

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

NICOLE HEBERT*

Parents may be free to become martyrs themselves. But it does not follow that they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion when they can make that choice for themselves.

- Judge Steinfeld

Strunk v. Strunk, 445 S.W.2d 145, 150 (Ky. 1969) (dissenting)

I. INTRODUCTION

The practice of organ and tissue donation between humans in America is quite young, but has changed significantly in a relatively short period of time. In 1936, Voronoy, a Russian surgeon, completed the first organ transplant between humans. He removed a kidney from a cadaver and transplanted it into a patient. Unfortunately, the patient did not survive for more than forty-eight hours and little detail about the procedure is known.¹ In 1955, Dr. David Hume performed, and thoroughly documented, nine renal transplants. Six of the kidneys were donated by cadavers and three by living donors.² Regrettably, the transplants were only moderately successful.³ The first human bone marrow grafting procedures were also

* J.D. Candidate, Class of 2008, University of Southern California Law School; B.A. in Psychology, B.A. in Communications, 2005, University of California, Los Angeles. I would like to thank Professor Carrie Hempel for her valuable assistance throughout the writing process. I would also like to thank my family, particularly my parents, Susan and Gabriel, and my fiancé, Brian Baker, for their unwavering support.

¹ David M. Hume, John P. Merrill, Benjamin F. Miller & George W. Thorn, *Experiences with Renal Homotransplantation in the Human: A Report of Nine Cases*, 34(2) J. CLINICAL INVESTIGATION 327, 330 (1955).

² *Id.* at 331-33.

³ *Id.* at 377-78 (summarizing that five of the nine transplants did not develop "measurable function" and the four out of nine transplants that did develop "measurable function" did so for only thirty-seven to one hundred and eighty days).

attempted during the 1950s⁴ and the first bone marrow transplant was conducted in 1956.⁵

The first kidney transplant deemed successful pursuant to medical standards was conducted in 1954 and spurred on a rapidly growing field of tissue and organ transplantation.⁶ Surgeons Joseph Murray and John Hartwell Harrison and nephrologist John P. Merrill removed a kidney from a living-related donor and successfully transplanted it into the donor's identical twin brother.⁷

Shortly after Murray's successful transplant between identical twins, the first transplant involving an organ harvested from a living child-donor was conducted, raising a number of ethical and legal concerns. The kidney transplant was completed once the surgeons had procured consent from the donor's parents, and after legal counsel concluded that consent from a donor's parents or guardians combined with the donor's informed consent would be sufficient to permit an organ donation from a minor.⁸ To minimize some of the ethical concerns regarding using children as donors following this initial transplant, subsequent organ donations from living minors were only permitted if the donor was above the age of twelve or thirteen.⁹

In the ensuing fifty years, the practice of harvesting tissue and organs has changed significantly, particularly in regards to child-donors. Today, a sizeable number of organ donations are procured from siblings of the transplant recipient, many of whom are minors.¹⁰ In fact, in California, as of 2006, twelve percent of organ donors were under the age of eighteen.¹¹ Nationwide, from 1989 to 1998, it was reported that ninety-six kidney donations were made from living minors between the ages of less than one to seventeen years old. Remarkably, the number of organ donations from living minors doubled each year from 1997 through 1999.¹² While no exact figures are available to demonstrate the number of minors who have

⁴ Herbert N. Brown & Martin J. Kelly, Clinical Report, *Stages of Bone Marrow Transplantation: A Psychiatric Perspective*, 38(6) PSYCHOSOMATIC MED. 439 (Nov.-Dec. 1976).

⁵ Mark F. Anderson, *Encouraging Bone Marrow Transplants from Unrelated Donors: Some Proposed Solutions to a Pressing Social Problem*, 54 U. PITT. L. REV. 477, 481 (1993).

⁶ Arnold G. Diethelm, *Ethical Decisions in the History of Organ Transplantation*, 211(5) ANNALS SURGERY 505, 507-08 (1990).

⁷ *Id.*

⁸ Diethelm, *supra* note 6, at 508-09.

⁹ *See id.*

¹⁰ Michael T. Morley, Note, *Proxy Consent to Organ Donation by Incompetents*, 111 YALE L.J. 1215, 1220 (2002) ("Since 1996, 109 children have received kidney transplants, and four children have received liver transplants, either from a full or half-sibling.")

¹¹ California Transplant Donor Network, Statistics, Donor Age, http://www.ctdn.org/resources_public.php (last visited Mar. 21, 2007). It should be noted that it is not clear what percentage of this twelve percent constitutes living donations. *Id.* In fact, it is quite difficult to locate statistics regarding the number of living minors who have donated organs. Many of the organizations that publish statistical information regarding organ transplants are transplant centers that clearly endorse donation and probably do not wish to publish information which some may interpret as demonstrating children are being taken advantage of when it comes to organ donation. *See generally* Laura Meckler, *The Dark Side of Organ Donation*, CBSNEWS.COM, Aug. 12, 2003, <http://www.cbsnews.com/stories/2003/08/12/health/main567903.shtml> (stating that transplant centers and programs make money and gain prestige with every transplant and therefore have the goal of doing more transplants) (last visited Jan. 5, 2008) [hereinafter *The Dark Side of Organ Donation*].

¹² Bryan Shartle, Comment, *Proposed Legislation for Safely Regulating the Increasing Number of Living Organ and Tissue Donations by Minors*, 61 LA. L. REV. 433, 450 (2001).

donated tissue,¹³ it is fair to assume that today minors are frequently called upon to donate bodily tissue, primarily to their siblings.¹⁴

The practice of procuring tissue and organs from children drastically changed in August 2000, when the media extensively covered a story in which a child was “manufactured” through the use of assistive reproductive techniques primarily for the purpose of being an organ donor.¹⁵ Mr. and Mrs. Nash, the parents of this “savior child,” employed two regularly used and accepted assistive reproductive techniques—preimplantation genetic diagnosis (PGD) and in vitro fertilization (IVF)—in a controversial manner to conceive a child who was a perfect Human Leukocyte Antigen (HLA) match for their ailing daughter, Molly. They genetically “manufactured” their son, Adam, hoping that he could provide the stem cells that Molly needed to survive.¹⁶ Umbilical cord blood was harvested from Adam at birth and weeks later transplanted into Molly.¹⁷ Approximately two weeks after the transplant, the procedure appeared to have been successful and doctors predicted that Molly would have the chance to lead a relatively normal life.¹⁸

The success of the transplant not only had significant implications for Molly and her family, but also gave parents of ailing children hope for significant changes in tissue and organ donation procurement methods.¹⁹

¹³ *Id.*

¹⁴ *Id.* at 437 (“Data on the donation of tissue are not as prevalent as data on organ donation because there is no central registry for donative tissue; however, medical and legal literature only discuss the donation of blood and bone marrow by minors, which gives rise to a fair assumption that blood and bone marrow are the primary, if not the exclusive tissues currently donated by living minors.”); Louise M. Terry & Anne Campbell, *Protecting the Interests of the Child Bone Marrow Donor*, 23 *MED. & L.* 805, 806 (2004) (stating that children are “frequently used” by their “families and doctors who are extracting their bone marrow to try to save the life of another, usually a sibling”); Anderson, *supra* note 5, at 484.

¹⁵ See Health News, *Sibling Selection*, WEBMD.COM, June 26, 2001, <http://www.webmd.com/news/20010626/sibling-selection> (last visited Jan. 6, 2008) [hereinafter *Sibling Selection*]. But see *Genetic Selection Gives Girl a Brother and a Second Chance*, CNN.COM, Oct. 3, 2000, <http://archives.cnn.com/2000/HEALTH/10/03/testtube.brother/index.html> (last visited Jan. 5, 2008) [hereinafter *Genetic Selection*] (quoting Mrs. Nash as saying she “wanted Molly to have siblings” and stating that “the Nashes wanted more children, but were afraid to conceive because both [parents] carry a faulty version of the Fanconi gene”). The Nash family was not the first family to conceive a child for the primary purpose of being a tissue or organ donor, but their case was more publicized than most. See Susan Kerr Bernal, *Ethical Offspring?*, 25 *J. ANDROLOGY* 667 (2004) (stating that in 1990 Mr. and Mrs. Ayala naturally conceived a child, without the assistance of assistive reproductive techniques, hoping that she would be a compatible donor for their sixteen-year-old daughter who was in dire need of a bone marrow transplant); Susan M. Wolf, Jeffrey P. Kahn & John E. Wagner, *Using Preimplantation Genetic Diagnosis to Create a Stem Cell Donor: Issues, Guidelines & Limits*, 31 *J.L. MED. & ETHICS* 327, 328 (2003) (“Between 1985 and 1993, thirty-two pregnancies occurred without assisted reproductive techniques for the expressed purpose of creating a donor.”).

¹⁶ See *Genetic Selection*, *supra* note 15.

¹⁷ *Id.*

¹⁸ *Doctors Say First-of-its-kind Transplant was a Success* CNN.COM, Oct. 18, 2000, <http://archives.cnn.com/2000/HEALTH/10/18/testtube.brother.ap/index.html> (last visited Jan. 6, 2008). The media has not covered the Nash case since July 2003, so it is a safe assumption that Molly has not experienced any significant health problems after receiving the initial cord blood transplant from her brother and is leading a relatively normal life. See generally Fred Guterl, *To Build a Baby: A Quick Genetic Test is a Godsend and a Moral Dilemma*, NEWSWEEK INT’L, July 7, 2003 (in what appears to be the last news story to cover the story of the Nash Family, Fred Guterl reports that Molly “seems like a typical second grader”).

