time, however, there is more at stake than the creation, or destruction, of the embryo.⁷ Participation in pre-

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¹ See generally INSTITUTE OF MEDICINE: COMMITTEE ON THE SOCIAL AND ETHICAL IMPACTS OF DEVELOPMENTS IN BIOMEDICINE, SOCIETY’S CHOICES: SOCIAL AND ETHICAL DECISION MAKING IN BIOMEDICINE (Ruth E. Bulger et al. eds., 2005) (discussing the ethical implications of innovations in biotechnology); Robert Baker, The Ethics of Bioethics, in THE PENN CENTER GUIDE TO BIOETHICS 9, 9-20 (Vardit Ravitsky et al. eds., 2009) (discussing the events that compelled bioethicists to seek a uniform code of ethics).

² See David King, Why We Should Not Permit Embryos to be Selected as Tissue Donors, in BIOETHICS: AN ANTHOLOGY 158, 161 (Helga Kuhse & Peter Singer eds., 2006) (analyzing the strong emotional sentiments surrounding reproductive technology).

³ Id. at 158. King discusses the public response to the Whitaker case in which the family selected an embryo to be a tissue-matched donor for the benefit of the existing ill sibling. Id.


⁵ See Pasquale Patrizio & Dorothy Greenfeld, Ethics of Reproduction, in CLINICAL REPRODUCTIVE MEDICINE & SURGERY 147, 153 (Tommaso Falcone & William Hurd eds., 2007) (discussing the difficulty in determining the moral status of the embryo).


⁷ See Frances C. Batzer & Vardit Ravitsky, Preimplantation Genetic Diagnosis: Ethical Considerations, in THE PENN CENTER GUIDE TO BIOETHICS 339, 345 (Vardit Ravitsky et al. eds., 2009) (discussing
implantation genetic diagnosis ("PGD") with human leukocyte antigen ("HLA") matching would not only create a life, but potentially save another. The embryo created would be a definite HLA match, and, upon birth, could begin to serve as a hematopoietic stem cell transplant ("HSCT") donor for a compatible person in need, such as a sick sibling.

In the United States, there are no federal regulations that directly regulate PGD. Moreover, courts have not reformed the doctrine of parental consent in the medical context. Thus, after the birth of an HLA matched newborn, the law entitles the parents to give consent on the newborn’s behalf to any of the types of HSCT which may be necessary to preserve the life of the sick sibling. These procedures could range from immediate umbilical cord blood harvests to bone marrow harvests, and could eventually escalate to partial or full organ harvests for transplant.

This note will begin in Part I by discussing the background of the assisted reproductive technologies involved in a full PGD with HLA matching cycle. Part II parents’ weighing the burden of raising a disabled child against the use of preimplantation genetic diagnosis).

8 See id. This procedure became widely discussed after the parents of Molly Nash, a sufferer of Fanconi anemia, elected to utilize the technology to create an HLA matched embryo to serve as donor to their ailing daughter. Id. See also infra notes 48-54.

9 See Batzer & Ravitsky, supra note 7, at 345. This use is often referred to as the creation of a “savior sibling.” Id.


11 See Bryan Shartle, Comment, Proposed Legislation for Safely Regulating the Increasing Number of Living Organ and Tissue Donations by Minors, 61 LA. L. REV. 443, 448-50 (2001) (discussing national regulation of living organ and tissue donations by minors employed by courts since the 1960s).

12 See generally infra note 138 and accompanying text.

13 See King, supra note 2, at 159 (discussing donor child, Jamie Whitaker and the likelihood future procedures would be performed if the transplant failed); Committee on Bioethics, Policy Statement—Children as Hematopoietic Stem Cell Donors, 125 PEDIATRICS 392, 400 (2010), available at http://aappolicy.aappublications.org/cgi/reprint/pediatrics;125/2/392.pdf [hereinafter Policy Statement] (introducing the possible uses of hematopoietic stem cell transplants); infra note 59 and accompanying text.

will provide a thorough review of the current legal framework of these procedures, including the involvement of the medical industry in the regulation of PGD, and the constitutional limitations on such regulation. Part II will then review the legal rights of the parents after the HLA matched child is born, as well as at the harvest and donation stage. Part III will present an analysis of the alternative methods of regulating the technology given the existing constitutional protections in the U.S. Finally, this note will conclude by arguing that statutory reform is needed to balance reproductive medicine with the vital protection of minors.

I. Explaining the Medical Procedures

A. What is IVF?

Securing an HLA matched embryo requires the performance of at least two interrelated medical processes: in vitro fertilization ("IVF") and PGD with HLA matching. The first step in the process, IVF, is typically employed as an alternative fertilization technique for women who have trouble becoming pregnant or are at a higher risk of miscarriage. The IVF procedure consists of collecting and manually

biopsy).

15 See discussion infra Part II.A-D (discussing the current legal status and constitutional limitations of PGD); see also supra note 10 and accompanying text.

16 See discussion infra Part II.E-F (discussing the legal and constitutional issues faced by parents after the HLA matched child is born and at the harvest and donation stage); see also infra note 126 and accompanying text.

17 See generally U.S. CONST. amend. XIV, § 1 (providing individuals the right to due process); Katrien Devolder, Preimplantation HLA Typing: Having Children to Save Our Loved Ones, 31 J. OF MED. ETHICS 582 (2005), available at http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1734026/pdf/v031p00582.pdf; Shuppnner, supra note 10 (proposing expanded government regulation of PGD technology). See also infra Part III (analyzing regulation alternatives of reproductive technology involved in PGD and HLA matching).

18 See infra Part III.D (arguing that statutory reform need be commenced).

19 See Batzer & Ravitsky, supra note 7, at 346 (acknowledging IVF combined with PGD for HLA typing as an effective and timely option for parents seeking to save the life of an ill offspring).

20 See John Gordon & Michael DiMattina, 100 Questions & Answers About Infertility 69-112 (2010) (discussing IVF as an option for parents having difficulty conceiving); Richard Evan Jones & Kristin H. López, Human Reproductive Biology 447 (2007) (describing the first successful IVF baby and the scientific process behind the IVF cycle). Here, IVF is necessary as it creates an external, extra utero embryo that can be further analyzed after conception. Anick De Vos & André Van Steirteghem, Gamete and Embryo Manipulation, in Yen and Jaffe’s Reproductive Endocrinology 759, 773 (Saunders 2009) (explaining that PGD screening occurs after oocytes are obtained and inseminated during an IVF cycle).
combining the male and female gametes to achieve fertilization. The harvesting of female eggs from the ovaries, or oocyte retrieval, occurs after the woman has been administered fertility drugs to stimulate the production of multiple eggs. The eggs that are deemed healthy are then manually injected with individual sperm cells previously collected from the male. The goal of the insemination procedure, intracytoplasmic sperm injection (“ICSI”), is to produce several embryos, which are then inspected the next day for signs of normal fertilization. A healthy fertilized egg will have two identifiable pronuclei and two polar bodies.

The egg then begins to divide, creating an identifiable two-cell embryo at day two, an eight-cell embryo at day three, a ten to thirty-cell morula at day four, and a blastocyst embryo at day five. The stages of

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24 See JONES & LÓPEZ, supra note 20, at 448 (deeming ICSI an improved external fertilization technique); SHER ET AL., supra note 23 (explaining that “sophisticated” IVF programs will examine the eggs for the presence of the polar bodies at this time); Intracytoplasmic Sperm Injection (ICSI), IVF FERTILITY CLINIC, http://www.ivf1.com/lab-icsi/ (last visited Oct. 26, 2011) (commenting on the sperm injection procedure).
25 See SHER ET AL., supra note 23, at 86 (explaining that the embryologist will inspect for these features in determining the health of the egg post-ICSI). A pronucleus is “[t]he haploid nucleus of a sperm or egg before fusion of the nuclei in fertilization.” THE AMERICAN HERITAGE COLLEGE DICTIONARY 1096 (3d ed. 1993). A polar body is a “minute cell produced and ultimately discarded in the development of an oocyte, containing one of the nuclei derived from the first or second meiotic division.” Id. at 1057.
embryonic cell division are pertinent to an IVF-PGD cycle, as PGD may be optimally performed at certain times during early cell division.30

B. What is PGD?

Preimplantation genetic diagnosis, or PGD, is a biopsy procedure performed on an embryo created through IVF prior to implantation in the uterus.31 PGD is used to screen for possibly inherited disorders or other non-medical traits, like HLA type.32 The biopsy is performed using one of three methods: extraction of the polar bodies from the pre-embryo oocytes;33 a one to two cell extraction at the day three blastomere stage;34 or


30 See infra notes 33-35 and accompanying text.
32 See JONES & LÓPEZ, supra note 20, at 452, 565 (providing a technical definition and background on PGD).
33 See How PGD is Performed, GENOMA MOLECULAR GENETICS LABORATORY, http://www.preimplantationgeneticdiagnosis.it/polar-body-removal-blastomere-biopsy2.htm (last visited Oct. 26, 2011). Two polar bodies are produced after conception and may be tested for the purposes of PGD. Id. Testing of the polar bodies indicates only the egg’s genetic makeup and maternal contribution to the embryo. Id. Thus, it may be necessary to follow-up this procedure with a blastomere biopsy and screening if there is risk that the paternal genetic makeup carries a risk to the embryo. Id.; see also How PGD is Performed, GENOMA MOLECULAR GENETICS LABORATORY, http://www.preimplantationgeneticdiagnosis.it/polar-body-removal-blastomere-biopsy2.htm (last visited Oct. 26, 2011). This procedure is less controversial compared to the alternative biopsy methods as it bears the least amount of risk since cell division is yet to commence. Id. Additionally, this procedure is accurate for women who are heterozygous for an X-linked recessive disorder because at meiosis I, the X chromosome bearing the mutant allele may drift to the polar body or the oocyte. MICHAEL CUMMINGS, HUMAN HEREDITY: PRINCIPLES & ISSUES 343 (Cengage Learning, 8th ed. 2009). Thus, a finding of the mutant allele in the polar body ensures that the oocyte carries the normal allele. Id.
34 This method is often referred to as a “cleavage stage biopsy.” See How PGD is Performed, GENOMA MOLECULAR GENETICS LABORATORY, http://www.preimplantationgeneticdiagnosis.it/polar-body-removal-blastomere-biopsy2.htm (last visited Oct. 26, 2011) (describing blastomere biopsy procedure); Trophoderm Biopsy and PGD Testing and IVF, ADVANCED FERTILITY CENTER OF CHICAGO, http://www.advancedfertility.com/trophoderm-biopsy.htm (last visited Oct. 26, 2011). A day three blastomere biopsy entails a biopsy of one to two blastomeres from the embryo. How PGD is Performed, GENOMA MOLECULAR GENETICS LABORATORY, http://www.preimplantationgeneticdiagnosis.it/polar-body-removal-blastomere-biopsy2.htm (last visited Oct. 26, 2011). The blastomeres are separated from the embryo and removed from the zona pellucida, or shell surrounding the embryo. Id. The developing embryo is placed back in the incubator to resume cell division. Id. The separated cells are then subject to PGD. Id. See, e.g., G.A. Palmer, J. Traeger-Synodinos, S. Davies, M. Tzetis, C. Vrettou, M. Mastrominas & E. Kanavakis,
a one to two cell extraction at the day five blastocysts stage. Critics of PGD often scrutinize the cell extraction procedure used by the technicians; for example, a polar body extraction does not remove a cell produced by the egg division and may thus be seen as less controversial, whereas a day five extraction occurs much deeper into cell division cycle. After extraction of the specimen, the doctor will screen the cell for the designated trait.

PGD, also referred to as embryonic screening, was initially limited to the detection of genetic disorders in the embryo; however, it has evolved to include screening for a myriad of therapeutic and non-therapeutic purposes. The first

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Pregnancies Following Blastocyst Stage Transfer in PGD Cycles at Risk for β-thalassaemic Haemoglobinopathies, 17 OXFORD J. OF HUMAN REPROD. 1, 25 (2002), available at http://humrep.oxfordjournals.org/content/17/1/25.full.pdf+html (concluding that embryo biopsy on day three with delayed implantation until day five is an effective method when performing PGD). But see Cai, supra note 14, at 21-23 (discussing the ethical drawbacks of blastomere biopsy). This form of biopsy, although most prevalent, is also most controversial as it entails the removal of cells from the existing embryo and may cause damage to the embryo, by causing mosaicism in the remaining cells, or to the cells themselves, rendering the procedure purposeless. Id. at 22. Still, at this stage of development, all cells remaining in the embryo are identical and have not begun to differentiate. Id. Thus, the performance of the screen on these cells should accurately reflect the characteristics of all remaining cells. Preimplantation Genetic Diagnosis, INTEGRATED FERTILITY NETWORK, https://www.integramedfertility.com/inmdweb/content/cons/preimplan.jsp (last visited Oct. 26, 2011).

35 This method is known as a “blastocysts biopsy.” See Cai, supra note 14, at 22.

36 See Cai, supra note 14, at 22. More liberal critics may conclude that polar body extraction is less morally wrong than the other extraction methods based on an understanding of the science, whereas others may uniformly judge the practice. Id.

37 See DAVID GARDNER, MICHELLE LANE & ANDREW WATSON, A LABORATORY GUIDE TO THE MAMMALIAN EMBRYO 100-01 (Oxford University Press 2004) (outlining the methods that may be used, including polymerase chain reaction (“PCR”) and Fluorescence In Situ Hybridization (“FISH”), in diagnosing single cell gene defects). “In PCR, a specific fragment of DNA is amplified thousands of times . . . [which is] achieved by using specific primers that are usually designed to highlight the area of the DNA containing mutation.” Id. Thereafter, techniques are employed for analysis. Id. FISH is the method of choice used for diagnosing chromosomal abnormalities. Id. It is a laboratory technique used to detect specific DNA sequences on a chromosome by exposing it to a corresponding DNA sequence, which has a fluorescent molecule on it, thereby revealing the location of that piece of DNA in the starting genome. Fluorescence In Situ Hybridization (FISH), GENOME.GOV, http://www.genome.gov/Glossary/index.cfm?id=65&textonly=true (last visited Oct. 26, 2011).

38 See AUBREY MILUNSKY & JEFF MILUNSKY, GENETIC DISORDERS AND THE FETUS: DIAGNOSIS, PREVENTION AND TREATMENT 972 (2010) (discussing the use of PGD by couples risking transmission of disease or late-onset disorders to offspring, poor prognosis IVF patients, or those seeking HLA matching).

39 Id.
successful embryonic screening procedure occurred in 1967.\textsuperscript{40} Robert Edwards and David Gardner screened live rabbit blastocysts for gender, and the blastocysts remained viable for implantation.\textsuperscript{41} In 1989, Charles Coutelle developed a screen for cystic fibrosis using single female human oocytes.\textsuperscript{42} In 1990, Alan Handyside’s IVF and PGD testing led to the birth of a healthy girl free from cystic fibrosis, thus marking the first successful human birth post-PGD.\textsuperscript{43} Until recently, PGD was typically used to screen for genetic diseases like cystic fibrosis, Tay-Sachs, sickle cell, Huntington’s disease, Beta-thalassemia, or Duchenne’s muscular dystrophy.\textsuperscript{44} Today, the use of PGD has expanded beyond disease prevention to include aiding those suffering from infertility,\textsuperscript{45} seeking non-therapeutic characteristics,\textsuperscript{46} and, most pertinent to this discussion, seeking donors

\textsuperscript{40} See Cai, supra note 14, at 21.

\textsuperscript{41} Id.


\textsuperscript{45} See MILUNSKY & MILUNSKY, supra note 38, at 972. Contemporary PGD provides a solution for a range of adults seeking reproductive assistance. See id. (discussing the use of PGD by couples risking transmission of disease or late-onset disorders to offspring, poor prognosis IVF patients, or those seeking HLA matching). Like those of late maternal age electing to use IVF to help ensure pregnancy, PGD can further decrease the risk of aneuploidy, leading to Down’s syndrome, by screening for chromosomal abnormalities. JAN GERRIS, FRANCOIS OLIVENNES & PETRA DE SUTTER, ASSISTED REPRODUCTIVE TECHNOLOGIES: QUALITY AND SAFETY 225 (2004). Further, unbalanced inheritance of chromosomal abnormalities known as translocations, which are often the cause of recurring miscarriages, can be detected, and balanced embryos can then be selected. Joseph A. Hill, Recurrent Pregnancy Loss, in MATERNAL-FETAL MEDICINE: PRINCIPLES AND PRACTICE 579 (5th ed. 2003), available at http://www.fertilitycenter.com/fertility_cares_blog/tag/recurrent-pregnancy-loss/. With each chromosomally abnormal spontaneous abortion, the likelihood that the loss will happen again increases. Id. Chromosomal translocation is the most common chromosomal abnormality in cases of pregnancy loss and refers to chromosomes whose pieces have switched place in the individual’s genetic structure. Id. The benefits of PGD in this arena are the higher rate of implantation in the uterus, lower spontaneous loss rate, and the reduced risk of offspring with Down’s syndrome. Id.

\textsuperscript{46} WILLIAM SALETAN, BEARING RIGHT: HOW CONSERVATIVES WON THE ABORTION WAR 275 (2003). More controversial contemporary uses of PGD include screening for non-medical conditions. Id. (quoting letter by Judy Norsigian, Stuart Newman, and other left-feminists denouncing the American Society for Reproductive Medicine’s decision to permit the sale of PGD for gender selection in American clinics). The writers claimed the use of PGD for non-medical conditions “constitutes a major step toward the ‘designing’ of children.” Id. Embryonic
well-matched in HLA.47

C. What is PGD with HLA Matching?

When an individual is sick and in need of hematopoietic stem cell transplantation (“HSCT”), the individual will seek a donor whose HLA type is well-matched in HLA.47

screening for sex is used in foreign states where preference is given to male offspring. Jones & López, supra note 20, at 247. In the United States, it is often termed “family balancing.” Id. The benefits of PGD in the realm of gender identification before implantation are in its ability to decrease the number of amniocenteses, abortions, or even infanticides, which will take place if identification is delayed. Id. See, e.g., China Facing Major Gender Imbalance, MSNBC, Jan. 12, 2007, http://www.msnbc.msn.com/id/16593301/ (outlining Chinese gender imbalance due to the country’s one-child policy); Jill McGivering, India’s Last Girls, BBC, Feb. 4, 2003, http://news.bbc.co.uk/2/hi/south_asia/2723513.stm (discussing India’s use of prenatal scans resulting in abortions of female fetuses). Compare Monica Sharma, Twenty-First Century Pink or Blue: How Sex Selection Technology Facilitates Gendercide and What We Can Do About It, 46 FAM. CT. REV 198 (2008) (analyzing the relationship between sex-selection technology and the killing of female fetuses, as well as the societal impact of gender imbalance) with Ashley Burmgarner, A Right to Choose?: Sex Selection in the International Context, 14 DUKE J. GENDER L. & POL’Y 1289 (2007) (discussing the risk that lower-income groups in countries preferring male offspring will be unable to afford the new technology and left to the old methods, like infanticide and abortion). See also What is PGD, REPRODUCTIVEGENETICS.COM, http://www.reproductivegenetics.com/pgd.html (last visited Oct. 26, 2011). Today, PGD enables the performer to identify an expanding number of genetic diseases, while also presenting the ability to screen for chromosomal abnormalities and specific genetic disorders. Id. See generally Cai, supra note 14, at 21-23. Moreover, PGD may be performed to screen for physical traits. Jones & López, supra note 20, at 452. The use of PGD for selection of physical traits is perhaps its most controversial use, seen to many as entering the realm of eugenics and “designer babies.” Donna M. Gitter, Am I My Brother’s Keeper? The Use of Preimplantation Genetic Diagnosis to Create a Donor of Transplantable Stem Cells for an Older Sibling Suffering from a Genetic Disorder, 13 GEO. MASON L. REV. 975, 1017 (2006) (analyzing arguments against PGD with HLA matching, including the risk of treating children as commodities, the psychological impact on the children and the slippery slope toward eugenics). Further, PGD can be employed to search for markers that increase the embryo’s propensity to develop late-onset disorders. Avi Tsafrir et al., Preimplantation Genetic Diagnosis, in THE EMBRYO: SCIENTIFIC DISCOVERY AND MEDICAL ETHICS 166, 188-89 (Shraga Blazer and Etan Z. Zimmer eds., 2005). An individual’s propensity to late-onset disorders can be detected by identifying gene mutations in his or her DNA. Id. at 188. Since their identification, PGD has been used to avoid pregnancy with embryos containing the mutations for Alzheimer’s and Huntington’s disease makers, as well as the B53 mutation for breast and ovarian cancer. Id.

matched with his or her own HLA type. A biological relationship increases the likelihood that the individuals will be well-matched, maximizing the possibility of transplant success. HLA type is identified using a simple blood test. HLA refers to six proteins that are found on the surface of white blood cells and other bodily tissues. When each of the six proteins found within the embryonic cell biopsy match the donor’s, either in 5/6 or 6/6 match, that embryo is deemed a candidate for implantation. This matching process minimizes the risk of graft versus host disease in the recipient, and improves the chances of a successful HSCT. Creating a child through PGD with HLA matching nearly ensures that the child-donor and the recipient are well-matched in HLA.


49 See Policy Statement, supra note 13 (discussing the need for a donor and recipient well-matched in HLA); Grewal, supra note 48, at 1147; Hye Lim Jung, M.D., Shedding a New Light on the HLA Matching, 46 KOREAN J. HERMATOL. 1, 1-2 (2011), available at http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3065618/.

50 See generally Grewal, supra note 48.

51 See CHERNECKY & MURPHY-ENDE, supra note 47, at 223.

52 See id. Graft versus host disease is a complication that can occur after a HSCT where the transplanted cells attack the body of the recipient. Graft-Versus-Host Disease, TIMES HEALTH GUIDE, http://health.nytimes.com/health/guides/disease/graft-versus-host-disease/overview.html (last visited October 26, 2011) (providing background information on graft versus host disease).

53 See Guido Pennings et al. Ethical Considerations on Preimplantation Genetic Diagnosis for HLA Typing to Match a Future Child as a Donor of Haematopoietic Stem Cells to a Sibling, 17 HUMAN REPROD. 534, 535 (2002); Devolder, supra note 17, at 582 (discussing the importance of a donor well-matched in HLA). Prior to the use of PGD for HLA matching, researchers reported several cases in which parents had children hoping that one or more of them would be a match for an existing ill child in need of hematopoietic stem cell transplantation (HSCT). Devolder, supra note 17, at 582 (discussing the highly publicized 1993 Ayala case). Still, there only existed a one in four chance that the child would be a match for its sibling. Id. Moreover, in Western countries the chance of already having an HLA-matched sibling is a mere fifteen percent. Pennings, supra at 534. But see LAZARUS, supra note 47, at 313 (reporting a thirty percent chance of finding a match among existing siblings). PGD with HLA matching may be seen as a superior method to post-conception testing if the goal is to produce an HLA-matched child as rapidly as possible, with just one pregnancy. Devolder, supra note 17, at 582; see also GERRIS, supra note 45, at 225 (discussing the decision to terminate pregnancy upon a finding that the child was not an HLA
HSCT is typically used to cure diseases of the blood and bone marrow, or to treat certain cancers such as leukemia. Allogeneic HSCT, or a blood forming stem cell transplant from a genetically comparable donor, is often the only cure for such diseases. Hematopoietic stem cells are located in bone marrow, peripheral blood, and umbilical cord blood. Therefore, if the embryo is well-matched for HLA, harvesting can begin at the time of birth and umbilical cord blood can be extracted and transplanted into the sick family member. If this treatment fails for the recipient, more invasive procedures, such as repeated bone marrow transfusions, or even organ transplants, may be required.

While the recipient has an increased likelihood of success with a transplant whose source is well-matched in HLA, stem cell and live organ transplants still present a variety of psychosocial and physiological risks to both parties. The few reported studies of child HSCT donors demonstrate that sibling donors experience increased distress, anxiety, and lower self-esteem than non-donor siblings, as well as moderate

match); MILUNSKY & MILUNSKY, supra note 38, at 972; Policy Statement, supra note 13, at 400.

55 See Devolder, supra note 17, at 582. See generally Pennings, supra note 54 (discussing malignant and non-malignant diseases treated with HSCT).

56 See generally Pennings, supra note 54 (discussing hematopoietic stem cell transplantation); Policy Statement, supra note 13. See also Devolder, supra note 17, at 582 (explaining that HSCT is the only cure for Diamond Blackfan Anemia).

57 See Policy Statement, supra note 13, at 392 (discussing possible origins of HSC); see also Devolder, supra note 17, at 582 (explaining that HSCT is the only cure to Diamond Blackfan Anemia).

58 See Karen K. Ballen, New Trends in Umbilical Cord Blood Transplantation, 105 BLOOD 3786, 3787 (2005) (explaining that the umbilical cord harvest can be performed before or after delivery of the placenta); Policy Statement, supra note 13, at 395. The collection of umbilical cord blood in the delivery room poses no risk to the newborn unless the delivery is modified to increase the quantity of cells extracted. Ballen, at 3787. In the case of an umbilical cord blood-based HSCT transplant, however, the significance of the perfectly matched HLA type is diminished, as lymphocytes in cord blood are less immunologically reactive. Id.

59 See PGD for HLA Matching, FROEDTERT & MEDICAL COLLEGE OF WISCONSIN, http://www.froedtert.com/SpecialtyAreas/Fertility/Programs/Genetic-Screening/PGD-HLA-Matching.htm (last visited Oct. 26, 2011). The number of cells available for umbilical cord blood transplantation may not be sufficient. In such a case, a secondary cord blood sample, bone marrow, or peripheral blood stem cells may be required. See, e.g., John T. Horan, et al., Risk Factors Affecting Outcome of Second HLA-Matched Sibling Donor Transplants, 15 BIOL. BLOOD & MARROW TRANSPLANT 626, 626 (2009). Contra Pennings, supra note 54, at 535 (studying primary and secondary HSCT graft failure in severe acquired a plastic anemia patients who were HLA-matched to sibling donors).