¹⁹ See Press Release, Univ. of Minn., *Umbilical Cord Blood Transplant Succeeds for Molly Nash* (Jan. 4, 2001), available at <http://www.ur.umn.edu/FMPro?-db=releases&-lay=web&-format=umnnnewsreleases/releasesdetail.html&-RecID=33891&-Find>. Molly’s transplant surgeon on

After news headlines touted the Nash family's success, hundreds of other desperate parents, in the United States and other countries, sought out consultations with specialists to discuss the possibility of using PGD to create perfectly HLA-matched donors for their ailing children.²⁰

Some of the demand for the use of the controversial assistive reproductive techniques used in the Nash case has been tempered because the procedure is expensive, there are limited numbers of reproductive centers that offer the technique,²¹ and the process is time consuming.²² PGD costs approximately \$2500 per fertility cycle and IVF costs approximately \$12,400 per cycle. There are only about fifty reproductive centers worldwide that provide PGD services. The fact that only 2000 babies worldwide have been born with the use of PGD illustrates that this procedure, while highly divisive, is rarely used today.²³

However, despite the limited use of PGD today, the procedure will most likely be used extensively in the near future to conceive child-donors.²⁴ The cost of the procedure will decrease, the controversy will die down, and the number of reproductive centers offering the procedure will increase as technological advances are made and the technique becomes less novel. Just as the history of organ donation has evolved in a short period of time, so to will the use of PGD to create child-donors.

What is more worrisome than the fact that PGD will be used more prevalently in the future to create perfectly HLA-matched child-donors, is the fact that the potential effects, both physical and psychological, upon the child-donor are unknown, and may turn out to be extremely significant. While parents may be inspired by the Nash case to use PGD, the "success" of the Nash family's isolated experience must be taken with a grain of salt. Fortunately for the Nash family, the first stem cell transplant was successful. Nevertheless, there was a very real possibility that the transplant might not have been successful,²⁵ in which case Adam Nash may

eloquently summed up this hope by stating that "the work done to combine pre-implantation genetic diagnosis (PGD) and in vitro fertilization (IVF) to create a healthy cord blood donor holds great promise for those not only with Fanconi anemia, but also leukemia, thalassemia, Hurler syndrome and other diseases that cause the immune system and bone marrow to fail." *Id.*

²⁰ Wolf et al., *supra* note 15, at 329.

²¹ See 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, 982 (2005-2006).

²² A couple who undergoes PGD with IVF and HLA-matching must "undergo numerous tests and endure multiple IVF attempts, all of which are costly and time consuming." *Sibling Selection*, *supra* note 15.

²³ Gitter, *supra* note 21.

²⁴ See Wolf et al., *supra* note 15, at 329 (stating that demand for PGD is "likely to grow substantially," in part due to the fact that there are a significant number of disorders for which PGD with HLA-matching could be used to cure or put into remission, including: chronic myelogenous leukemia, acute lymphocyte leukemia, acute myelocytic leukemia, juvenile myelomonocytic leukemia, myelodysplastic syndrome, chronic lymphocytic leukemia, non-Hodgkin lymphoma, Hodgkin lymphoma, multiple myeloma, neuroblastoma, severe aplastic anemia, paroxysmal nocturnal hematuria, hemaglobinopathies (thalassemia, sickle-cell disease), immunodeficiencies (SCID, Wiskott Aldrich), inborn errors of metabolism, autoimmune disorders and solid tumors. PGD with HLA-matching could also be used for tolerance induction for solid organ transplantation).

²⁵ The initial cord blood transplant could have been unsuccessful for any number of reasons, including: inadequate cord blood dose, graft failure after cord blood transplant, or the recipient child experiencing a recurrence of leukemia after transplant. Wolf et al., *supra* note 15, at 329.

have been asked to donate his bone marrow. If a bone marrow transplant failed for any reason, then he may have been asked to donate other tissues and organs. In fact, children like Adam Nash, who are conceived via PGD combined with IVF and HLA-matching, face the real, and significant, possibility of being asked to be donors for their ailing siblings throughout their entire lives.²⁶

In light of the recent use of assistive reproductive technologies to conceive child-donors, the likelihood that PGD will be used much more extensively in the near future, and the fact that there may be significant psychological and physical harm to child-donors conceived via PGD, this Note presents the argument that the current legal framework under which child-donors are permitted to donate tissue and organs no longer adequately protects our nation's children and therefore proposes legislative standards to modify the framework.

Part II of this Note details the practice of using PGD to conceive child-donors. In addition, it describes the current lack of government regulation over the use of PGD and presents one proposed form of regulation. Ultimately, it concludes that such regulation is unlikely. Next, Part III discusses the considerable consequences that may result from using PGD to conceive child-donors. In particular, it demonstrates the possible negative psychological impact on both the child-donor and the ailing sibling of the child-donor. It also considers the probable negative physical impact on child-donors. Part IV examines the current legal framework under which tissue and organ donations from minors are permitted. This Part dissects the two common law standards currently applied in cases involving proposed tissue or organ donations from minors—the best interests standard and the substituted judgment standard—and comments on the shortcomings of each. Part V introduces findings from cognitive development research studies that demonstrate that children below particular ages are not capable of making informed medical decisions. Part VI builds upon the findings presented in Part V to present proposed legislative standards prohibiting tissue and organ donations from minors who do not meet particular age requirements. The bright line age requirements suggested are an attempt to ensure that child-donors, particularly those who may be conceived via PGD, are able to make informed decisions about whether to donate tissue or an organ, and are not coerced into donating by their parents or other family members. Part VII addresses, and rebuts, some of the arguments that may be mounted against the legislative standards proposed in Part VI. Part VII then concludes by stating that stringent legislative standards are necessary to protect the best interests of child-donors.

II. THE PRACTICE AND REGULATION OF PREIMPLANTATION GENETIC DIAGNOSIS

PGD has become a standard assisted reproductive technology and has been used since the early 1990s. Initially, the technology was used for the

²⁶ *Id.* at 328–29.

sole purpose of determining whether an embryo had a particular genetic disorder before implanting the embryo into a woman's uterus, thereby providing a chance for parents to prevent the transmission of a genetic defect and give birth to a healthy child. However, PGD has since expanded in its scope and application.²⁷

A. PRACTICE OF PREIMPLANTATION GENETIC DIAGNOSIS WITH HLA MATCHING

Used in the traditional manner, PGD is a detection method used to determine whether an embryo has a particular genetic disease or disorder.²⁸ If parents discover that an embryo has a particular disease or condition of concern they may opt not to have the affected embryo implanted in the mother's womb, thereby avoiding selective pregnancy termination.²⁹ The PGD process works in conjunction with IVF,³⁰ a process by which a woman's eggs are fertilized by sperm outside of her womb.³¹ After IVF, the PGD process begins with controlled ovarian stimulation, which produces a large number of oocytes,³² which are involved in reproduction.³³ Generally, several cycles of ovarian stimulation will need to be conducted in order to retrieve the ten embryos necessary for the PGD process.³⁴ Once all of the embryos have been obtained, a biopsy is conducted upon them to determine whether the particular disease or condition is present.³⁵ Any unaffected embryos are then transferred to the uterus. This traditional use of PGD has become a widely accepted method for protecting infants from genetic disorders.³⁶

However, PGD may also be used for more controversial purposes, including screening embryos for mere susceptibility to diseases and late onset disorders, selecting the sex of a potential child for "family balancing" purposes, and creating a child-donor who is a perfect HLA-match for a preexisting ailing sibling in need of a stem cell transplant.³⁷

²⁷ Caroline Mackie Ogilvie, Peter R. Braude & Paul N. Scriven, Brief Report, *Preimplantation Genetic Diagnosis—An Overview*, 53(3) J. HISTOCHEMISTRY & CYTOCHEMISTRY 255 (2005).

²⁸ *Id.*

²⁹ *See id.*

³⁰ *Id.*

³¹ LIZA CHARLESWORTH, *THE COUPLE'S GUIDE TO IN VITRO FERTILIZATION: EVERYTHING YOU NEED TO KNOW TO MAXIMIZE YOUR CHANCES OF SUCCESS* 3 (2004). If the egg is properly fertilized and an embryo results, the embryo is then implanted into the woman's uterus. *Id.*

³² *Definition of Oocyte*, MEDICINET.COM (2002), <http://www.medterms.com/script/main/art.asp?articlekey=4641> (defining an oocyte as "[A] female germ cell in the process of development." An "oocyte is produced in the ovary by an ancestral cell called an oogonium and gives rise to the ovum (the egg) which can be fertilized.") (last visited Jan. 6, 2008).

³³ *See* Ogilvie et al., *supra* note 27, at 255.

³⁴ The French National Consultative Ethics Committee for Health and Life Sciences, Opinion No. 72, Reflections Concerning an Extension of Preimplantation Genetic Diagnosis (July 4, 2002), available at <http://www.ccne-ethique.fr/english/pdf/avis072.pdf> [hereinafter Reflections].

³⁵ Ogilvie et al., *supra* note 27, at 255.