60 See Devolder, supra note 17, at 584-85; Policy Statement, supra note 13, at 392, 394-95 (explaining that a donation well-matched in HLA limits the risk of transplant failure, improves the likelihood that the donor will avoid subsequent procedures and that the recipient may be cured).
levels of post-traumatic stress. Physiological risks to child donors typically result from the medications used for anesthesia during the transplant procedure. However, additional adverse effects are possible depending on the nature of the transplant. Adult live organ donors remain at risk for infection, temporary or permanent disability, or death. Furthermore, the donor is disadvantaged from the organ removal in additional ways. Psychologically, the donor may become resentful, depressed, or grief stricken as a result of the donation or failure of the transplant. On the other hand, some donors have a positive psychological reaction, exhibiting feelings of closeness to the recipient and a sense of contribution to the family.

In its 2010 Policy Statement on Children as Hematopoietic Stem Cell Donors, The American Academy of Pediatrics (“AAP”) stated that the greatest risks to HSCT recipients are clinical in nature. After the transplant, the recipient must go into

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62 See id. For example, common side effects of bone marrow transplant include, “fatigue, pain at the donation site, low back pain, headaches, nausea, difficulty walking, problems sleeping, and less commonly, bleeding problems.” Id.


64 See Policy Statement, supra note 13, at 394-95.

65 Mary Amanda Dew, et al., Psychosocial Aspects of Living Organ Donation, in LIVING DONOR TRANSPLANTATION 7, 7-12 (Henkie P. Tan, Amadeo Marcos & Ron Shapiro, eds., 2007).

66 See id. See also David S. Snyder, Ethical Issues in Hematopoietic Cell Transplantation, in THOMAS’ HEMATOPOIETIC STEM CELL TRANSPLANTATION 488, 491 (Karl G. Blume, Stephen J. Forman & Frederick R. Appelbaum, eds., 3d ed. 2004) (reviewing bioethicist Julian Savulescu’s position that donation may be in the donor’s overall best interest). “Even for donors who are too young to understand at the time, the potential for a future sense of achievement and the love and gratitude of the saved sibling is important.” Id.

67 See Policy Statement, supra note 13, at 395-96 (discussing risks and benefits to the HSCT
isolation for a period of weeks to months until engraftment occurs, which has emotional
effects on both the donor and recipient. Thus, the implications of a commonly
performed IVF procedure dramatically expand in scope when coupled with PGD with
HLA matching, as the PGD child donor, recipient, and all non-medically participating
family members may be affected either psychosocially or physiologically.

II. Current Legal Status

 A. Public Sector Regulation: U.S. Federal Law Regarding PGD

 Various models of regulation for PGD exist globally. Some nations fully ban
the practice, whereas others subscribe to a partial-ban or even a profession-based
regulatory scheme. In the U.S., there is no specific federal regulatory scheme for
PGD. Moreover, as a result of the polarizing nature of the national debate over the
moral value and legal status of the human embryo, Congress has a history of limited
interference with assisted reproductive technology (“ART”) in general, including PGD.

69 See id. at 395. The AAP notes that while the recipient is in the isolation period, one or more
parents may have to spend long periods at the hospital, resulting in a feeling of neglect in both
the donor and non-donor siblings. Id.

70 See supra notes 67-69 and accompanying text (describing risks associated with PGD and HLA
matching that are not otherwise implicated by IVF procedures).

71 See generally Aaron Fahrenkrog, A Comparison of International Regulation of Preimplantation Genetic
Diagnosis and a Regulatory Suggestion for the United States, 15 TRANSNAT’L L. & CONTEMP. PROBS. 757, 762-68 (2006) (outlining types of regulatory schemes and their respective applications in
model countries); Bartha M. Knoppers & Rosario M. Isasi, Regulatory Approaches to Reproductive Genetic Testing, 19 HUM. REPROD. 2695 (2004) (analyzing the ethical and legal aspects of
reproductive genetic testing in eleven countries), available at http://humrep.oxfordjournals.org
/content/19/12/2695.full.pdf+html.

72 See Fahrenkrog, supra note 71, at 762-67. The article discusses the statutory ban implemented
in Germany, statutory mandatory licensing for PGD in the UK, and regulation by professional
organizations in Japan. Id.

73 See generally Cho, supra note 10 and accompanying text; Jaime King, Predicting Probability:
Regulating the Future of Preimplantation Genetic Diagnosis, 8 YALE J. HEALTH POL’Y, L. & ETHICS 283, 331 (2008) (discussing the federal government’s ability to regulate through congressional
legislation or administrative agencies under the Commerce Clause); Shuppner, supra note 10, at
455.

74 See Andrea L. Bonnicksen, Oversight of Assisted Reproductive Technologies: The Last Twenty Years, in
REPROGENETICS: LAW, POLICY, AND ETHICAL ISSUES 64, 65-66 (Lori P. Knowles & Gregory E.
Kaebnick eds., 2007) (explaining why Congress has avoided initiating ART policies); Karen
Schiavone, Playing the Odds or Playing God? Limiting Parental Ability to Create Disabled Children through
Preimplantation Genetic Diagnosis, 73 ALB. L. REV. 283, 290-92 (2009) (summarizing the extent of
federal and state legislation regulating human reproduction).
Direct regulation by the federal government over PGD has been sparse; rather, the government has delegated that power to the states and the professional industry. The federal government’s ability to regulate doctors and laboratories performing PGD is spread among several agencies whose jurisdictions do not explicitly encapsulate PGD, but rather cover a broader category of medical procedures. These agencies often employ a method of oversight by recommendation, which has only an indirect effect on PGD. For example, while facility standards may be recommended, the PGD biopsy


76 Susanna Baruch, Preimplantation Genetic Diagnosis and Parental Preferences: Beyond Deadly Disease, 8 HOUS. J. HEALTH L. & POL’Y 245, 262 (2008). The United States Department of Health and Human Services (“DHHS”), a cabinet department of the federal government, contains several operating divisions whose jurisdiction may permit regulating PGD. Id. “[T]hree federal agencies within the U.S. DHHS have some authority over PGD-related matters.” Id. At least one author suggests that PGD regulation may fall under the jurisdiction of the Food and Drug Administration (“FDA”) because the FDA may regulate all laboratory tests designated as “diagnostic or medical devices.” Shuppner, supra note 10, at 451 (claiming that the FDA may assert its authority to regulate PGD under FDCA section 201(h)). Nevertheless, because many laboratories design their own tests, and because oversight of physician testing is directed exclusively to the profession, PGD may fall outside the scope of FDA regulation. See Bartha Maria Knoppers & Thu Minh Nguyen, Prenatal and Preimplantation Diagnosis: International Policy Perspectives, in GENETIC DISORDERS AND THE FETUS: DIAGNOSIS, PREVENTION, AND TREATMENT 1081, 1086 (Aubrey Milunsky & Jeff Milunsky eds., 2010) (recognizing that the FDA’s ability to oversee PGD matters may be limited due to genetic laboratories designing their own tests). Any FDA or Center for Disease Control and Prevention (“CDC”) regulation that would function to impact PGD would be doing so indirectly and only in relation to safety and effectiveness. See supra Baruch, at 262; Shuppner, supra note 10, at 451.

77 See 42 U.S.C § 263a (1996) (granting the Clinical Laboratory Improvement Amendments
procedure has not been directly regulated. Similarly, the private sphere has failed to directly regulate PGD, but established professional standards recommended to practitioners of these ART procedures.

B. Private Sector Regulation: Professional Self-Regulation of PGD

Professional societies and private advocacy groups are influential in the creation of ART policy because they are the only groups to directly address PGD standards. The American Society for Reproductive Medicine (“ASRM”) is an organization supported by health care professionals in the field of reproductive medicine. ASRM has issued guidelines for PGD performance and has additionally instituted a program, in conjunction with the College of American Pathologists (“CAP”), to maintain laboratory conditions and accreditation.

Further, other interest groups have an impact on PGD screening procedures. Further, other interest groups have an impact on PGD screening procedures. Further, other interest groups have an impact on PGD screening procedures. Further, other interest groups have an impact on PGD screening procedures.

See 42 U.S.C § 263a (1996) (granting the CLIA its authority to regulate clinical laboratories); FDA Human Tissue Intended for Transplantation, 21 C.F.R. § 1270.1(a) (2000) (regulating facilities handling human tissues intended for transplantation); Shuppner, supra note 10, at 447, 451 (analyzing the indirect steps the CDC takes to regulate PGD by imposing standards for clinical testing labs which perform PGD); Centers for Disease Control and Prevention, MMWR 2009; 58 (No. RR-6), Good Laboratory Practices for Molecular Genetics Testing for Heritable Diseases and Conditions 1-25 (2009) (discussing Centers for Medicare & Medicaid Services (“CMS”) and CDC recommendations). See Bonnicksen, supra note 74, at 64 (discussing the guiding principles considered by private groups when establishing voluntary guidelines).

See Shuppner, supra note 10, at 448-550 (outlining the measures taken in the private sector to regulate ART). While the federal government has left some areas of PGD regulation “untouched,” the private sector has been granted “permissive regulation over PGD.” Baruch, supra note 76, at 264 (commenting on voluntary nature of the regulations).


See Bonnicksen, supra note 74, at 78.

See, e.g., J.B. Younger, ASRM Position on Gender Selection, ASRM MEDIA RELEASE, Oct. 1, 2001
oversight: the PGD International Society (“PGDIS”) propagates practice guidelines and
the National Infertility Association’s RESOLVE has expressed positions on government
regulation. Moreover, the President’s Council on Bioethics has made
recommendations for improved oversight of genetic testing.

The aforementioned organizations confront challenges to ART by offering
ethical solutions to moral dilemmas inherent in the practice. Various worldwide
organizations are adamantly opposed to the performance of IVF and PGD, as each
result in the destruction of human embryos. Similarly, PGD presents an ethical
quandary for individuals and religious groups who view the embryo as a living being.
Still, others object to the procedure as being inorganic because it enables parents to
“select” children. Proponents of the practice attempt to minimize the ethical quandary
of destroying unused embryos by encouraging couples to donate the unused embryos
for research, or to infertile couples seeking assistance. Still, this recommendation does
not acknowledge nor remedy the ethical dilemma inherent in using ART to create a child
whose purpose, at the time of birth, is to serve as a well-matched stem cell transplant
donor for an ailing sibling. Thus, constitutional law must be considered when one
questions the parents’ legal right to reproduce a child with such intent in mind.

(assuming sex-selection of embryo is sometimes ethically permissible); Ethics Committee of the
American Society for Reproductive Medicine, Ethics Committee Report: Preconception Gender Selection
asrm.org/publications/detail.aspx?id=719 (discussing the ethical arguments for and against
“preconception” sex-selection).

See Shuppner, supra note 10, at 452.

See THE PRESIDENT’S COUNCIL ON BIOETHICS, REPRODUCTION AND RESPONSIBILITY: THE
georgetown.edu/pcbe/reports/reproductionandresponsibility/_pcbe_final_reproduction_and_
responsibility.pdf (discussing the federal regulation of genetic testing).

See Robert J. Boyle & Julian Savulsecu, Ethics of Using Preimplantation Genetic Diagnosis to Select a
www.bmj.com/content/323/7323/1240.full.pdf (discussing the destruction of embryos).

See id.

See Cho, supra note 10, at 40. The official doctrine of the Catholic Church has stated firm
opposition to ART, finding it to be an unnatural process. Id.

See id.; Boyle & Savulsecu, supra note 86, at 1242 (observing societal disapproval).

Boyle & Savulsecu, supra note 86, at 1242.

See supra note 2 and accompanying text; infra note 253 and accompanying text. See generally
Hebert, supra note 75.

See infra note 93 and accompanying text.
C. Constitutional Limitations on Regulating Procreation

The U.S. Supreme Court has interpreted the U.S. Constitution as providing a series of protected liberties and fundamental rights. The right to procreate flows from these liberties, and both the federal and state governments are limited in their ability to interfere with this protected realm. Still, these fundamental rights are not absolute, warranting government intrusion when the state can meet a prescribed burden of proof.

1. The “Moral Status” of the Embryo

The question of when life begins elicits a diverse spectrum of answers from individual members of American society. The U.S. legal system has confronted the issue at both the state and federal level by defining the legal status of the embryo, and in some cases, by permitting its destruction. A minority of states have elected to grant the embryo legal status as a “person,” indicating their belief that life begins before an embryo reaches viability. However, the U.S. Supreme Court has not classified the

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93 Griswold v. Connecticut, 381 U.S. 479, 484 (1965) (holding right to privacy found in the “penumbras” of other Constitutional protections). Reproductive rights, such as the decision to procreate or procure an abortion, are considered so private to the individual that they must remain protected and guaranteed. Id.; see also Skinner v. Oklahoma, 316 U.S. 535, 541 (1942) (holding the right to procreations as “fundamental to . . . survival of the race”). See generally U.S. CONST. amend. I (purporting privacy as protected through the Constitution’s acknowledgment of associational rights); U.S. CONST. amend. III; U.S. CONST. amend. IV; U.S. CONST. amend. V; U.S. CONST. amend. IX; U.S. CONST. amend. XIV.

94 See infra text accompanying notes 113-121.

95 See infra note 133 and accompanying text (discussing the parens patriae power of the state).

96 See Debating the Moral Status of the Embryo, HARV. MAG., July-Aug. 2004, available at http://harvardmagazine.com/2004/07/debating-the-moral-statu.html (last visited Oct. 26, 2011) (comparing the “equal moral status” philosophy with a more developmental perspective under which the embryo is seen as potential life). Under the former view, embryos are to be treated equally with human beings, and should not be used as a “means to an end,” such as to save another life. Id. The latter philosophy concedes that the embryo need be treated with a heightened level of respect due to its potential, however supports stem cell research and therapeutic cloning. Id.


98 See LA. REV. STAT. ANN. §§ 9:123, 9:129 (2008) (declaring “[a]n in vitro fertilized human ovum exists as a juridical person . . .” and holding “[a] viable in vitro fertilized human ovum is a juridical person which shall not be intentionally destroyed by any natural or other juridical person or
embryo as a “person.”"  

Constitutional precedent does not determine when life begins, but instead establishes the embryo’s legal status through the cases pertaining to abortion. In the through the actions of any other such person’); MO. REV. STAT. § 1.205(1) (2009) (deeming life to begin at the time of conception); 18 PA. CONS. STAT. § 3203 (2010) (defining an “unborn child” and “fetus” to mean “an individual organism of the species homo sapiens from fertilization until live birth”); TEX. CIV. PRAC. & REM. CODE ANN. § 71.001(4) (West 2011) (providing the civil definition of the embryo at every phase of gestation as a person); TEX. PENAL CODE ANN. § 1.07 (26) (West 2011) (defining the embryo at every phase of gestation as a person in the criminal code). Although these states grant the embryo a form of legal status, the right to an abortion must remain under these state’ laws, as under the Supremacy Clause, no state may not create a law more liberal than a federal law. U.S. CONST. art. VI, § 2; Roe, 410 U.S. at 164 (overturning a Texas ban on abortion). Nevertheless, the availability of abortions is diminished through state action. See, e.g., MO. ANN. STAT. §§ 108.027, 334.245 (West 2011). Under the new law, the practitioner must ask the woman if she wishes to hear the heartbeat, and must tell her that fetuses may feel pain, and must give her a pamphlet that reads, “[t]he life of each human being begins at conception. Abortion will terminate the life of a separate, unique, living human being.” Id. at § 108.027 (1)(q)(2). But see Mallory Simon, Mississippi Gov. Supports Amendment to Declare Fertilized Egg a Person, CNN, Nov. 4, 2011, http://www.cnn.com/2011/11/04/us/mississippi-personhood-amendment/ (discussing the ballot measure “Initiative 26”). The measure attempted to define “personhood” as “every human being from the moment of fertilization, cloning or the functional equivalent thereof,” and would have had an impact on a woman’s ability to secure birth control pills, morning-after pills, an abortion, or in vitro fertilization, in the state of Mississippi. Id. Further, Personhood USA, the group behind the ballot initiative, sought to use the term “personhood” as found in the amendment to challenge the Roe v. Wade ruling. Id. Ultimately, Mississippi voters rejected the amendment at the polls on November 5, 2011. Katherine Q. Seelye, Mississippi Voters Reject Anti-Abortion Measure, N.Y. TIMES, Nov. 8, 2011, http://www.nytimes.com/2011/11/09/us/politics/votes-across-the-nation-could-serve-as-a-political-barometer.html?scp=4&sq=personhood%20amendment&st=cse.


100 See, e.g., Gonzalez, 550 U.S. at 147 (upholding the Partial-Birth Abortion Ban Act of 2003); Casey, 505 U.S. at 845 (upholding parts of a Pennsylvania abortion law); Roe, 410 U.S. at 158 (upholding that the word “person” does not include the unborn). Cf. A.Z. v. B.Z., 431 Mass. 150, 162 (2000) (holding that the wife was permanently enjoined from obtaining and utilizing frozen pre-embryos as the husband’s interest to not become a biological parent outweighed the wife’s interest to have more children); Angela Riley, Couples in California Take Embryo Dispute to Mediation, MISSOURI LAWYERS MEDIA, Apr. 14, 2010, http://findarticles.com /p/articles/mi_q7992/is_20100414/ai_n53227681/ (discussing California’s embryo suit brought under a breach of contract claim). Although the suits were brought under contract law and property principles, some argue that the sale of embryos should be classified as adoptions. Karen
landmark case *Roe v. Wade*,\(^{101}\) the Court upheld a woman’s right to an abortion as a fundamental right guaranteed under the Due Process Clause.\(^{102}\) The Court reasoned, however, that the state holds a legitimate interest in preserving the health of the pregnant woman and protecting the potentiality of life.\(^{103}\) Therefore, after the fetus reaches the point of viability under the trimester model, the state may regulate in limited circumstances.\(^{104}\) The holding in *Roe* was affirmed in *Planned Parenthood v. Casey*,\(^{105}\) however, the Court downgraded the right of abortion from a fundamental right to a protected liberty, effectuating a lower standard of review.\(^{106}\) Contemporary *stare decisis* illustrates that the embryo’s legal status as a “person” remains unrecognized.\(^{107}\) Nevertheless, the standard of review established in *Casey* continues to control, making it more difficult to exercise the right to have an abortion.\(^{108}\) Moreover, it is important to note that the woman’s right to abortion is supported based on the fundamental right to privacy, and thus to her body.\(^{109}\) When conception occurs outside of the womb it is less clear who, if anyone, holds the right to an abortion.\(^{110}\)

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\(^{102}\) 410 U.S. 113 (1973).

\(^{103}\) See *Roe v. Wade*, 410 U.S. 113, 164 (1973) (invalidating a Texas statute that made it illegal to procure an abortion except in the case to save the life of the mother).

\(^{104}\) *Id.* at 162 (explaining that “[t]hese interests are separate and distinct”).


\(^{106}\) See *id.* at 851-52, 876 (plurality opinion). The undue burden test outlined by the Court deems a law unconstitutional for imposing an “undue burden” if it places a substantial obstacle in the path of a woman seeking to exercise her right to an abortion. *Id.* at 877.


\(^{109}\) See *Roe*, 410 U.S. at 152-53. *Roe* was primarily concerned with balancing the liberty interests of the woman with the government’s interests in protecting the health and safety of the woman and the “potential life” of the fetus. *Id.* at 153-54. If the potential for human life exists in an embryo, and there is no competing interest of a mother’s decisional or physical autonomy to balance with that potential life, some scholars have argued that the legal analysis should be different than in cases of pregnancy. Cf. *id.* at 152-54.

2. The Fundamental Right to Procreate Versus the States’ Rights to Regulate

The Constitution is paramount in analyzing a parent’s right to engage in an IVF-PGD with HLA-matching cycle given that ART procedures may be considered nearly synonymous with procreation. Still, the Court in Roe and Casey did not address the motives of the individuals seeking to terminate pregnancy, but rather based its analysis on the individual’s right to privacy. Additionally, the Court has held that procreation is a fundamental right, rooted in privacy, and guaranteed due process. In Griswold v. Connecticut, the Court held that the Constitution protected a right to privacy found in the “penumbras” of other Constitutional protections. In Skinner v. Oklahoma, the Court opined that the right to procreate is “fundamental to the very existence and survival of the race.” The Court emphasized equal protection dictates that a court must apply strict scrutiny when evaluating a state law that in any way limits an individual’s right to procreate. In Eisenstadt v. Baird, the Court extended the ruling in Griswold, stating, “[i]f the right of privacy means anything, it is the right of the individual . . . to be free from unwarranted governmental intrusion into matters so

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111 See Roe, 410 U.S. at 152. In the IVF-PGD context, a parent’s usual motive for utilizing ART is to have a child for the benefit of a third party, although purposes such as screening for genetic illness and gender selection are other reasons the procedure could be employed. See generally Andrea L. Kalfoglou, PGD Patients’ and Providers’ Attitudes to the Use and Regulation of Preimplantation Genetic Diagnosis, 11 REPRODUCTIVE BIOMEDICINE ONLINE 486 (2005), available at http://www.umbc.edu/happ/AK/Kalfoglou10-05%20final.pdf.
113 See U.S. CONST. amend. XIV, § 1; Skinner v. Oklahoma, 316 U.S. 535, 541 (1942) (holding that compulsory sterilization could not be imposed as punishment for a crime).
114 381 U.S. 479, 481-86 (1965) (invalidating law that prohibited use of contraceptives by married persons on grounds that it violated marital right to privacy); see also Skinner, 316 U.S. at 541 (acknowledging marriage and procreation as “basic civil rights of man” not enumerated in Constitution).
115 Id.
116 316 U.S. at 541.
117 Id.
fundamentally affecting a person as the decision whether to bear or beget a child.”

Under the Equal Protection Clause, the Court expanded the right to privacy by protecting the distribution of contraceptives to unmarried persons, invalidating a Massachusetts statute that made it a crime to sell, lend, or give away these products. The right to procreate, however, is demonstrably not absolute, as courts have repeatedly held since Griswold that a state has met its burden by showing a compelling interest to regulate the procreative liberty of an individual. Moreover, the government, through its parens patriae power—the right to protect children from harm and ensure they receive adequate resources—has authority to regulate parents after the procreative stage and subsequent to the birth of the child. Thus, children born from ART involving PGD could potentially be protected by the government from the harms associated with serving as a donor if the government was warranted to do so through its parens patriae power.

D. Constitutional Limitations on Regulating Parental Rights

1. Parental Right to Direct the Care, Custody, and Control of Children, Versus the State’s Right to Regulate

States may attempt to protect children, born as a result of PGD technology, who remain under the care, custody, and control of their parents, by invoking its parens patriae power.

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120 Id. (emphasis omitted).
121 Id.
122 See Griswold v. Connecticut, 381 U.S. 479, 481-86 (1965); In re Angela D., 83 Cal. Rptr. 2d 411, 422-23 (Cal. Ct. App. 1999) (authorizing conservators of a “severely developmentally disabled” woman to consent to her sterilization); In re Grady, 426 A.2d 467, 475 (N.J. 1981) (holding that the decision to sterilize woman with severe Down’s Syndrome rests with court); see also Turner v. Safley, 482 U.S. 78, 81 (1987) (finding regulation denying prisoners’ the right to marry without warden’s permission unconstitutional under lower standard of review); Buck v. Bell, 274 U.S. 200, 207 (1927) (upholding a statute instituting compulsory sterilization of the “feeble-minded”). The courts employ a rational basis test when evaluating laws that do not infringe on fundamental rights under which the state or local law is upheld as constitutional so long as it is rationally related to a legitimate government purpose. Schiavone, supra note 74, at 306.
124 See id.
power to enact regulations aimed at protecting children from harm. The U.S. Supreme Court, since its initial ruling on the matter, has recognized the fundamental right of parents to raise their children without undue influence from the government. This right, however, is balanced against the right of the child to remain safe from harm and receive adequate care. In *Meyer v. Nebraska*, the Supreme Court held that under the Fourteenth Amendment, the individual is afforded the right to raise children and to “establish a home.” Subsequent cases have further elaborated on this guarantee.

125 See Stanley v. Illinois, 405 U.S. 645, 651 (1972) (stating a parent’s interest in custody and control of his child “undeniably warrants, deference and, absent a powerful countervailing interest, protect”); Lassiter v. Department of Social Services of Durham County, N.C., 452 U.S. 18, 27 (1981) (articulating the state’s urgent interest in the welfare of a child which is similar to the parents interest).


127 See Flavin, supra note 126, at 141. See generally *Prince v. Massachusetts*, 321 U.S. 158 (1944) (explaining the government’s broad authority over children’s activities that are specifically public and endanger the child).

128 262 U.S. at 399-400. *Id.* The Court listed the various liberty guarantees found in the Fourteenth Amendment, including the right to dictate how one raises one’s child. *Id.*

129 See Schiavone, supra note 74, at 286. In the 1925 case of *Pierce v. Society of Sisters*, the Court declared the Nebraska Act in question, which required children be sent to public schools, was in violation of the “liberty of parents and guardians to direct the upbringing and education of children under their control.” See *Pierce v. Society of Sisters*, 268 U.S. 510 at 534-35 (1925) (holding public schooling law in violation of the parents’ liberty interests). In the 1944 *Prince* case, the Court affirmed its prior holdings and declared, “[i]t is cardinal with us that the custody, care and nurture of the child first reside with the parents, whose primary function and freedom include preparation for obligations the state can neither supply nor hinder.” *Prince v. Massachusetts*, 321 U.S. 158, 166 (1944).
Still, the Court’s reasoning explains that claims of religious liberty and parenthood are not absolute, and do not bar the state from entering this sacred realm. The Supreme Court has consistently held parenthood as a fundamental right since the initial ruling. Regardless, the state has chosen to regulate parental decision-making in the medical context, but only in limited circumstances.