³⁶ Wolf et al., *supra* note 15, at 327; *Genetic Selection*, *supra* note 15. "Preimplantation genetic diagnosis has been used to screen for single-gene diseases such as cystic fibrosis, thalassemia, sickle cell anemia, and muscular dystrophy, as well as chromosomal abnormalities such as Down [sic] syndrome and trisomy 18. Presently, more than 100 different conditions can be identified via PGD." Bernal, *supra* note 15, at 668.

³⁷ Wolf et al., *supra* note 15, at 327.

The desire to create perfectly-matched HLA donors is driven by the fact that there are a number of diseases, malignant and non-malignant, that may be cured or kept at bay with a perfectly-matched hematopoietic stem cell³⁸ transplant.³⁹ Hematopoietic stem cells may be transplanted in an ailing individual via the transfer of umbilical cord blood or bone marrow.⁴⁰

For a transplant to be successful, the potential stem cell recipient needs to find an available HLA-matched donor in the form of a related donor or a volunteer, unrelated donor.⁴¹ Since each individual carries two different HLA haplotypes that are co-dominantly inherited from each parent, the likelihood that a child conceived naturally would be a perfect HLA-match for an ailing sibling is approximately twenty-five percent.⁴² This small percentage of success has posed a significant problem for families that have tried to naturally conceive an HLA-identical match for an ailing child. Parents who try to naturally conceive may be faced with the decision of whether or not to terminate a pregnancy if the fetus is not a perfect HLA-match.⁴³ If parents do not want to risk trying to naturally conceive an HLA-matched child, they have the option of looking for an HLA-matched volunteer, unrelated donor. The likelihood of finding such a donor, by conducting a donor search in national 'Registries,' is approximately seventy-five percent.⁴⁴ However, there is a higher incidence of recipient mortality in cases involving unrelated donors due to the fact that there is an increased chance for HLA mismatches.⁴⁵

The difficulty of naturally conceiving an HLA-matched donor and the high incidence of mortality associated with hematopoietic stem cell transplants from volunteer, unrelated donors, has led the medical community to embrace the use of standard PGD and IVF procedures combined with HLA-matching techniques to create compatible donors. This process involves the aforementioned standard PGD procedure, plus an additional step—once all of the unaffected embryos are collected, they are screened further and classified according to their HLA types.⁴⁶ Only the embryos that are perfect HLA-matches to the parents' ailing child are implanted into the mother's uterus. In the documented cases in which PGD was used for HLA-matching, once the mother successfully carried a

³⁸ Hematopoietic stem cells are stem cells that are found in the bone marrow. They can be replaced in individuals with a number of diseases if the individual receives a transplant of bone marrow, umbilical cord blood, or peripheral blood. Patrick Tan, *Hematopoietic Stem Cells for Leukemias and other Life Threatening Hematological Disorders*, in *STEM CELLS: FROM BENCH TO BEDSIDE* 293 (Ariff Bongso & Eng Hin Lee eds., 2005).

³⁹ See Wolf et al., *supra* note 15, and accompanying text.

⁴⁰ G. Pennings, R. Schots & I. Liebaers, Opinion, *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(3) *HUMAN REPRODUCTION* 534 (2002).

⁴¹ *Id.*

⁴² *Id.* (noting that given the tendency to have smaller families in Western countries, the likelihood of naturally conceiving a perfect HLA-matched sibling for an ailing child is really no more than fifteen percent).

⁴³ Wolf et al., *supra* note 15, at 328.

⁴⁴ Pennings et al., *supra* note 40.

⁴⁵ *Id.* at 535.

⁴⁶ *Id.*

perfectly HLA-matched child-donor to term, the umbilical cord blood from the infant was donated to the infant's ailing sibling.⁴⁷

B. REGULATION OF PREIMPLANTATION GENETIC DIAGNOSIS

“The U.S. is a virtually regulatory-free environment when it comes to reproductive technologies”⁴⁸ Therefore, PGD, like many other assisted reproductive technologies, remains largely unregulated in the United States.⁴⁹ In fact, only four states—Louisiana, Maine, Minnesota, and Pennsylvania—regulate PGD and prohibit its therapeutic use unless it is proven that there will be no harm to the embryos and that the procedure will be beneficial.⁵⁰ There are no state or federal regulations that prohibit the non-therapeutic use of PGD.⁵¹ Furthermore, Congress has decided not to regulate PGD in the private sector. Thus, the use of PGD is left primarily to the discretion of the PGD service providers and patients.⁵² PGD service providers are directed only by guidelines issued by two ethics committees: the American Society for Reproductive Medicine that has guidelines that address the use of PGD generally and for sex selection, but not for HLA-matching; and the American Medical Association that has published the Code of Medical Ethics, which merely states that the use of PGD is permissible so long as it is used “to prevent, cure, or treat genetic disease” and not for the “selection on the basis of non-disease related characteristics or traits.”⁵³

This lack of regulation may be a blessing for parents who desire to use this controversial procedure, but does little to protect the rights of the innocent children who are conceived via PGD with HLA-matching, particularly in light of the fact that the children conceived in this manner may be coerced into donating tissue and/or organs continually throughout their ailing sibling's life. Thus, there is a dire need for regulation of PGD with HLA-matching.

One proposed form of regulation would entail creating or appointing an existing federal agency to oversee the use of PGD.⁵⁴ Such regulation would be akin to that in place in the United Kingdom.⁵⁵ The United Kingdom

⁴⁷ See *Genetic Selection*, *supra* note 15 (stating that “Doctors . . . infused stem cells from Adam’s umbilical cord blood into his sister.”); Gitter, *supra* note 21, at 979–80 (describing a case in Britain in which the Hashmi family “wished to undergo IVF and then to use PGD to select an embryo that would develop into a sibling who would be a suitable donor of umbilical cord stem cells”); *id.* at 1006 (describing another case in Britain in which the Whitaker family sought to conceive a perfectly-matched infant via PGD with HLA-matching to donate umbilical cord blood to their ailing son).

⁴⁸ Gitter, *supra* note 22, at 984 (quoting Judith F. Daar, *Assisted Reproductive Technologies and the Pregnancy Process: Developing an Equality Model to Protect Reproductive Liberties*, 25 AM. J.L. & MED. 45, 464 n. 93 (1999)).

⁴⁹ *Id.*

⁵⁰ *Id.* at 984–85. See LA. REV. STAT. ANN. §§ 9:122, 9:129 (1991); ME. REV. STAT. ANN. tit. 22, § 1593 (1992); MINN. STAT. ANN. § 45.421 subd. 1, 2 (West 1998); 18 PA. CONS. STAT. ANN. § 3216(a) (West 2000).

⁵¹ Gitter, *supra* note 21, at 985.

⁵² *Id.*; Laurie Barclay, *Preimplantation HLA Typing: A Newsmaker Interview With Anver Kuliev, MD, PhD*, MEDSCAPE MEDICAL NEWS, May 5, 2004, available at <http://www.medscape.com/viewarticle/475082>.

⁵³ Wolf et al., *supra* note 15, at 329.

⁵⁴ Gitter, *supra* note 21, at 1027.

⁵⁵ *Id.*

established the Human Fertilisation and Embryology Authority (HFEA), a statutory body, in 1991. The HFEA's primary responsibilities are to "[l]icense and monitor clinics that carry out in vitro fertilization (IVF) and donor insemination; [l]icense and monitor research centres undertaking human embryo research; [and r]egulate the storage of gametes and embryos."⁵⁶ Like the HFEA, the United States federal agency appointed with the role of overseeing PGD could be responsible for "issuing regulations listing acceptable and unacceptable uses; [a]djudicating specific requests for use of PGD tests; [a]pproving new uses of PGD tests and techniques, [and l]icensing and inspecting facilities that engage in PGD."⁵⁷

Unfortunately, many critics point out that creating a federal agency to oversee PGD in the United States would be next to impossible. First and foremost, it would be "extremely difficult to find a majority of lawmakers who could agree on the scope and powers of such an entity."⁵⁸ Additionally, lawmakers who do not agree with decisions made by federal agencies have the power to make those agencies inefficient by failing to provide funding, therefore making it extremely difficult to create a stable and effective federal agency.⁵⁹ Moreover, creating a federal agency to oversee PGD would be a "significant, even unprecedented, intrusion into private medical practice."⁶⁰ There is also a significant and valid constitutional challenge to the establishment of such an agency, or any type of regulation of PGD, on the basis that decisions made by the agency may limit reproductive choice.⁶¹ Finally, given the current lack of regulation of assistive reproductive technology and the high value placed on reproductive choice in the United States, it is likely that a vast majority of the American public would vehemently reject the formation of a federal agency to oversee the use of PGD.⁶² The reality is that creating an effective agency to regulate PGD would be next to impossible and highly controversial. Furthermore, even if an effective federal agency was established to regulate the use of PGD with HLA-matching, or laws were enacted that prohibited its use altogether, parents would still attempt to conceive child-donors naturally.⁶³

⁵⁶ *Id.* at 980.

⁵⁷ *Id.* at 1027.

⁵⁸ *Id.* at 1028.

⁵⁹ *Id.*

⁶⁰ Gitter, *supra* note 21, at 1029.