2. Government Non-Interference with Parental Decision-Making in the Medical Context

U.S. courts and state legislatures have shown deference to parents’ decision-making regarding the medical treatment of their children, even in cases that ultimately resulted in the death of the child. The law generally protects families who adopt a controversial medical approach that reflects their religious philosophies. Outcomes

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131 See *Prince*, 321 U.S. at 167-68. “The right to practice religion freely does not include liberty to expose the community or the child to communicable disease or the latter to ill health or death.” *Id.*


133 KERN ALEXANDER & M. DAVID ALEXANDER, AMERICAN PUBLIC SCHOOL LAW 258 (2005). The common law doctrine *parens patriae*, meaning parents to all persons, is the mechanism by which states may exercise plenary custodial authority in the welfare and development interests of its children, and in a broader sense, over all its citizens. *Id.* This doctrine is the basis for the requirement that all children, to a certain age, receive the benefits of education. Richard J. Gelles & Carol Wilson Spigner, *Child Welfare Policy, in 4, § 3 COMPREHENSIVE HANDBOOK OF SOCIAL WORK AND SOCIAL WELFARE: SOCIAL POLICY AND POLICY PRACTICE* 295, 300 (2008). For example, the United States Children's Bureau, founded in 1912, was one of the first twentieth century United States government initiatives concerning the “welfare of children and child life.” *Id.* In the second major federal initiative in 1974, Congress enacted the Child Abuse and Prevention and Treatment Act, which sought to prevent child abuse and neglect and treat those subject to such conditions. *Id.* See also *Schiavone*, supra note 74, at 287. Under the Act, child abuse is defined as the “physical or mental injury, sexual abuse or exploitation, negligent treatment, or maltreatment of a child… by a person … responsible for the child’s welfare under circumstances indicating harm or threatened harm to the child’s health or welfare.” *Schiavone*, supra note 74, at 287 (quoting 45 C.F.R. § 1340.2(d) (2010)). Both acts and omissions may constitute abuse. *Id.* Moreover, the Social Security Act of 1935 generally targeted the welfare of poor children in single parent homes with the purpose to protect this group of children from the risks inherent to their economic and social status. Gelles & Wilson Spigner, supra, at 300.


135 See *id.* Spiritual exemptions of varying degree are present in most states ranging from exemptions from vaccinations to the providing of religious defenses for manslaughter, murder of a child, capital murder and even homicide by abuse. *Id.* See, e.g., *In re Boyd*, 403 A.2d 744, 752-53 (D.C. 1979) (applying the substituted judgment rationale and remanding to decide whether the patient would reject medical treatment if the patient would objected to medical care on religious
have varied, however, in criminal prosecutions around the U.S. for the medical neglect of a child when the parent-defendant asserts a religious defense, and parental decision-making led to the child’s death.  

Further, courts have ruled inconsistently in cases of parental consent for medical procedures involving bone marrow and organ transplant—procedures similar to those an HLA matched child may endure. For example, when a sick family member seeks the organ donation of a child family member, parents can give consent on behalf of the child for the organ harvest. Because minors are considered too immature to give consent on their own, parents are entitled to act on their minor child’s behalf, thus protecting caregivers from tort claims. Even in jurisdictions where minors have the

grounds. See also Cruzan v. Dir. Mo. Dep’t of Health, 497 U.S. 261, 285 (1990) (holding the Constitution does not require the state to defer to a patient’s parents’ wishes in decision to remove life sustaining life support from a patient).

Hermanson v. State, 604 So.2d 775, 782-83 (Fla. 1992); Commonwealth v. Twitchell, 617 N.E.2d 609, 618 (Mass. 1993). Several courts have held that no parental liability exists where parents argued that the language of the spiritual exemption was misleading and thus failed to put them on notice of potential criminal liability if their child were to die. Hermanson, 604 So.2d at 782-83. Twitchell, 617 N.E.2d at 618. In other courts, parents have been found liable for the death of their child caused by illness that could have been controlled. See, e.g., Commonwealth v. Nixon, 761 A.2d 1151, 1152 (Pa. 2000); Douglas County v. Anaya, 694 N.W.2d 601 (Neb. 2005) (concluding that the State had a compelling interest in the screening of infants for metabolic diseases which did not infringe upon the parents’ religious beliefs).


Griffith, supra note 123 at 283, 289 (discussing the twenty-first century shift from heightened pern patriae power to greater constitutional protections for the parents). The right of the parent to consent to medical treatment for their child rests in the parent’s Fourteenth Amendment fundamental right to the care, custody, and control of his or her child. Id. Still, this right is in constant conflict with the state’s paren patriae power to protect the best interests of the child. See also Allan H. Goroll & Albert G. Mulley, PRIMARY CARE MEDICINE: OFFICE EVALUATION AND MANAGEMENT OF THE ADULT PATIENT 5 (6th ed., Lippincott Williams & Wilkins 2009) (discussing nature of informed consent as an integral part to the patient–physician relationship); Beth A. Schenberg, Harvesting Organs from Minors and Incompetent Adults to Supply the Nation’s Organ Drought: A Critical Review of the Substituted Judgment Doctrine and the Best Interest Standard, 4 IND. HEALTH L. REV. 319, 323 (2007) (explaining guardian or court may similarly issue consent); Shurtle, supra note 11, at 447-48. Contra Kathleen M. Quinn & Barbara A. Weiner, Legal Rights of Children, in LEGAL ISSUES IN MENTAL HEALTH CARE 306, 311 (Springer ed., 1993) (outlining exceptions to rule that children are legally incompetent to make own medical decisions). In many states, minors may seek “emancipated minor” status by court order, which, if granted, would permit the minor to be treated as an adult. Id. Also, under the “mature minor” doctrine, a minor may consent to a treatment on her own if she is found to hold “sufficient intelligence and maturity to understand the risks and benefits of a proposed treatment.” Id at 311-12.
right to consent to their own procedures in certain circumstances, the exception does
not extend to consent for medical procedures involving tissue or organ harvesting.\textsuperscript{140}
While it is presumed that a parent will act in the best interest of the child in deciding
whether or not to give consent to medical procedures,\textsuperscript{141} the case becomes more
complicated when the substituted consent effectuates a benefit to a third party to whom
the parents also owe a duty.\textsuperscript{142} States do have the authority to intervene when the state’s
interest in preserving human life trumps the parental right to care, custody, and control
of their child.\textsuperscript{143} Accordingly, the courts have attempted to balance the fundamental
familial right of parents with the \textit{parens patriae} power of the state in a series of cases
pertaining to the medical treatment of minors.\textsuperscript{144}

\textbf{E. The Constitutional Rights of Minors in the Medical Context}

Limited case law exists pertaining to instances in which parents gave consent on
behalf of their minor child for HSCTs. The most analogous cases involve scenarios in

\textsuperscript{140} See Schenberg, supra note 139, at 323-24.
\textsuperscript{141} See Jenkins v. Pye, 37 U.S. 241, 254 (1838) (discussing the nature of the parents’ acts in
relation to the child and the presumption that the “advancement of the interest of the child was
the object in view”); Troxel v. Granville, 530 U.S. 57, 68 (2000) (employing an assumption that
“fit parents act in the best interests of their children”); see also Adi Koll, “Parents Act in the Best
Interest of Their Children”: An Inquiry into the Development of the Supreme Court Parental
http://proquest.umi.com/pqdlink?did=1268619041&Fmt=7&clientId=79356&RQT=309&VName=PQD.
\textsuperscript{142} See Gloria J. Banks, \textit{Legal \\& Ethical Safeguards: Protection of Society's Most Vulnerable Participants in
court rulings where organ donation was from an incompetent or child and for the benefit of a
third party).
\textsuperscript{143} See Shartle, supra note 11, at 446-48. The court will apply either the substituted judgment
doctrine or the best interest standard in deciding whether to intervene. \textit{Id.} at 448.
\textsuperscript{144} Id. Note that the same reasoning applies to the scenario where an offspring is considered
1972) (holding that a kidney transplant between identical twins could be consented to by parents
considering the underlying factors); Curran v. Bosze, 566 N.E. 2d 1319 (Ill. 1990) (holding father
could not unilaterally decide consent for one twin in a bone marrow harvest given the best
interests of the twins); Strunk v. Strunk, 445 SW.2d 145 (Ky. 1969) (holding court was capable of
authorizing a kidney transplant from one twin to another upon petition by mother); \textit{In re Richardson},
284 So.2d 185 (La. Ct. App. 1973) (holding neither parents nor state could authorize
“surgical incursion on minor mental retardate” for purposes of kidney donation); Little v. Little,
576 S.W.2d 493 (Tex. Civ. App. 1979) (holding that the court did not exceed its authority in
authorizing a minor mental retardate to participate in a kidney transplant); \textit{In re Pescinski}, 226
N.W.2d 180 (Wis. 1975) (holding that the court lacked authority to permit a kidney transplant
between siblings where there was no consent, nor benefit to the ward).
which organs were harvested from children or incompetent persons for the benefit of family members. In deciding these cases, courts have employed two divergent rationales that are unique in title and theory but often lead to consistent outcomes. The substituted judgment standard, which originated in English courts, permits the fact finder to determine what the incompetent or minor would have chosen had she been confronted with the decision, and act upon that finding. Alternatively, the best interest standard, derived from the states’ parens patriae power, allows the fact finder to make a decision based on the minor or incompetent’s best interest. To determine an individual’s best interest in an organ donation case, the court compares the psychological and physiological effects on the minor or incompetent of going through with the donation to the psychological effects of abstaining from the harvest.

The 1969 Strunk v. Strunk case and the 1990 Curran v. Bosze case appear to be the clearest applications of the substituted judgment and best interest standards, respectively. These are the relevant standards of review for a court reviewing a parental consent conflict over an HLA matched child’s HSCT donation. Discerning which of the two standards the court has employed is often difficult, however, without an explicit indication by the court. In the Strunk case, Kentucky’s highest court authorized a kidney donation from an adult incompetent to his twenty-eight-year-old brother. In reaching the ruling, the court considered the benefits to the incompetent in authorizing the harvest, and the degree of risk associated with the procedure. The court

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145 See Wolf, supra note 137, at 334. But see Curran, 566 N.E. 2d at 1319.
146 See Schenberg, supra note 139, at 327 (stating “[a]lthough both standards may result in the same outcome, the distinction between the two approaches is not merely semantic.”) (quoting Rachel M. Dufault, Comment, Bone Marrow Donations by Children: Rethinking the Legal Framework in Light of Curran v. Bosze, 24 CONN. L. REV. 211, 212 (1991)).
147 See Schenberg, supra note 139, at 328-29 (discussing the early years of the substituted judgment doctrine).
148 See Schenberg, supra note 139, at 336; see also In re Conroy, 486 A.2d 1209, 1231 (N.J. 1985).
150 See Schenberg, supra note 139, at 337. The benefit of the donation is then compared to the risks of the harvest. Id.
151 445 S.W.2d 145 (Ky. 1969).
152 566 N.E.2d 1319 (Ill. 1990).
154 See generally Strunk, 445 S.W.2d 145; Curran, 566 N.E.2d 1319.
155 See Strunk, 445 S.W.2d at 149.
156 See id. at 146 (discussing psychiatrist’s testimony and Department of Mental Health’s amicus brief detailing overriding negative impact on the incompetent if procedure denied).
157 See id. at 148-49 (discussing the low risks associated with renal transplants).
ultimately applied the substituted judgment doctrine and authorized the transplant because the court believed it was what the incompetent would do if he were able to make the decision himself.\textsuperscript{158} The court’s failure to recognize the risks presented to the donor resulted in an incompetent acting as a live organ donor.\textsuperscript{159}

In a case analogous to \textit{Strunk}, the Texas Court of Appeals in \textit{Little v. Little}\textsuperscript{160} employed a relatively simple balancing test, weighing the benefits to the donor of undergoing the procedure against the risks and discomfort that would occur as a result of the donation.\textsuperscript{161} In \textit{Little}, the mother of a mentally retarded minor sought the removal of her daughter’s kidney to be donated to her daughter’s ill brother.\textsuperscript{162} Again, the court authorized the donation given the mother’s consent, and because the benefit

\textsuperscript{158} See \textit{id.} at 148 (holding the right to act for the incompetent is the right to substituted judgment). The right to give substituted judgment “is broad enough . . . to cover all matters touching on the well-being of the ward.” \textit{Id.} The dissent in \textit{Strunk} reviewed case law from the 1940s in arguing that parents may not give consent for their child to donate part of the child’s body. \textit{Id.} at 150 (Steinfeld, J., dissenting); see also \textit{Prince v. Massachusetts}, 321 U.S. 158 (1944) and \textit{Bonner v. Moran}, 126 F.2d 121 (1941). Further, the dissent expressed concern that this practice was too similar to genocide practices where programs of experimentation with human bodies were supported by the government. \textit{Strunk}, 445 S.W.2d at 149. See also \textit{Hart v. Brown}, 289 A.2d 386, 391 (Conn. Super. Ct. 1972). In \textit{Hart}, the court reviewed the reasoning in the \textit{Strunk} case, a series of Massachusetts cases, and the 1941 \textit{Bonner} case, in evaluating whether the court had the power to authorize the kidney donation of a seven-year-old girl to her twin sister. \textit{Hart}, 289 A.2d at 387-90; see also \textit{Bonner}, 126 F.2d at 121; \textit{Masden v. Harrison}, No. 68651 (Mass. Eq. 1957); \textit{Hushey v. Harrison}, No. 68666 (Mass. Eq. 1957); \textit{Foster v. Harrison}, No. 68674 (Mass Eq. 1957). The Massachusetts cases reviewed in \textit{Hart} illustrated the Commonwealth’s position that biological parents of minor twins may consent to organ harvest and donation between the children. \textit{Hart}, 289 A.2d at 387; \textit{Masden}, No. 68651; \textit{Hushey}, No. 68666; \textit{Foster}, No. 68674. Although the court seemed to adopt the substituted judgment standard, it never held that the parents must act in the way the child would act if the child were competent to act for herself. Schenberg, supra note 139, at 330-31 (discussing the \textit{Hart} court’s reasoning and rationale). Rather, the court authorized the donation on the grounds that the parents’ “motivation and reasoning” behind their decision to give consent on behalf of their minor daughter was “favorably reviewed by a community representation, which includes a court of equity.” \textit{Id}; \textit{Hart}, 289 A.2d at 391.

\textsuperscript{159} See \textit{Strunk}, 445 S.W.2d at 148-49.

\textsuperscript{160} 576 S.W.2d 493 (Tex. App. 1979).

\textsuperscript{161} See \textit{Little v. Little}, 576 S.W.2d 493, 500 (Tex. Civ. App. 1979). The court acknowledged that in cases where the potential donor is incompetent due to mental incapacity, the ability of the incompetent to realize the benefits of the operation is unclear; thus, the court follows a less strict substituted judgment doctrinal approach. \textit{Id.} at 498. Whereas a strict interpretation of the substituted judgment doctrine would limit the court to authorize the donation solely if the donor would have consented to the donation herself had she been competent to do so, the court here applied a looser interpretation of the doctrine under which the conclusion to authorize the procedure is based upon the benefits gained by the incompetent donor. \textit{Id.}

\textsuperscript{162} \textit{Id.} at 494-95.
to the donor child outweighed the risks of harm.\textsuperscript{163}

The courts in \textit{In re Richardson}\textsuperscript{164} and \textit{In re Pescinski}\textsuperscript{165} conducted best interest analyses in deciding whether to authorize live organ transplants from minors and incompetents. This standard of review gave more weight to the risks associated with live organ donation, which can be analogized with the risks of tissue and organ donation by PGD child donors, and proved to be more comprehensive than a substituted judgment analysis.\textsuperscript{166}

In \textit{Richardson}, the Louisiana Court of Appeals, in applying the best interest standard, strongly considered the absence of consent on the part of the ward and ultimately declined authorization of a kidney donation from a seventeen-year-old mentally disabled boy to his sister.\textsuperscript{167} In conducting the best interest analysis on behalf of the incompetent minor, the court evaluated the risks associated with undergoing the procedure, the possibility of future donations by the incompetent donor, and the likelihood that the donor would directly benefit from the procedure.\textsuperscript{168}

Similarly, in \textit{Pescinski}, the Supreme Court of Wisconsin denied a petition to authorize the harvest of an incompetent adult’s kidney for the benefit of his sister.\textsuperscript{169} There, the potential donor was a ward of the state diagnosed with schizophrenia, and there was no evidence he consented to the transplant.\textsuperscript{170} The court explicitly accepted the best interest standard, and reasoned “the guardian must act, if at all, ‘loyally in the

\textsuperscript{163} \textit{See id.} at 500 (explaining the standard used to determine whether a donation is appropriate for the minor child).
\textsuperscript{164} 284 So.2d 185 (La. Ct. App. 1973).
\textsuperscript{165} 226 N.W.2d 180 (Wis. 1975).
\textsuperscript{166} \textit{See In re Richardson}, 284 So.2d 185, 187 (La. Ct. App. 1973) (holding that neither courts nor parents can authorize kidney transplant of incompetent minor for sibling); \textit{In re Pescinski}, 226 N.W.2d 180, 181 (Wis. 1975) (holding that guardian of ward must act in the best interest of the ward and cannot permit removal of ward’s kidney).
\textsuperscript{167} \textit{Richardson}, 284 So.2d at 185. The incompetent minor had the mental capacity of a three or four year old. \textit{Id.} at 186.
\textsuperscript{168} \textit{Id.} at 187. The court also noted that the benefits to the sister were not significantly great, as the longest successful kidney transplant had only added 11 years to a life and the sister was not in immediate need of the transplant. \textit{Id.}
\textsuperscript{169} \textit{See Pescinski}, 226 N.W.2d at 182. The sister had both kidneys surgically removed as a result of kidney failure and was kept alive by a dialysis machine, which acted as an artificial kidney. \textit{Id.} at 180.
\textsuperscript{170} \textit{Id.} at 181. As a result of the schizophrenia, the potential donor was estimated to have the mental capacity of a 12 year-old. \textit{Id.}
best interests of his ward.” 171 The court declined to authorize the transplant, given the absence of a manifestation of consent and no showing of a benefit to the ward. 172 In Pescinski, however, the potential donor was an adult incompetent individual whose consent could be issued by the state—a party whose sole duty is to represent the interests of the incompetent. 173 The scenarios above are in stark contrast to that of the HLA matched child, whose parents are issuing consent on behalf of the matched child after deliberating over more than one interest. 174

Still, in In re Doe, the New York Supreme Court Appellate Division alternatively authorized the harvest under the best interest standard where the competing interests of two siblings were at stake. 175 In Doe, the plaintiff petitioned the court to permit the bone marrow harvesting of an incompetent to save the life of the incompetent’s brother. 176 Exercising the state’s parens patriae power, the court affirmed the trial court’s finding that the benefits of the potential recipient surviving were greater than the physiological and psychological risks to the donor in undergoing the procedure. 177

Finally, in the landmark case of Curran v. Bosze, the Illinois Supreme Court rejected the substituted judgment doctrine, adopted the best interest standard, and outlined a three-part test that must be satisfied in order to declare that the bone marrow transplant was in fact in the best interest of the child. 178 The court considered whether: (1) the parent giving its consent on behalf of the child was on notice of all the risks and benefits of the procedure; (2) emotional support was available to the child by the caretaker; and (3) a “close relationship” existed between the parties to the transplant. 179

172 Pescinski, 226 N.W.2d at 182.
173 Id. at 181-82. The court declined to adopt the “substituted judgment” doctrine. Id.
174 Batzer & Ravitsky, supra note 7 and accompanying text.
175 In re Doe, 481 N.Y.S.2d 932 (N.Y. App. Div. 1984). The court concluded that its power to authorize invasive medical procedures against an incompetent is only permissible to the extent that it is in the incompetent’s best interest. Id. at 933.
176 Id. (arguing that the incompetent’s brother was the only family member who made medical decisions for the incompetent and that the bone marrow transplant was the only option to save the brother’s life).
177 See id.; see also Schenberg, supra note 139, at 340.
178 See Curran v. Bosze, 566 N.E.2d 1319, 1320-21 (Ill. 1990) (describing the relationship between the sick child and the twins); Schenberg, supra note 139, at 341; see also Curran, 566 N.E.2d at 1326 (holding “the doctrine of substituted judgment is not relevant and may not be applied to this case”).
179 See Curran, 566 N.E.2d at 1343.
The Curran court concluded that the required affirmative finding of all three elements was not present.180

F. Public & Private Sector Regulation of Organ Donation by Minors

After an HLA matched child is born using PGD technology, the government’s objective shifts from regulating PGD to protecting the child from harm.181 Federal and state courts play perhaps the strongest role in regulating organ donation by minors because they are often the final arbiters granting or declining authorization of the procedure.182 Still, such authorization must be in accordance with existing laws governing organ donation.183 The Uniform Anatomical Gift Act (“UAGA”), enacted by every state government, regulates cadaveric organ and tissue donations.184 There is, however, no broad law in place regulating living tissue donation by minors.185 This determination that it will be in the best interests of a child to donate bone marrow to a sibling. . . . First, the parent who consents on behalf of the child must be informed of the risks and benefits inherent in the bone marrow harvesting procedure to the child. . . . Second, there must be emotional support available to the child from the person or persons who take care of the child. . . . Third, there must be an existing, close relationship between the donor and recipient.

Id. 180 See id. at 1344-45. Although both parents knew of the risks and benefits of the procedure, the mother’s position on the procedure may have limited the amount of emotional support the children would receive if subject to the procedure, and further, no close relationship between the potential donors and recipient was present. Id.

181 See Flavin, supra note 126, at 141 (describing the balance between government’s interest in protecting children and the parents’ interest in raising their children); Shartle, supra note 11, at 445 (explaining that the state has interest in protecting minors, as they are unable to protect themselves).

182 See Shartle, supra note 11, at 447-48 (maintaining that states do not have legislation regulating “living organ donation” by minors). Because of the lack of legislation, courts have some regulation power by deciding to grant or deny donations usually by using the “substituted judgment” standard or the “best interest” standard. Id. at 448.

183 See BERKLEY, supra note 134, at 20 (declaring that all fifty states have laws governing organ donation). Moreover, the federal government has passed the Uniform Anatomical Gift Act which allows individuals to donate organs for a variety of purposes. Id.; Uniform Anatomical Gift Act § 6, 8 U.L.A. (1987) (authorizing the gift of all or part of a human body after death to be construed uniformly among adopting states).

184 See Shartle, supra note 11, at 447-48. “Cadaveric organs” are those transferred from the body of a deceased. Id. at n. 6.

185 See Uniform Anatomical Gift Act § 1 (1987) (limiting gifting to deceased donors by defining “anatomical gift” as a donation upon or after death).
effectually leaves the judiciary with the power to adjudicate the disposition of a donation.\textsuperscript{186}

Moreover, medical professional associations have balanced ethical and legal considerations, and enunciated positions on minors as living organ donors.\textsuperscript{187} In 2000, the U.S. Live Organ Donor Consensus Group ("the Group"), and other representatives of various organizations,\textsuperscript{188} put forth a statement on current organ donation practices.\textsuperscript{189} While generally opposed to live organ donations for minors, the Group concluded that minors could ethically serve as live organ donors if four conditions were met. Generally, these conditions required a showing that the donation would be the final option for the ill child and will be of benefit to the donor.\textsuperscript{190} Additionally, in 2008 the AAP put together a team of bioethicists, doctors, and legal counsel who published a report entitled, "Minors as Living Solid-Organ Donors," detailing specific criteria that must be met in order for minors to serve as living organ donors.\textsuperscript{191} In the team’s evaluation, it considered the benefits received by the donor and recipient, the surgical risk for the

\textsuperscript{186}See Shartle, supra note 11, at 448 (stating that any regulation of organ and tissue donations by minors is implemented at the judge’s discretion).

\textsuperscript{187}See Michael Abecassis et al., Consensus Statement on the Live Organ Donor, 284 J. AM. MED. ASS’N 2919, 2919 (Dec. 13, 2000), available at http://www.kidney.org/transplantation/livingdonors/pdf/jama_article.pdf (concluding that a consenting live organ donor “should be competent, willing to donate, free of coercion, medically and psychosocially suitable, fully informed of the risks and benefits as a donor, and fully informed of the risks, benefits, and alternative treatment available to the recipient.”). Moreover, a cost-benefit analysis must be performed under which the benefits to both the donor and recipient must outweigh the risks of donation and transplantation. Id. See, e.g., Lainie Freidman Ross, et al., Minors as Living Solid-Organ Donors, 122 PEDIATRICS 454, 454-61 (August 2008), http://pediatrics.aappublications.org/content/122/2/454.full.pdf+html (outlining specific circumstances in which minors may ethically serve as living organ donors).  

\textsuperscript{188}Abecassis, supra note 187, at 2919. The other organizations included: representatives from the National Kidney Foundation and the American Societies of Transplantation, Transplant Surgeons, and Nephrology. Id.

\textsuperscript{189}Abecassis, supra note 187, at 2926.

\textsuperscript{190}Abecassis, supra note 187, at 2925-26. The four conditions under which a minor may ethically act as a live organ donor included:

- When the potential donor and recipient are both highly likely to benefit.
- When the surgical risk for the donor is extremely low. When all other opportunities for transplantation have been exhausted, no potential adult living donor is available, and timely and/or effective transplantation from a cadaver donor is unlikely. When the minor freely agrees to donate without coercion.

\textsuperscript{191}See Friedman Ross, supra note 187, at 456-57 (setting forth the Organ Donation Consensus Group’s four conditions, as well as the AAP’s fifth added condition, in which a minor may participate as a living organ donor).
donor, the existence of other options, the consent of the donor, and the emotional and psychological risks to the donor. Moreover, it elaborated on the findings of the Organ Donation Consensus Group, and added a fifth requirement, that the emotional and psychological risks to the donor child be minimized. Still, the AAP declared that children who are unable to provide informed consent should not be subjected to the procedure. Bioethicists have similarly promulgated guidelines thought to be more protective of the donor child and more restrictive on medical professionals than other advisory groups.

III. Regulating Preimplantation Genetic Diagnosis

Assisted reproductive technologies are a hot topic for debate despite their protection under the current U.S. reproductive rights paradigm. Now, more than ever, medical practitioners can identify the fundamental genetic characteristics of an embryo. They can classify gender and diagnose the propensity for early onset disease, Down’s syndrome, and disability in the first days following conception. Parents who couple this technology with HLA matching do so to ensure that the child is compatible for live tissue transfer with another existing family member in need of a transplant. As a result, children may be born for the purpose of serving as an organ host for their ill siblings without interference or protection from the United States government.