⁶¹ See *Griswold v. Connecticut*, 381 U.S. 479 (1965); *Eisenstadt v. Baird*, 405 U.S. 438, 453 (1972) ("If the right to privacy means anything it is the right of the individual, married or single, to be free from unwarranted governmental intrusion into matters so fundamentally affecting a person as the decision whether to bear or beget a child."); Morley, *supra* note 10, at 1247 ("Putting aside the thorny issue of human cloning, a prohibition on conceiving children for the purpose of consenting to donate their organs would be patently unconstitutional."); Judith F. Darr, *Regulating Reproductive Technologies: Panacea or Paper Tiger?*, 34 HOUS. L. REV. 609, 639-40 (1997) (stating that one of the reasons that assistive reproductive techniques are not regulated is because "the issue of assisted human reproduction is highly politically charged because of its perceived affiliation with the abortion debate"). Despite the fact that there may be privacy and due process concerns with the issues discussed in this Note, they will not be addressed because at the time of publication no case directly supports the existence of a Constitutional right to donate one's organs to an immediate family member.

⁶² Gitter, *supra* note 21, at 1029.

⁶³ See Bernal, *supra* note 15 (discussing the Ayala case in which Mary and Abe Ayala naturally conceived a child hoping that she would be a compatible donor for their sixteen-year-old daughter who was in dire need of a bone marrow transplant).

III. IMPLICATIONS OF CONCEIVING A CHILD-DONOR VIA PREIMPLANTATION GENETIC DIAGNOSIS WITH HLA-MATCHING

Given that regulating the use of PGD with HLA-matching to conceive child-donors would be virtually impossible,⁶⁴ the considerable consequences for children conceived in this manner and their families cannot be ignored. No conclusive psychological research has yet been conducted on child-donors conceived via PGD with HLA-matching or their families. However, studies have been conducted assessing the psychological and physical impact on child-donors conceived through natural methods. These studies demonstrate that there are significant psychological and physical consequences for child-donors. It may also be reasonable to assume that children conceived for the primary purpose of being a donor—having their entire existence primarily predicated on their status as a tissue or organ donor—will likely suffer similar, if not even more considerable, negative effects. Other studies have even demonstrated that ailing siblings who receive tissue or organ transplants from sibling-donors may suffer psychological harm as a result of the transplant. From these studies, it may be concluded that children who receive tissue or organ donations from a sibling-donor conceived primarily to be a donor may suffer the same psychological harm, if not more.

A. POTENTIAL PSYCHOLOGICAL IMPACT ON THE CHILD-DONOR

Children conceived via PGD with HLA-matching for the primary purpose of being an organ or tissue donor to an ailing sibling will undoubtedly experience significant psychological effects.⁶⁵ Child-donors conceived in this controversial manner may feel psychological pressure from their parents to donate organs and tissue throughout their lives, if the need arises.⁶⁶ The small number of children that have been conceived via PGD with HLA-matching have, as of yet, only had to donate umbilical

⁶⁴ See discussion *supra* Part II.B.

⁶⁵ Many individuals argue that children who donate tissue and/or organs to their siblings will benefit psychologically from their altruistic act. Proponents of minor organ donation argue that child-donors will experience “increased self-esteem from performing an altruistic act . . . continued companionship of the surviving sibling . . . [and] avoidance of possible guilt on discovery later in life that one could have saved his sibling’s life.” Mark Sheldon, *Guest Editorial: Children as Organ Donors: A Persistent Ethical Issue*, 13 CAMBRIDGE Q. HEALTHCARE ETHICS 119, 120 (2004) (quoting Norman Frost, *Children as Renal Donors*, 296 NEW ENG. J. MED. 363–67 (1977)). Furthermore, some hypothesize that a child conceived via PGD with HLA-matching may come to feel highly valued when she learns of all of the efforts her parents went through to conceive her to be the “savior child.” Reflections, *supra* note 34. See Pennings et al., *supra* note 40, at 537 (arguing that when a child-donor conceived via PGD with HLA-matching is told that she was conceived to help her sibling this knowledge “may give the child a greater sense of self-esteem and self-worth”). Studies have demonstrated that children who participate in *successful* tissue transplants experience “a predominantly positive impact on many life domains, including relationships, view of world, feelings about self and decreased helplessness, and insight into their sibling’s illness.” Kendra D. MacLeod, Stan F. Whitsett, Eric J. Mash & Wendy Pelletier, *Pediatric Sibling Donors of Successful and Unsuccessful Hematopoietic Stem Cell Transplants (HSCT): A Qualitative Study of Their Psychosocial Experience*, 28 J. PEDIATRIC PSYCHOL. 223, 227 (2003) (noting however, that these psychological benefits are less prevalent in child-donors who undergo unsuccessful tissue transplants). Thus, there is some evidence to support the argument that children conceived via PGD with HLA-matching may experience psychological benefits *if they participate in successful transplants*.

⁶⁶ See Gitter, *supra* note 21, at 1019.

cord blood to their ailing siblings.⁶⁷ However, it is possible that, if an initial cord blood transplant is not ultimately successful at keeping their siblings' illness at bay they may also be asked to donate bone marrow.⁶⁸ If a bone marrow transplant is completed, but turns out to be unsuccessful, a child-donor may then be asked to donate more bone marrow.⁶⁹ Even after a bone marrow transplant, the child-donor's ailing sibling may suffer from organ failure due to immunosuppressive drugs or toxicities caused by chemotherapy and irradiation and the child-donor may then be called upon to donate a kidney or liver.⁷⁰

A psychological study completed by Kendra MacLeod, Stan Whitsett, Eric Mash, and Wendy Pelletier found that children who are "asked" to donate tissue or organs to their ailing siblings believe that they do not have the ability to choose whether to consent to the donation because they feel compelled to comply with their parents' wishes.⁷¹ In their findings, they noted, "One could only imagine the psychological consequences a potential sibling donor would face within the family system if she or he were to refuse donation. The sibling donor's status as a family member would likely be affected, and feelings of guilt might also result"⁷² The children who participated in this study were not conceived via PGD with HLA-matching; they were conceived naturally and not for the primary purpose of serving as a donor for their ailing sibling.⁷³ However, if children who are conceived naturally experience significant psychological pressure to donate tissue or organs, a child conceived primarily to be a donor would undoubtedly experience the same pressure, if not more.

If a child-donor conceived via PGD with HLA-matching does not experience psychological pressure to donate tissue or organs, the child may nevertheless experience negative psychological effects prior to, and after, donating tissue or an organ.⁷⁴ The study conducted by MacLeod, Whitsett, Mash, and Pelletier found that children who donated hematopoietic stem cells experienced fear prior to undergoing the medical procedure.⁷⁵ Other studies have found that related donors may come to resent their ailing siblings because of the significant amount of attention the siblings receive

⁶⁷ See *id.* at 1020 ("The HLA-matched child in the Nash case has thus far escaped further need for tissue or organs by his sister. However, he is quite young. He and all children created as donors face the potential of requests for donation throughout their lives.").

⁶⁸ See *id.* at 1020.

⁶⁹ See *id.*

⁷⁰ See *id.*

⁷¹ See MacLeod et al., *supra* note 65, at 226.

⁷² *Id.* at 229. But see Robert J. Boyle, *Education and Debate: Ethics of Using Preimplantation Genetic Diagnosis to Select a Stem Cell Donor for an Existing Person*, 323 *BMJ* 1240, 1242 (2001) ("[P]sychological harm to the offspring is unpredictable, unlikely to occur, and, even if it did occur, unlikely to be so severe that it would be better for that particular child never to have existed.").

⁷³ MacLeod et al., *supra* note 65, at 224.

⁷⁴ See Grace Chang, Carol McGarigle, Thomas R. Spitzer, Steven L. McAfee, Fred Harris, Kay Piercy, Margaret Ann Goetz & Joseph H. Antin, *A Comparison of Related and Unrelated Marrow Donors*, 60 *PSYCHOSOMATIC MED.* 163, 166 (1998) ("[R]elated donors have more negative feelings after donation and do not feel as good about themselves for having donated when compared with un-related donors.").

⁷⁵ MacLeod et al., *supra* note 65, at 227.

from their parents.⁷⁶ These feelings of resentment may lead to post-surgical depression.⁷⁷

Moreover, child-donors who participate in unsuccessful transplants may suffer significant psychological pain. While much attention has been given to the alleged psychological benefits a child-donor experiences when her sibling survives the tissue or organ transplant, little emphasis has been placed on researching the potential negative psychological impact on a child-donor when her sibling does not survive the transplant. In the study conducted by MacLeod, Whitsett, Mash, and Pelletier, the researchers found that child-donors who underwent unsuccessful tissue transplants were less likely to benefit psychologically from the experience and more likely to suffer negative psychological effects such as anger, guilt, and blame. The negative psychological impact was magnified when child-donors felt neglected by doctors or their family members after the transplant procedure. Many of the child-donors in the unsuccessful transplant group stated that it was difficult not to feel responsible for their sibling's death and "resisting the development of negative feelings was harder for sibling donors who lacked adequate emotional support following the death or when the death was directly related to complications" as a result of the transplant procedure.⁷⁸ It is important to note that "[f]or some participants, [the] guilt and blame did not develop right away, but grew over time."⁷⁹ Thus, even child-donors who do not immediately exhibit signs of post-surgical depression, anger, guilt, or blame may still potentially suffer years after the unsuccessful transplant.