Once again, technology is moving faster than law, resulting in an inadequate

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192 See Friedman Ross, supra note 187, at 456-57 (describing in more detail the five conditions for a minor living organ donor).
193 See Friedman Ross, supra note 187, at 457 (highlighting the need of a fifth condition in order for minor living organ donations to occur only in the rarest of circumstances).
194 See Friedman Ross, supra note 187, at 458.
195 See generally Wolf, supra note 137 (detailing nine more stringent guidelines to further protect the donor child).
196 See King, supra note 2 and accompanying text (emphasizing the ethical divide on advances in the biotechnological and biomedical field). But see infra notes 201-203 and accompanying text (expanding on the constitutionally protected privacy rights).
197 See generally Cai, supra note 14 (providing an overview of the negative aspects of a blastomere biopsy); see also supra note 34 and accompanying text (detailing a blastomere biopsy).
198 See generally Milunsky & Milunsky, supra note 38 (discussing the various functions of PGD). See also supra note 33 and accompanying text (discussing PGD performance on the two polar bodies formed after conception); supra note 34 and accompanying text (discussing PGD performance on the day three blastomere).
199 See generally Devolder, supra note 10 (discussing the federal and private PGD regulations).
200 See Fahrenkrog, supra note 71, at 768-69 (discussing the United States’ lack of regulation on PGD).
legal framework for PGD with HLA matching technology. As a remedy, nations around the globe have enacted full or partial bans on PGD and the associated screening procedures such as HLA matching. U.S. courts, however, would likely deem such restrictions to be unconstitutional given the procreative liberties afforded to all citizens by the Supreme Court’s present interpretation of relevant provisions of the Constitution. Further, this route would be ineffective because the goals of regulation are to protect children born to this technology from the invasive procedures that follow their birth, not to limit the amount of children susceptible to such peril. As PGD children remain under the care, custody, and control of their parents, the state must invoke its "parens patriae" power and enact statutory prohibitions of live tissue donations from minors to protect those born as a result of PGD with HLA matching technology.

A. Partial or Full Ban Not a Viable Remedy

The U.S. Constitution provides the parameters for PGD regulation. Through
the Supreme Court’s interpretation of the Constitution, it has established that a fundamental right to privacy, namely to procreate or avoid procreation, must be afforded to all citizens.\textsuperscript{207} Still, this fundamental right is not absolute, as courts have upheld scenarios limiting the right when a state has presented a compelling reason to do so.\textsuperscript{208}

A ban on PGD would fail based on its inherent connection with the destruction of embryos.\textsuperscript{209} In cases such as \textit{Roe} and \textit{Casey}, the Court recognized the woman’s right to an abortion, while contemporaneously denying the embryo legal status as a “person.”\textsuperscript{210} While embryos destroyed as a result of PGD are not \textit{in utero}, like in \textit{Roe} and \textit{Casey},\textsuperscript{211} these cases still illustrate that PGD could not be banned based on the argument that it is the destruction of a life.\textsuperscript{212}

The fundamental right to reproduce does not likely encompass the right to perform PGD with HLA matching on an embryo.\textsuperscript{213} The \textit{Eisenstadt} case, which struck down a Massachusetts law prohibiting the distribution of contraceptives, established that the fundamental right to reproduce is rooted in an individual’s right to “bear or beget child.”\textsuperscript{214} PGD, although an ART, is not a necessary step in conception and reproduction; rather, it entails a series of diagnostic procedures that take place after

\begin{addendum}
\item See \textit{Griswold}, 381 U.S. at 484; \textit{Skinner}, 316 U.S. at 541. See generally U.S. CONST. amend. I (privacy is protected through its protection of associational rights, including those encompassed in: U.S. CONST. amend. III; U.S. CONST. amend. IV; U.S. CONST. amend. V.)
\item See generally \textit{Buck} v. \textit{Bell}, 274 U.S. 200 (1927) (holding the state may provide for the sterilization of the “feeble minded” inmate); \textit{In re Angela D}, 83 Cal. Rptr. 2d 411 (Cal. Ct. App. 1999) (authorizing the sterilization of a mentally retarded woman as in the interest of the state in accordance with state law). \textit{Contra In re Grady}, 426 A.2d 467, 486 (1981) (rejecting the parents’ right to exercise substituted consent for the sterilization of their mentally impaired daughter).
\item See generally \textit{Roe} v. \textit{Wade}, 410 U.S. 113 (1973) (recognizing the right to procure an abortion as well as the state’s right to regulate after the point of viability); Planned Parenthood v. Casey, 505 U.S. 883 (1992) (maintaining the holding in \textit{Roe} while downgrading the right to an abortion from a fundamental right to a protected liberty interest).
\item See \textit{generally} Roe, 410 U.S. at 113; \textit{Casey}, 505 U.S. at 883.
\item See \textit{generally} \textit{In Vitro Fertilization: IVF, supra} note 21 (outlining the IVF cycle).
\item See \textit{Schiavone, supra} note 74, at 303-04 (stating, “precedent tells us that [PGD] should not be a fundamental right.”)
\end{addendum}
insemination for both medical and non-medical purposes. Individuals who have had difficulty achieving full-term pregnancy may argue that performing PGD to screen for healthy embryos is a fundamental right because the non-employment of the technology may hinder their ability to ever achieve a viable pregnancy. Still, this argument is not relevant to the HLA discussion, as the ultimate goal of HLA matching is not specifically to ensure a healthy, successful pregnancy. Rather, it is designed to identify and compare the HLA type of the embryo to the HLA type of the potential transplant recipient. Accordingly, PGD with HLA matching would not be protected as a fundamental right to procreation because it is not a necessary step in the reproductive process.

Laws interfering with the ability to provide or obtain services for PGD with HLA matching would, therefore, be subject to the rational basis test. Under this standard of review, the courts uphold such laws so long as they are deemed to serve a legitimate government purpose and are drafted in a way that is rationally related to the achievement of that purpose. Thus, a court would have to find that prohibition of PGD serves a legitimate government purpose and that a ban is rationally related to achieve that purpose.

This finding leads to a subsequent question: Who has the authority to regulate PGD, and by what means may they do so? The federal government has not played an

215 See Schiavone, supra note 74, at 305.
216 See Hill, supra note 45, at 579 (discussing the use of PGD to detect chromosomal translocations affecting the ability of the individual to hold child). See also Schiavone, supra note 74, at 303-304 (citing J.R. v. Utah, 261 F. Supp. 2d 1268 (D. Utah 2003)). The J.R. court held that biological parents of children carried by a gestational carrier had “fundamental rights and liberty interests” in the parent-child relationship because the surrogacy presented these parents with their “singular opportunity to procreate.” J.R., 261 F. Supp. 2d at 1274-76.
217 See supra note 54 and accompanying text.
218 See supra note 53 and accompanying text. See also Devolder, supra note 17, at 585 (suggesting the HLA donor’s risk).
219 See supra note 53 and accompanying text.
220 See Schiavone, supra note 74, at 306-07 (comparing the rational basis test with the strict scrutiny standard of review). See also McCulloch v. Maryland, 17 U.S. 316, 421-23 (1819) (contemplating means to an end standard of review). See generally United States v. Carolene Products Co., 304 U.S. 144, 152 (1938) (distinguishing rational basis as a necessary factor in the legislature’s decision to adopt a law).
221 See Schiavone, supra note 74, at 306-07.
222 See Carolene Products Co., 304 U.S. at 152 (suggesting due process would be denied if the rational basis for a law that deprived life, liberty or property was not ascertained).
223 See Cho, supra note 10, at 40 and accompanying text; see also Shuppner, supra note 10, at 455.
active role in ART regulation, as is evidenced by the lack of a current federal regulatory scheme. Private regulation is at the forefront of PGD regulation, but it has proven to be more suggestive than compulsory, and lacks penalties for non-conformance. In order to ensure that PGD with HLA matching will not be used to exploit the life it creates, regulation must go beyond the imposition of laboratory standards and recommendations to medical practitioners performing the procedures.

Even so, neither a full nor partial ban would effectuate the ultimate goal of regulation, which is protection of the donor child. Even if a full ban were implemented, parents could elect to reproduce naturally and continuously until one of the naturally conceived children proved to be a strong HLA match with the ill sibling. The increasingly common performance of PGD with HLA matching has revealed the need for legal intervention to better reflect all stakeholder interests—an intervention not likely to occur in the judicial arena as evidenced by the staggering results in the court cases involving the varying standards that aim to protect minors and incompetent individuals.

B. Proposed Reformations of Law

1. Limited Judicial Intervention Likely for HLA Babies

Contemporary reproductive medicine gives parents the ability, in many ways, to design their offspring. The judicial system has played the strongest role in balancing the state’s power to protect the best interests of the child, with the parents’ right to

224 See Cho, supra note 10, at 40 and accompanying text.
225 See id. (naming two private regulators but stressing that their standards are “legally unenforceable”).
226 See Cho, supra note 10, at 40 (highlighting the professional industry’s standards as unenforceable and easily manipulable); see also MILUNKSY & MILUNKSY, supra note 38 and accompanying text; Bonnicksen, supra note 74, at 77.
227 See Devolder, supra note 17, at 583 (detailing the ethical considerations of PGD with HLA matching and risks to the donor child).
228 See Devolder, supra note 17, at 582 (discussing ability to reproduce and create an HLA matched sibling but with a one in four chance of success).
229 See Nicole Herbert, Creating a Life to Save a Life: An Issue Inadequately Addressed by the Current Legal Framework Under Which Minors are Permitted to Donate Tissue and Organs, 17 S. CAL. INTERDIS. L.J. 337, 340-41 (2008) (discussing the future increased use of PGD with HLA matching to conceive child donors); Devolder, supra note 17, at 582. See generally supra note 49 and accompanying text (discussing the correlation between donation success and donors and recipients well matched in HLA).
230 See MILUNKSY & MILUNKSY, supra note 38, at 972.
exercise care, custody, and control over their child. Nevertheless, the landmark cases adjudicating organ donations among sibling minors have not confronted the specific situation where the child at issue was born as a result of a PGD with HLA matching technology. Still, if a court were confronted with this scenario, the substituted judgment, and in some applications the best interest standard, would likely be applied. Neither standard, however, would sufficiently protect the interest of the HLA matched child in its first years of life.

If the substituted judgment standard were applied to a case in which the donor was a PGD with HLA matching child, the court may fail to properly analyze the risks and benefits posed to the donor child, as such a limited acknowledgement of risks was afforded in previous analogous cases. For example, in Strunk, the court stepped into the shoes of the incompetent individual in an attempt to analyze the factors from his perspective. Here, the nature of the child’s conception as well as the likelihood of the child being subjected to additional procedures, further complicates the decision, limiting the court’s ability to comprehend the position of the PGD child and give “substituted” judgment on his behalf. The substituted judgment standard is both non-uniform and subjective in its application as it allows the court to perform a type of cost-benefit analysis on behalf of the child.

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233 See Banks, supra note 142, at 89-93 (discussing court rulings where organ donation was from an incompetent or child and for the benefit of a third party).
234 See id. at 90 (discussing the faults of the substituted judgment standard due to its subjective nature and use in cases involving “never competent” individuals).
235 See Strunk, 445 S.W.2d at 148 (applying the substituted judgment standard in the case of an incompetent, ward of the state); see also Little, 576 S.W.2d at 496-99 (discussing the origin and application of the substituted judgment standard); Schenberg, supra note 139, at 328-30 (discussing the history of the substituted judgment standard).
236 See Strunk, 445 S.W.2d at 148; Policy Statement, supra note 13, at 400; supra note 66 and accompanying text (discussing the potential psychological impact of donation on a child donor).
237 See Schenberg, supra note 139, at 334 (calling the court’s conclusion, after conducting a substituted judgment analysis, a “legal fiction”). In Strunk, the court applied four general factors in deciding whether to authorize the donation. 445 S.W.2d 145, 146-49 (Ky. 1969). The court found it had the authority to apply the substituted judgment standard and act on behalf of the incompetent, as he would do for himself if he were able. Id. at 148. Psychiatric testimony pertaining to the benefit to the incompetent as to the operation was weighed. Id. at 146-47. The chance of success of the transplant was considered, and finally the risk to the donor. Id. at 148-49.
the court strayed from the Strunk analysis and prescribed an even looser standard of review which would provide even less protection to the donor child.238 Thus, the substituted judgment standard, as applied in Strunk and Little, fails to give appropriate weight to the donor’s risks from the organ transplant, and would similarly fail to protect a child born as a result of PGD with HLA matching technology.239

Alternatively, the best interest standard, applied by courts in the context of organ donation among minor siblings, has proven to be more objective in determining which outcome is in the best interest of the incompetent or minor child.240 For example, the factors the court considered in Richardson, including the risks of harm from the procedure, the possibility of future harvests, and the likelihood the child would directly benefit from the procedure, would address serious concerns for a child born specifically as an HLA match, as he or she would likely be subjected to more than one harvest of increasingly harmful degree or risk.241 Similarly, the best interest standard as applied in Pescinski, where the court refused to authorize a transplant when the potential donor did not manifest consent, would afford greater protection to a PGD donor child, as many are young minors at the time the harvest occurs and unable to understand the procedure to consent to it.242 The court in Doe recognized the psychological and physiological risks of a bone marrow transplant, but still authorized the transplant.243 Notably, the beneficiaries of the transplants in both Richardson and Doe were caretakers of their institutionalized incompetent recipient siblings, a scenario not likely to occur in the context of PGD with HLA matching, because the recipient is often a young child born with the disease requiring the HSCT.244