While the children who participated in this study were not conceived via PGD with HLA-matching, it is nevertheless reasonable to assume that children who are conceived through the use of this controversial method for the primary purpose of being an organ or tissue donor for their ailing siblings may suffer more psychological harm if their siblings die as a result

⁷⁶ See Chang et al., *supra* note 74, at 163 (citing a study conducted by JP Kempf, *Renal failure, Artificial Kidney and Kidney Transplant*, AM. J. PSYCHIATRY 113:1213-1221, 1967). See also Søren Holm, *The Child as Organ and Tissue Donor: Discussions in the Danish Council of Ethics*, 13 CAMBRIDGE Q. HEALTHCARE ETHICS 156, 157 (2004) ("In most cases, the focus of attention in the family has for a long time been on the person who is ill, and the healthy child may already feel neglected before the donation. After the transplant, the focus is even more concentrated on the recipient.... The donor, therefore, often receives even less attention in the immediate posttransplantation period than before the transplant. In many cases, this creates a feeling of rejection and of not getting appropriate recognition for a truly good and altruistic act."); Pennings et al., *supra* note 40, at 537; MacLeod et al., *supra* note 65, at 228 (stating that children who participate in successful hematopoietic stem cell transplants may experience negative emotions if their sibling develops severe and long-lasting complications from the procedure).

⁷⁷ Chang et al., *supra* note 74, at 163. See Maurice S. Fisher, *Psychosocial Evaluation Interview Protocol for Living Related and Living Unrelated Kidney Donors*, 38(1) SOC. WORK IN HEALTHCARE 39, 44 (2003) (citing to a study conducted by R.G. Simmons, S.D. Klein & R.L. Simmons, *Living Related Donors: Costs and Gains*, in GIFT OF LIFE: THE SOCIAL AND PSYCHOLOGICAL IMPACT OF ORGAN TRANSPLANTATION 153-97 (1977), finding that "[t]here have been care reports of donors exhibiting symptoms of emotionality, depression, acute psychosis and despair after transplantation" and also stating that "post-operative donor surgery has served to enhance a sense of 'loss,' and in some cases, regret.").

⁷⁸ MacLeod et al., *supra* note 65, at 228.

⁷⁹ *Id.* One child-donor in the study shared her experience: "I knew that I was the last chance and knowing it didn't work, I felt guilty. Now I know I should never of [sic] felt that way, but people didn't discuss it afterwards and make me really understand that I shouldn't feel that way. It was something that built up and nobody probably even realized that I felt that way." *Id.*

of unsuccessful transplants. In such a situation, child-donors may experience a complete loss of sense of self and purpose in life if their sibling dies. The potential psychological consequences on a child conceived for the purposes of donation are therefore startling and significant.

Proponents of the use of PGD with HLA-matching argue that there is no evidence to support the idea that children conceived for the primary purpose of being an organ or tissue donor will suffer considerable psychological harm. The Human Fertilisation and Embryology Authority in the United Kingdom has declared that they have not found any evidence demonstrating that children conceived via PGD with HLA-matching suffer any detrimental psychological effects.⁸⁰ Some proponents will even go so far as to proclaim that “a child-donor might even be considered more special by its parents because of its role in saving the life of an existing sibling.”⁸¹ Since the use of PGD to conceive child-donors is relatively new, there have yet to be any conclusive studies that have determined the actual psychological impact on children conceived via PGD. However, the studies that have assessed the psychological impact of tissue and/or organ donation between siblings seem to suggest that there would be a similar negative psychological impact on children conceived via PGD with HLA-matching.

B. POTENTIAL PHYSICAL IMPACT ON THE CHILD-DONOR

When parents conceive a donor-child through the use of PGD with HLA-matching they are potentially subjecting their child to a life filled with physical pain resulting from numerous donation procedures. While taking the umbilical cord blood from an infant-donor is relatively harmless,⁸² the subsequent donations that the child-donor may be asked to make⁸³ are not. In a cord blood donation the blood from the infant-donor’s umbilical cord is collected only after the umbilical cord has been removed,⁸⁴ and removing the cord is a standard procedure immediately after an infant’s birth.⁸⁵ Therefore, it is not a persuasive argument that compelling a newborn baby to donate cord blood would subject her to physical pain.

However, a child who is conceived for the primary purpose of being a perfectly-matched donor may be asked numerous times over the course of her life to donate tissue and possibly even organs,⁸⁶ in which case there would be a compelling argument that that child would be subjected to an inappropriate amount of physical pain for which she will reap little benefit.

⁸⁰ Gitter, *supra* note 21, at 1023.

⁸¹ *Id.* See Pennings et al., *supra* note 40, at 537 (“The child[-donor] may feel proud of its role in attempting to save a sibling’s life.”).

⁸² Bernal, *supra* note 15, at 670.

⁸³ See discussion *supra* Part III.A.

⁸⁴ Bernal, *supra* note 15, at 670.

⁸⁵ *Id.*

⁸⁶ See discussion *supra* Part III.A

Bone marrow donation⁸⁷ involves a number of risks to the donor.⁸⁸ The risk of primary concern is that of general anesthesia.⁸⁹ Other risks include: infection, pain, discomfort, and the risks associated with blood transfusions.⁹⁰ While the risk of any of the aforementioned occurring is relatively low,⁹¹ a study conducted by Grace Chang and colleagues found that bone marrow donors who were related to the recipient reported significantly more acute physical pain following donation than unrelated donors.⁹²

Furthermore, donating an organ involves significantly more physical risk than a bone marrow donation.⁹³ The risks of donating a kidney include a possible “adverse reaction to anesthesia, unexpected blood loss, infection,” and most critically, the possibility of loss of function in the donor’s remaining kidney.⁹⁴ The risks of donating a liver include: bleeding, infection, bile leakage, possible death,⁹⁵ adverse reaction to general anesthesia,⁹⁶ lung collapse, stomach irritation, scarring on the abdomen, and liver failure.⁹⁷ There is data indicating that one in three living liver

⁸⁷ The harvesting of bone marrow involves inserting a long needle into the hip bone and “[s]everal bone punctures on each hip will be required to remove the necessary amount of marrow.” ROBERT FINN, ORGAN TRANSPLANTS: MAKING THE MOST OF YOUR GIFT OF LIFE 113 (2000).

⁸⁸ Gitter, *supra* note 21, at 1020.

⁸⁹ See *id.*; Louise M. Terry & Anne Campbell, *Patient’s Right: Protecting the Interests of the Child Bone Marrow Donor*, 23 MED. & L. 805, 812 (2004) (“Anesthesia carries risks and the child bone marrow donor is likely to require anaesthesia on at least two occasions, the first being to obtain a sample of marrow from the hip or sternum, the second when actually harvesting the marrow for donation.”).

⁹⁰ *Id.* There are also a number of other risks involved in donating bone marrow. If bone marrow is harvested from the patient’s chest, there is a chance that the needle will penetrate the patient’s sternum and ultimately her heart, if the pressure on the needle is too heavy. If bone marrow is harvested from the patient’s hip there is also a possibility that the needle will break off and become embedded in the patient’s hip. There are also risks associated with certain drugs which are used to stimulate bone marrow before the harvesting procedure. The following are additional risks associated with bone marrow donation: “musculoskeletal pain, transient hypotension, disturbances in liver enzymes and serum uric acid, thrombocytopenia, urinary abnormalities, allergic reactions, proteinuria, haematuria, transient decrease in blood glucose, cutaneous vasculitis, splenic enlargement, hepatomegaly, headache, diarrhoea, anaemia, epistaxis, alopecia, osteoporosis, [and] rash and reactions at injection site.” *But see* Morley, *supra* note 10, at 1222 (stating that bone marrow donation “poses no serious health risks, even for child-donors”).

⁹¹ Bernal, *supra* note 15, at 670.

⁹² Chang et al., *supra* note 74, at 166. *But see* Bernal, *supra* note 15, at 670 (“[Y]oung children with developing nervous systems do not experience the same intensity of pain as do adults and based on anecdotal evidence from other cases involving very young bone marrow donors, they have little if any memory of the procedure or accompanying pain.”).

⁹³ “Researchers found that the typical living [organ] donor is hospitalized for about 10 days, takes [two-and-a-half] months off work and needs an additional month for complete recovery.” *The Dark Side of Organ Donation*, *supra* note 11.

⁹⁴ See Kimberly Sterner, Nataliya Zelikovsky, Cynthia Green, Bernard S. Kaplan, *Psychosocial Evaluation of Candidates for Living Related Kidney Donation*, 21 PEDIATRIC NEPHROLOGY 1357 (2006); *The Dark Side of Organ Donation*, *supra* note 11 (stating that as of 2002, 56 living kidney donors needed a kidney transplant themselves because they lost function in their only remaining kidney). *But see* Morley, *supra* note 10, at 1221–22 (stating that “transplant procedures have become fairly commonplace and pose little risk to donors” and that “[k]idney donation . . . is for the most part safe and painless” and that “[k]idney donors do not have a heightened risk for renal failure later in life”).

⁹⁵ Columbia University Department of Surgery, Transplantation Procedures: Living Donor Transplantation Explained, http://hora.cpmc.columbia.edu/dept/liverMD/tx_donor.html (last visited Mar. 22, 2007).