238 See Little v. Little, 576 S.W.2d 493, 499-500 (Tex. Civ. App. 1979); Banks, supra note 142, at 90.
239 See Strunk, 445 S.W.2d at 148-49 (claiming that the risks to the donor from the procedure are minimal); Little, 576 S.W.2d at 499 (summarizing the facts of the case and alleging that the risks associated with a kidney transplant are “minimal”); see also Matas, et al., supra note 64, at 830-34 (discussing risks associated with kidney transplants).
241 See Richardson, 284 So.2d at 187.
242 See Pescinski, 226 N.W.2d at 181 (explaining refusal to approve transplant because child did not provide consent and would not benefit from procedure).
243 See Doe, 481 N.Y.S.2d at 932 (approving transplant because incompetent donor benefited from future company and advocacy of brother).
244 See generally id. (emphasizing that the recipient is the potential donor’s brother and sole caretaker); Richardson, 248 So.2d at 185 (addressing a situation where the recipient is sister of, and lives with, potential donor).
Curran presented perhaps the most protective standard, which consisted of a three-part test that is comparable to the recommendations of the professional associations.245 The court required the informed consent of the parents, availability of emotional support to the child from the child’s parents or caretakers, and “an existing, close relationship between the donor and recipient,” before it would declare the procedure in the best interest of the child.246 The third factor proves critical for the protection of minors as it may prevent the donor child from being subjected to invasive procedures for the benefit of a third-party, unrelated beneficiary.247

While some courts have acknowledged that the risks presented to the donor usually outweigh the benefits, a pattern of arbitrary, subjective standards has been established that does little to protect children born for the purpose of serving as host.248 This point reveals the essential reason why the government must enact statutory intervention to limit both family requested or court mandated tissue and organ donation by minors.249

C. Statutory Barriers to Prohibit Live Tissue Donations from Early Minors

Medical professionals in both the reproductive and pediatric fields have issued positions on the use of PGD technology.250 However, as several of the advisory bodies

245 See Curran v. Bosze, 566 N.E. 2d 1319, 1343 (Ill. 1990) (focusing on the donation of bone marrow from minor to half-sibling).
246 See id. The court focuses on the following three critical factors: (1) the consenting parent is informed of both the risks and benefits to the child of the procedure used to harvest bone marrow; (2) there is emotional support for the child from the child’s caretaker because a child needs emotional support of a person he loves and trusts while undergoing such a procedure, and needs such support to alleviate any fears associated with the unfamiliarity of the procedure; and (3) there must be a close relationship because for a bone marrow transplant to be of benefit to the donor child, it would be a psychological benefit. Id.
247 See id. at 1343-44. The third factor encompasses the psychological benefit of the donation that is based upon the known family relationship of donor and recipient. Id. at 1343. The court recognizes that it is only instances where this existing relationship is present, that there can be any real chance of a psychological benefit to the child donor because the best interest of the donor child is affected by both the existing relationship and the possible future continuing relationship. Curran v. Bosze, 566 N.E. 2d 1319, 1344 (Ill. 1990).
248 See generally Schenberg, supra note 139 (analyzing legal, ethical, and moral issues of live organ donation involving minors and incompetent individuals).
249 See generally Hebert, supra note 75 (arguing the legal framework for child donors does not protect children and requires legislative reform).
250 See Bonnicksen, supra note 74, at 76-77 (explaining how professional societies self-regulate by publishing guidelines addressing ethics and informed consent); Schuppner, supra note 10, at 448-
are specific to a single area of practice, the regulations promulgated often do not address the full spectrum of issues. Only the AAP has directly recognized the need for stronger regulation of the procedures performed on children born to PGD technology.

There are stark distinctions between the common law and professional associations’ recommendations. The courts’ use of the substituted judgment standard and best interest doctrine, while giving consideration to the psychological and physiological impact on the child, does not always result in the prohibition of the harvest. On the other hand, the AAP’s recommendation seeks to limit the procedure to include only those who are appropriate candidates, are likely to achieve adequate recovery, and are able to recognize the benefits of the harvest. Moreover, the AAP recommendation excludes young minors and incompetents who are incapable of

552 (discussing private sector’s ART regulations and the current state of PGD policies).

251 See, e.g., Bonnicksen, supra note 74, at 77 (relating to the role of ASRM in its oversight of PGD); Schuppner, supra note 10, at 452 (discussing practice guidelines of both PGDIS and RESOLVE); ASRM Position on Gender Selection, supra note 83; Bonnicksen, supra note 74, at 78 (discussing that CAP concerns itself with laboratory standards for those performing PGD). See generally Friedman Ross, supra note 187. ASRM and PGDIS have issued guidelines on the performance of PGD procedures, whereas RESOLVE has expressed positions on government regulation. Id.

252 See Bonnicksen, supra note 74, at 78 (discussing current regulations, without reference to need for heightened regulation for children born to PGD). See generally Friedman Ross, supra note 187. The AAP discusses the ethical issues of minors serving as living donors, relying on the traditional benefit/burden calculus and providing an analysis of the instances when a minor may morally serve as a living donor, how to minimize risks, and what the informed-consent process should require. Id.

253 Compare Strunk v. Strunk, 445 S.W.2d 145, 148-49 (Ky. 1969) (explaining and then applying the substituted judgment standard), and Curran v. Boszec, 566 N.E.2d 1319, 1324-26 (Ill. 1990) (employing the best interest standard), with Abecassis, supra note 187 (summarizing the Consensus Statement on the Live Organ Donor), and Friedman Ross, supra note 187, at 456-57 (outlining the specific and limited criteria required to ethically authorize a living organ transplant). Interestingly, the conclusion in Little implored the legislature to address the issue of living organ donations from minors and incompetents, acknowledging that “legislators are better qualified to conduct the necessary investigations which will yield a system of rules to adequately protect minors and other incompetents from exploitation.” Little v. Little, 576 S.W.2d 493, 500 (Tex. Civ. App. 1979).

254 See Curran, 566 N.E.2d at 1343 (discussing three-part analysis used to determine whether a court should authorize an organ donation). The court considered whether the parents provided informed consent, whether there was emotional support available to the donor child, and whether there was a close relationship between the donor and recipient. Id.

255 See Friedman Ross, supra note 187, at 456-57 (outlining five conditions for a minor to participate as a living organ donor).
understanding the benefits of the procedure and unable to voluntarily consent to it.\textsuperscript{256}

The court in \textit{Curran}, by enacting the more protective three-factor test, took a stance similar to that of the AAP.\textsuperscript{257} Still, the element that “an existing, close relationship between the donor and recipient” be present before the court authorizes the transplant is seemingly subjective, as a close relationship could be present in a sibling relationship, despite the fact that one sibling is an infant or young minor.\textsuperscript{258} This element, while in line with the general sentiment of the AAP proposed guidelines, does not prove stringent enough to limit organ donations by minors to rare or exceptional circumstances, which is the stated goal of the AAP.\textsuperscript{259}

\section*{D. Statutory Intervention}

Recommendations from professional societies integrated with existing judicial standards must be adopted to protect young minors from being exploited by live tissue or organ harvests.\textsuperscript{260} As all states have enacted the UAGA, which regulates the cadaveric organ and tissue donations after death, states must similarly enact a broad law regulating live organ donation by minors.\textsuperscript{261} In effect, courts would look to precedent while simultaneously giving consideration to the new regulation, making neither the sole

\begin{itemize}
\item \textsuperscript{256} See \textit{id.} at 467 (requiring the minor to freely assent without coercion to the living organ donation). This final distinction exemplifies a fundamental difference between common law and the private industry standard. \textit{See, e.g.}, Hart v. Brown, 289 A.2d 386, 391 (Conn. Super. Ct. 1972) (granting parents’ request for authorization of a kidney transplant from a seven year-old donor to her twin sister). Furthermore, this particular harvest is not the youngest to have occurred. \textit{See} Gitter, supra note 46, at 978. In 2000, Lisa and Jack Nash give birth to a PGD baby, Adam, matched in HLA and screened for the genetic disorder of his sister. \textit{Id.} Adam’s umbilical cord blood was infused into his sister, who showed bone marrow recovery after four weeks. \textit{Id.}
\item \textsuperscript{257} See supra note 251 and accompanying text. The three-factor test specifically resembled “Condition 4” and “Condition 5” adopted by the AAP. \textit{See} Friedman Ross, supra note 187, at 457.
\item \textsuperscript{258} \textit{Curran} v. \textit{Bosze}, 566 N.E. 2d 1319, 1343 (Ill. 1990).
\item \textsuperscript{259} See \textit{id.} at 1343 (discussing the “existing, close relationship” requirement); \textit{see also} Friedman Ross, supra note 187, at 456 (suggesting the AAP’s concurrence with the US Live Organ Donor Consensus Group that minors’ organ donations be limited to rare situations).
\item \textsuperscript{260} \textit{See} King, supra note 73, at 323-24 (suggesting professional societies, existing government agencies, or a new government agency could best regulate live tissue donations and organ harvests); \textit{see also} Gitter, supra note 46, at 983 (suggesting the demand for PGD with HLA matching will only increase).
\end{itemize}
If this form of statutory intervention were enacted, infants, toddlers, and young minors would not be subject to live organ donations; the courts would only have authority to approve the harvest years later, when this class of individuals is able to freely assent to the procedures.

Live tissue harvests require additional regulation, as the proposed organ harvest regulation will be too narrow to protect children born as HLA matches for sick siblings. Tissue harvest regulations should be drafted to reflect judgments made by the AAP, as this organization has extensively studied the subject and has taken the interests of the child into account. Children matched for HLA may be subjected to umbilical cord blood transfers before, during, or after birth, as well as bone marrow transfusions, because the transplantation of HLA matched stem cells found within the blood and marrow may be the last remaining treatment for an ailing sibling. Umbilical cord blood excised during or after birth should have no impact on the newborn; however, cord blood drawn before birth may affect the infant’s health. Further, bone marrow extraction causes acute pain and poses risk of residual psychosocial and physiological effects on the donor. The use of minors as bone marrow donors must be statutorily regulated in a fashion similar to that of children as live organ donors in order to protect unknowing and non-consenting minors from such invasive procedures.

The following questions still remain: What happens when parents need the assistance of an HLA matched donor immediately? Will doctors be encouraged to extract stem cells from a growing, in utero fetus for the benefit of the living, ill child? If so, would the next step be an attempt to grow and extract extra utero, perhaps with no

262 See U.S. CONST. art. VI, cl. 2. Under the Supremacy Clause, federal statutes are the “law of the land.” Id.
263 See Abecassis, supra note 187, at 2925-26 (discussing whether minors can truly give voluntary consent); see also supra note 190 and accompanying text. Under this framework, minors would only be prospective organ donors after maturing to the extent that they may be able to give consent without coercion. Abecassis, supra note 187, at 2925-26.
264 See Abecassis, supra note 187, at 2925-26; see also supra note 187 and accompanying text. These proposed regulations are exclusive to organ donation. Abecassis, supra note 187, at 2925-26.
265 See generally Friedman Ross, supra note 187, at 456-57 (discussing the AAP report entitled, “Minors as Living Solid-Organ Donors”). This report did not discuss hematopoietic stem cell transplants but, rather, live organ donations. Id. at 456.
266 See Pennings, supra note 54, at 535.
267 See Ballen, supra note 58, at 3787.
268 See supra Part C, pp. 8-12; supra text accompanying note 63, 69. But see supra note 67 and accompanying text.
269 See supra note 59 and accompanying text.
desire to reproduce a child at all? Could such cells become articles of commerce, bought and sold on the open market? Questions of ownership, greed, and power would follow. The practice of PGD for non-medical purposes challenges society to consider not only the ramifications of these practices on the genetic makeup of the human race, but also to question whether the values embodied in these practices are those which are representative of the nation as a whole. The response to these questions will be unique to the individual depending on his or her personal morals and interests. Still, society’s answer must be clear. It must be memorialized and upheld through our legislative system, and must protect the agency of the child from birth. These principles were those upon which our nation was founded and must, once again, be invoked to preserve the dignity and autonomy of the human from birth.

PGD with HLA-matching remains unregulated by the federal government today. Its oversight is left to private groups associated with the medical profession. This lack of public intervention may be grounded in the government’s concerns that any regulation would be in violation of the Constitution. Procreative liberties are deeply rooted in the Fourteenth Amendment, and ART will likely fall within its protected sphere.

Nevertheless, PGD with HLA matching for the purposes of creating a donor child is perhaps the most ethically questionable among the associated PGD screenings, and it presents an additional set of ethical and legal dilemmas. The procedure results in a human life whose purpose, from the time of its conception, is to serve as host for an ailing sibling. Furthermore, the extent of the harvesting is unknown at the outset, as it is uncertain whether the umbilical cord blood will cure the sibling or whether future procedures will be necessary. Subsequent procedures may range from bone marrow extraction to organ harvesting. The psychological impact of these procedures, and the repercussions of being born into a donor role within the family, may have severe, negative effects on the donor child. Thus, the rights of the child must be protected. Inherently tied to the discussion of HLA matching is the right of the parent to consent to medical treatment of the child. Parents who create an HLA matched child rely on their right to give consent on behalf of that child so he or she can serve as donor. Thus, statutory law governing the ability of minors to serve as live tissue donors must be reformed to protect minors in the first years of life from being subjected to invasive medical procedures by the consent of their parents.

Every individual born as a citizen of the United States deserves to be protected from invasive medical procedures that are solely for the benefit of another. In defense of the liberty interest of the child, and in sacrifice of the benefits that may be derived
from the invasion of that child’s independence, “I would rather be exposed to the inconveniences attending too much Liberty than those attending a too small degree of it.” —Thomas Jefferson\textsuperscript{270}