⁹⁶ See Duke Transplant Center, Living Liver Transplant: Donor Information, Are There Risks to me if I Donate Part of my Liver, <http://organtransplant.mc.duke.edu/LiverDonor.asp#4> (last visited Mar. 22, 2007).

⁹⁷ Living Donation, Introduction to Partial Liver Donation for Living Donors, http://surgery.med.unc.edu/AbdominalTransplant/pdfs/liver/Living_Donor_Handbook.pdf (last visited

donors face complications as a result of the transplant, including additional surgery, hospitalization, and extended recovery times. While some claim that the probability of a donor experiencing any of the possible complications is extremely low, the facts remain that no reliable statistics about donors' surgical complications are ever reported⁹⁸ and "[t]hese potential negative outcomes assume greater importance because the surgery puts the donor at risk for no personal physical gain."⁹⁹ Moreover, a child who has been conceived via PGD with HLA-matching to be a donor is more likely to be compelled to donate tissue and/or organs numerous times over the course of his or her life, and therefore will be exposed to these risks more often, thereby increasing the likelihood that the child will experience one of the potential negative outcomes.

The problem is that while the medical benefit to the recipient is great, all the risk of the donation falls to the donor. So we must ask whether the benefit to the donor of seeing a loved one's life saved or health improved, along with the benefit of doing a remarkably good deed, is sufficient to balance the risk they are asked to undergo.¹⁰⁰

C. POTENTIAL PSYCHOLOGICAL IMPACT ON THE AILING SIBLING OF THE CHILD-DONOR

Very little psychological research has been conducted to determine the potential negative psychological effect on the recipient of a tissue or organ donation from a sibling-donor, but there is nonetheless an argument that there may be a significant negative psychological impact on the recipient child. Pursuant to the nature and logic of gift-giving, the recipient of a gift often feels obligated to reciprocate by giving a gift of similar value to the initial gift-giver.¹⁰¹ When an ailing child receives the gift of life from a sibling there will generally not be an opportunity for that child to reciprocate and give her sibling the gift of life or any other gift of similar magnitude. The virtual impossibility for reciprocation may cause the recipient-child to perpetually feel like she owes the child-donor something more. This may lead to a decrease in the recipient-child's self-esteem and may ultimately have profound consequences for the relationship between the siblings.¹⁰²

Doctors Herbert Brown and Martin Kelly conducted one of the few studies assessing the psychological stress that recipients of tissue donations experience throughout the transplant process. Their research demonstrates that recipients suffer significant psychological stress at various stages throughout the transplant process.¹⁰³ Brown and Kelly broke the transplant

Mar. 22, 2007). *But see* Morley, *supra* note 10, at 1221 (stating that liver transplants are safe "because only a portion of the donor's liver is removed" and "[d]ue to the liver's regenerative capacity, both the transplanted portion as well as the donor's own liver are able to grow into whole, functioning organs").

⁹⁸ *The Dark Side of Organ Donation*, *supra* note 11.

⁹⁹ Sterner, et al., *supra* note 94.

¹⁰⁰ Jeffrey P. Kahn, *Dying to Donate?*, CNN.COM, Jan. 21, 2002, <http://archives.cnn.com/2002/HEALTH/01/21/ethics.matters/index.html> (last visited Jan. 6, 2008).

¹⁰¹ Holm, *supra* note 76.

¹⁰² *See id.*

¹⁰³ *See generally* Brown & Kelly, *supra* note 4.

process up into eight different stages:¹⁰⁴ the decision to accept treatment (the “anticipation” stage),¹⁰⁵ the initial admission evaluation and care planning (the “preparation” stage),¹⁰⁶ immunosuppression and entry into isolation (the “point of no return” stage),¹⁰⁷ the transplant, graft rejection or take (the “waiting” stage),¹⁰⁸ graft-versus-host disease, preparation for discharge from the hospital, and adaptation out of the hospital.¹⁰⁹

During the first stage, Brown and Kelly found that in deciding whether to undergo a transplant and reading a “frighteningly explicit consent form that outlines the entire bone marrow transplantation process in detail,” many patients are actually not fully “informed” about the procedure because they “protect themselves psychologically from the helplessness and anxiety posed by this massive threat with defense mechanisms.”¹¹⁰

In the third stage, they found that patients “consider themselves exposed and defenseless—not only immunologically but also psychologically,” hence the stage has been aptly coined “the point of no return.” It is in the third stage that patients become more aware of the possibility of death. Also during this stage, patients begin to experience the negative physical side-effects of the immunosuppressive drugs and start “to wonder why they agreed to the procedure in the first place.” While patients are on the immunosuppressive drugs they are kept in rigid isolation in a sterile room, which leads them to feel emotionally alone.¹¹¹

They also found that in the fourth stage, when the transplant occurs, “the implications of such a profound giving and taking are not usually expressed” by the patient.

During the fifth stage, dreams and nightmares about the procedure are generally frequent and patients may feel extreme anxiety as they wait in isolation to hear whether the “graft their life will depend on has taken.”¹¹²

If a patient enters into the sixth stage—graft-versus-host disease—then the patient may be overcome with anger and depression. Also, it is important to note that during this stage the donor may feel significant psychological pressure, particularly due to the fact that many donors who find their recipient in this stage believe that it is their fault that the “marrow is hurting or failing” the recipient.

As a patient prepares to leave the hospital in stage seven, there is an “admixture of joy at the anticipated discharge and fear of leaving the security of the hospital.”¹¹³

Brown and Kelly admit that not much is known about stage eight: how the patient adapts outside of the hospital. However, they do state that “one

¹⁰⁴ *Id.*

¹⁰⁵ *Id.* at 440.

¹⁰⁶ *Id.* at 441.

¹⁰⁷ *Id.* at 442.

¹⁰⁸ *Id.* at 443.

¹⁰⁹ Brown & Kelly, *supra* note 4, at 444.

¹¹⁰ *Id.* at 440–41.

¹¹¹ *Id.* at 442.

¹¹² *Id.* at 443.

¹¹³ *Id.* at 444.

issue that has emerged repeatedly concerns the balance that must be struck between the patient's feelings of entitlement, being the survivor of such a challenging process, and *feelings of persistent indebtedness*, having needed so much help from the donor and others."¹¹⁴

These possible negative effects may be even more pronounced in cases in which a child has been conceived to be a perfectly-matched donor for her ailing sibling. The gift of tissue or an organ from a sibling that was conceived to be a perfectly-matched donor is particularly significant. Not only has the child-donor given a piece of herself to save her sibling, but she was born to save her sibling. Therefore, the recipient of such a remarkable gift may feel even more indebted to her sibling-donor and may suffer from a more marked decrease in self-esteem, or even depression. The relationship between the recipient and the sibling-donor may become more strained in these cases.

IV. CURRENT LEGAL FRAMEWORK GOVERNING PERMISSIBILITY OF TISSUE AND ORGAN DONATIONS FROM MINORS

Despite the marked increase in the use of children as tissue and organ donors¹¹⁵ and the fact that parents are now able to conceive perfectly-matched donors for their existing children,¹¹⁶ the legal framework under which minors are permitted to donate tissue and organs has remained essentially the same since the late 1960s and early 1970s. Part IV presents the current legal framework that is applied to cases involving tissue and organ donations from minors and discusses its shortcomings.

A. MEDICAL CONSENT GENERALLY

All medical procedures, whether performed on competent adults, incompetent individuals, or minors, require informed consent¹¹⁷ prior to being performed.¹¹⁸ While competent adults may themselves intelligently consent to medical procedures after being adequately informed of all of the details of the procedure and the risks, incompetent individuals and minors are deemed incapable of providing informed consent because it is assumed that they are not able to fully comprehend the risks of the medical procedure.¹¹⁹ In cases involving minors and incompetents, a parent or

¹¹⁴ *Id.* at 444–45 (emphasis added).

¹¹⁵ See discussion *supra* Part I.

¹¹⁶ See discussion *supra* Part II.A.

¹¹⁷ BLACK'S LAW DICTIONARY 323 (8th ed. 2004) defines informed consent as "a person's agreement to allow something to happen, made with full knowledge of the risks involved and the alternatives."

¹¹⁸ See *Bonner v. Moran*, 126 F.2d 121, 122 (D.C. Cir. 1941) ("There can be no doubt that a surgical operation is a technical battery, regardless of its results, and is excusable only when there is express or implied consent by the patient.")

¹¹⁹ See *Teena-Ann V. Sankoorikal, Using Scientific Advances to Conceive the "Perfect" Donor: The Pandora's Box of Creating Child Donors for the Purpose of Saving Ailing Family Members*, 32 SETON HALL L. REV. 583, 600–01 (2002).

guardian must consent to the medical procedure on behalf of the patient in order for the consent to be binding.¹²⁰

B. SUBSTITUTING PARENTAL CONSENT FOR MINOR CONSENT

Historically, parents and guardians have been given significant leeway within the legal system to consent to medical procedures on behalf of minors and incompetents because it is presumed that they will act in the patients' best interests.¹²¹ In situations where a parent or guardian is consenting on behalf of a minor to a medical procedure that will cure the minor patient's illness or provide some other benefit to the patient, such a presumption is accurate, and parental consent is generally sufficient.¹²²

An issue arises, however, when a parent attempts to consent to a medical procedure that will not confer any direct benefit to the minor patient. Such is the case with both tissue donations and organ donations from minors because the donors will not receive any physical benefits as a result of the donation.¹²³ In fact, a child faces significant physical risks when she undergoes a tissue¹²⁴ or organ harvesting procedure.¹²⁵ Case law supports that non-beneficial operations, "can be legally permitted on a minor as long as the parents or other guardians consent to the procedure."¹²⁶ However, a parent's attempt to consent to a non-beneficial medical procedure on behalf of a minor child may be limited by the state's *parens patriae* power¹²⁷ "if it appears that parental decisions will jeopardize the health or safety of the child, or have a potential for significant social burdens."¹²⁸

A more complicated issue arises when parents attempt to consent to tissue and organ donations from one sibling to another sibling. In these situations, the parents are more concerned with saving the dying sibling and are not basing their decision on the minor donor's best interests, but rather on the dying sibling's and their own best interests.¹²⁹ Therefore, a

¹²⁰ *Id.* at 601; Rachel M. Dufault, Comment, *Bone Marrow Donations By Children: Rethinking the Legal Framework in Light of Curran v. Bosze*, 24 CONN. L. REV. 211, 217 (Fall 1991).

¹²¹ Sankoorikal, *supra* note 119, at 601–02.

¹²² *Id.* at 603. *But see* discussion *infra* on pages 25–26.

¹²³ See Sterner et al., *supra* note 94; Rebecca D. Pentz, Ka Wah Chan, Joyce L. Neumann, Richard E. Champlin & Martin Korbling, *Designing an Ethical Policy for Bone Marrow Donation by Minors and Others Lacking Capacity*, 13 CAMBRIDGE Q. HEALTHCARE ETHICS 149 (2004) ("Although harvesting bone marrow usually exposes the donor to minimal risk, there is no therapeutic benefit.").

¹²⁴ Taking umbilical cord blood from a newborn poses no physical risk to the infant. "[C]ord blood is considered biological waste and either discarded outright or used for research." Bernal, *supra* note 15, at 670. In contrast, bone marrow harvesting is an invasive procedure completed under general anesthesia. It includes the following risks: infection, risks associated with general anesthesia, physical pain and discomfort, and risks associated with blood transfusion. Wolf et al., *supra* note 15, at 334.

¹²⁵ The risks of donating a kidney include: "adverse reaction to anesthesia, unexpected blood loss, infection," and most critically, the possibility of loss of function in the donor's remaining kidney. Sterner et al., *supra* note 94.

¹²⁶ *Hart v. Brown*, 289 A.2d 386, 390 (Conn. Super. Ct. 1972).

¹²⁷ BLACK'S LAW DICTIONARY, *supra* note 117, at 1144 defines "parens patriae" as "the state in its capacity as provider of protection to those unable to care for themselves."

¹²⁸ *Wisconsin v. Yoder*, 406 U.S. 205, 233–34 (1972).

¹²⁹ Sankoorikal, *supra* note 119, at 603. See Mark Sheldon, *Children as Organ Donors*, in ORGAN AND TISSUE DONATION ETHICAL, LEGAL, AND POLICY ISSUES 116 (Bethany Spielman ed., 1996) (citing to Norman Fost, *Children as Renal Donors*, 296 NEW ENG. J. MED. 363 (1977), and stating that there is a conflict of interest when parents attempt to substitute their judgment for a their child by consenting to a

conflict of interest arises when parents consent to tissue or organ donations between siblings.¹³⁰ When there is such a conflict of interest, parental consent to the medical procedure to benefit a sibling is typically not adequate.¹³¹ However, despite this inherent conflict of interest, parental consent alone has generally been deemed sufficient to permit a tissue donation from a minor to benefit the minor's ailing sibling.¹³²

In contrast, court approval is often sought in cases involving organ donation between minor siblings.¹³³ While some may attribute this different legal standard to the fact that there is an inherent conflict of interest in cases involving donation between minor siblings,¹³⁴ this cannot be the complete answer. As aforementioned, there is also an inherent conflict of interest in cases involving tissue donation between minor siblings. Therefore, this different legal approach most likely stems from the fact that organ donation involves more physical risk to the donor than tissue donation.¹³⁵

C. THE COURT APPROVAL PROCESS FOR CONTESTED TISSUE DONATIONS AND ORGAN DONATIONS FROM MINORS

In determining whether a minor may be compelled to donate an organ, the court must look to common law, not statutory law, for legal guidance.¹³⁶ Despite the increasing use of minors as organ and tissue donors, very little case law has developed addressing when it is permissible for a minor to donate tissue or an organ.¹³⁷ The limited amount of case law results from the fact that a significant number of cases are unreported and many donations are never challenged by the parents, surgeons, or guardians ad litem¹³⁸ who are appointed to represent the potential donor in particular

tissue or organ donation between siblings because “[o]bviously, the parents want *both* children to survive”).

¹³⁰ Sankoorikal, *supra* note 119, at 603.

¹³¹ *See id.* at 604 (“Because of potential conflicts between the interests of the parents and child-donor, hospitals and physicians are increasingly seeking court approval of tissue and/or organ donation procedures on minors.”).

¹³² *See Sheldon, Children as Organ Donors, supra* note 129, at 111–12. However, in some cases regarding a potential tissue donation from a minor, the minor’s parents may disagree about whether to provide their consent, a guardian ad litem may oppose the donation, the physicians may oppose the donation or desire court approval, or the parents may simply want court approval to ensure that they are protecting the best interests of their children. If any of these issues arise a petition may be filed with the court for approval of the donation. *See Curran v. Bosze*, 566 N.E.2d 1319, 1320 (Ill. 1990) (the father of three-year-old identical twins filed a petition with the court to compel the twins’ mother to consent to tests on behalf of the twins to determine if they would be compatible bone marrow donors for their half-brother).

¹³³ *See Sheldon, Children as Organ Donors, supra* note 129, at 112 (citing to ANGELA RODDEY HOLDER, LEGAL ISSUES IN PEDIATRICS AND ADOLESCENT MEDICINE (1975) and stating that “kidney donations require both parental consent and court review”). Pursuant to the doctrine of *parens patriae*, the court can protect the interests of individuals within its jurisdiction, including minors. *In the Matter of John Doe*, 481 N.Y.S.2d 932 (N.Y. 1984); Sankoorikal, *supra* note 119, at 604.

¹³⁴ Sankoorikal, *supra* note 119, at 604.

¹³⁵ The risks of organ donation are very similar to risks of tissue donation, but with one important difference—the minor faces the significant risk that what remains of her organ (whether it be one functioning kidney or a portion of her liver) may cease to function in the future. *See Sterner et al., supra* note 94.

¹³⁶ Sankoorikal, *supra* note 119, at 605; Shartle, *supra* note 13, at 448.

¹³⁷ Shartle, *supra* note 12, at 450.

¹³⁸ BLACK’S LAW DICTIONARY, *supra* note 117, at 725 defines a guardian ad litem as “[a] guardian, usu[ally] a lawyer, appointed by the court to appear in a lawsuit on behalf of an incompetent or minor

cases.¹³⁹ In the small number of cases that have been reported, two legal standards have emerged to guide the courts in approving contested tissue donations and live solid organ donations from minors—the best interests standard and the substituted judgment standard.¹⁴⁰ While courts will often declare what standard they are using, most of the time, even if they claim to be using the substituted judgment standard, they are really using the best interests standard.¹⁴¹ This confusion with regard to the appropriate standard to be applied and the proper way to apply the given standard has led to a muddled mess of jurisprudence that provides limited guidance to courts in an area of law where protecting children is of vital importance.

1. *Best Interests Standard*

In applying the best interests standard during the court approval process for tissue or organ donations from minors, the court attempts to determine whether allowing the child to donate an organ or tissue would best serve the child's needs.¹⁴² The court will weigh the potential risks of the harvesting procedure against the potential benefits.¹⁴³ Since donors do not physically benefit from donating tissue or organs, the court must consider other benefits that the potential donor may receive. The court places a significant emphasis on the psychological benefits a donor may experience as a result of the transplant procedure.¹⁴⁴ This means that courts will often assess the relationship between the sibling-donor and the recipient and if they determine that the siblings have a close relationship, the court will most likely conclude that the potential minor-donor would be psychologically better off growing up in an intact family.¹⁴⁵ Interestingly,

party.” Minors do not have procedural capacity to sue or be sued. 2 CHILDREN AND THE LAW: RIGHTS AND OBLIGATIONS § 7:13. Therefore, in cases where the potential donor is a minor who does not consent to the donation, a guardian ad litem may be appointed to represent the child in a suit against her parents. *See id.* The court also has discretion to appoint a guardian ad litem to represent a minor whenever it deems such an appointment necessary. *Id.* The court will often use its discretion and appoint a guardian ad litem to represent a potential child-donor in litigation regarding a transplant, even if the child consents to the donation, because there is an inherent conflict of interest in such cases. *See id.*; Sankoorikal, *supra* note 119, at 603. Parents in organ donation cases involving siblings will often be primarily focused on what they consider to be in the best interests of their ailing child and not on the best interests of the potential donor. Sankoorikal, *supra* note 119, at 603.

¹³⁹ *See* Shartle, *supra* note 12, at 450.

¹⁴⁰ JAN L. WALLANDER, ADOLESCENT HEALTH PROBLEMS: BEHAVIORAL PERSPECTIVES 85 (1995); Sankoorikal, *supra* note 119, at 605–06; Shartle, *supra* note 12, at 448.

¹⁴¹ WALLANDER, *supra* note 140; David S. Lockemeyer, *At What Cost Will the Court Impose a Duty to Preserve the Life of a Child?*, 39 CLEV. ST. L. REV. 577, 586 (1991) (“[I]n applying the substituted judgment doctrine in a case involving a minor, a court is simply applying a form of the best interest test. The court is making a decision based upon its perception of what a reasonable person would do if he were in the minor’s position.”). *See* Strunk v. Strunk, 445 S.W.2d 145, 147 (Ky. 1969) (stating that they were applying the substituted judgment standard in which “the chancellor has the power to deal with the estate of the incompetent in the same manner as the incompetent would if he had his faculties”). *But see* Little v. Little, 576 S.W.2d 493, 498 (Tex. Civ. App. 1979) (stating that the court in *Strunk* based its decision on the benefits that the incompetent donor would derive, not on what the incompetent donor would decide to do if he was competent as should have been under the traditional substituted judgment standard that the *Strunk* court purported to use).

¹⁴² Sankoorikal, *supra* note 119, at 606.

¹⁴³ Shartle, *supra* note 12, at 448–49; WALLANDER, *supra* note 140, at 85.

¹⁴⁴ *See* Pennings et al., *supra* note 40, at 536.

¹⁴⁵ *See id.* at 536. “The child will certainly have an interest in growing up in an intact family. The child once born will benefit if his or her older sibling survives. If the situation of a possible child that can serve as a donor is compared with the situation of a child that is unsuitable as a donor, the former has an advantage compared with the latter. The child that cannot donate will see its sibling die and will grow

the court will not consider the child's personal wishes at all.¹⁴⁶ If it ultimately concludes that the donation would be in the best interests of the donor, the court will approve the donation.¹⁴⁷

The decision in *In re Richardson*¹⁴⁸ vaguely illustrates the proper application of the best interests standard, without providing an abundance of written detail.¹⁴⁹ In this case, Mr. and Mrs. Richardson petitioned the court to compel a kidney donation from their son, Roy Allen, a seventeen-year-old with the mental capacity of a three- or four-year-old,¹⁵⁰ to their daughter Beverly Jean.¹⁵¹ Beverly was thirty-two years old, divorced, and living with her parents. She suffered from an almost complete loss of kidney function and medical findings indicated that if she was not put on dialysis or given a kidney transplant, her death would occur "within months."¹⁵² The Richardsons had a number of children and had all but one of them tested for compatibility with Beverly. The tests concluded that a kidney donated from Roy had only a four to five percent chance of being rejected once transplanted into Beverly, whereas kidneys from Beverly's other siblings had a twenty to thirty percent chance of being rejected.¹⁵³

The court refused to apply the substituted judgment standard, stating that "[i]n Louisiana our law is designed to protect and promote the best interest of a minor." It then analogized the case of organ donation to cases in which minors attempt to convey property or gifts. Relying on Louisiana

up in a family that is marked by the death of a family member." *Id.* See also *Strunk*, 445 S.W.2d at 146 (stating that if the potential child-donor's "well-being would be jeopardized more severely by the loss of his brother than by the removal of a kidney.").

¹⁴⁶ Sankoorikal, *supra* note 119, at 606.

¹⁴⁷ Lynn A. Jansen, *Child Organ Donation, Family Autonomy, and Intimate Attachments*, 13 CAMBRIDGE Q. HEALTHCARE ETHICS 133, 134 (2004).

¹⁴⁸ *In re Richardson*, 284 So.2d 185 (La. Ct. App. 1973).

¹⁴⁹ The entire decision is contained within three pages. *Id.*

¹⁵⁰ Cases, such as *Richardson*, 284 So.2d 185, in which the potential donor is above the age of majority but has the mental capacity of a minor, are discussed in this article because they are analogous to cases involving children in that children are essentially considered incompetent. Ann Eileen Driggs, *The Mature Minor Doctrine: Do Adolescents Have the Right to Die?*, 11(2) HEALTH MATRIX 687, 689 (Spring 2001) ("[C]hildren have traditionally been recognized legally as incompetents lacking the necessary capacity to make valid decisions."). Furthermore, the legal analysis used in both types of cases is the same. See *Strunk v. Strunk*, 445 S.W.2d 145 (Ky. 1969) (purporting to apply the substituted judgment standard to a case involving a potential donor who was a twenty-seven-year-old incompetent with an IQ of 35); *Hart v. Brown*, 289 A.2d 386 (Conn. Super. Ct. 1972) (purporting to apply the substituted judgment standard to a case involving a potential donor who was seven-and-a-half-years-old); *Richardson*, 284 So.2d 185 (applying the best interests standard to a case involving a potential donor who was a seventeen-year-old with the mental capacity of a three or four-year-old); *In re Pescinski*, 226 N.W.2d 180 (Wis. 1975) (purporting to apply the best interests standard to a case involving a potential donor who was a thirty-nine-year-old incompetent with the mental capacity of a twelve-year-old who was suffering from schizophrenia); *Little v. Little*, 576 S.W.2d 493 (Tex. Civ. App. 1979) (purporting to apply the substituted judgment standard to a case involving a potential donor who was a fourteen-year-old minor with Down's Syndrome); *In the Matter of John Doe*, 481 N.Y.S.2d 932 (N.Y. 1984) (applying the best interests standard to a case involving a potential donor who was a forty-three-year-old incompetent with the mental capacity of a two-year-old); *Curran v. Bosze*, 566 N.E.2d 1319 (Ill. 1990) (applying the best interests standard to a case involving potential donors who were three-and-a-half-years-old).

¹⁵¹ See *Richardson*, 284 So.2d at 185-86 (Mr. Richardson initially filed a suit against his wife, Mrs. Richardson, seeking to compel her to consent to the donation, but he did so only as a "procedural vehicle for placing the matter before the court" and Mrs. Richardson did not really object to the donation).

¹⁵² *Id.* at 186.

¹⁵³ *Id.* at 186-87.

law that prohibited an “unmarried minor . . . from making an inter vivos donation of his property,” the court reasoned that

since [Louisiana] law affords this unqualified protection against intrusion into a comparatively mere property right, it is inconceivable to us that it affords less protection to a minor’s right to be free in his person from bodily intrusion to the extent of loss of an organ unless such loss be in the best interest of the minor.

After rejecting the substituted judgment standard, the court proceeded to apply the best interests standard. In assessing the medical necessity for the transplant, the court relied upon evidence that demonstrated that a kidney transplant was not an “absolute immediate necessity in order to preserve Beverly’s life,” and therefore concluded that the lack of necessity was not worth the “surgical intrusion and loss of a kidney.”¹⁵⁴ In accordance with the best interests standard, it appears that the court considered the potential risk to Roy if he were to donate his kidney, although it did not articulate what those risks were. Additionally, pursuant to the intended application of the best interests standard, the court considered the possible benefits that Roy might experience if he was compelled to donate his kidney. The plaintiffs argued that if Roy donated his kidney to Beverly she would be able to care for Roy after their parents passed away, thus conferring a significant benefit on Roy. Ultimately, the court rejected this argument and concluded that any potential benefits that Roy might experience as a result of donating his kidney were entirely speculative.¹⁵⁵ After employing what appeared to be the proper balancing approach of the best interests standard—weighing the speculative benefits against the possible risks to Roy—the court determined that the kidney donation would not be in Roy’s best interests and subsequently declined to compel the procedure.¹⁵⁶ While it seems that the court applied the best interests standard in its traditional, intended form, the court neither fully explained why it considered the benefits to Roy to be speculative nor what it concluded the specific risks to be if Roy donated his kidney.¹⁵⁷ Therefore, this decision, while illustrating the appropriate use of the best interests standard, leaves little by way of guidance for courts grappling with similar issues.

*In the Matter of John Doe*¹⁵⁸ also illustrates the proper application of the best interests standard, but like *In re Richardson*,¹⁵⁹ does so without providing a detailed analysis.¹⁶⁰ In this case the petitioner, a thirty-six-year-old suffering from chronic myelogenous leukemia, sought an order from the New York Court of Appeals authorizing a bone marrow transplant from his brother, John Doe, a forty-three-year-old incompetent with the mental capacity of a two-year-old.¹⁶¹ The court refused to use the substituted

¹⁵⁴ *In re Richardson*, 284 So.2d 185, 187 (La. Ct. App. 1973).

¹⁵⁵ *Id.*

¹⁵⁶ *Id.*

¹⁵⁷ See generally *id.*

¹⁵⁸ *In the Matter of John Doe*, 481 N.Y.S.2d 932 (N.Y. 1984).

¹⁵⁹ *In re Richardson*, 284 So.2d at 185.

¹⁶⁰ The entire decision is contained within two pages. *Doe*, 481 N.Y.S.2d 932.

¹⁶¹ *Id.* As aforementioned, generally parental consent to a bone marrow transplant between minor siblings is sufficient to authorize the procedure. However, sometimes parents seek court authorization in

judgment standard and instead opted to use the best interests standard. It believed that the best interests standard was the only standard that conformed to the principle of *parens patriae*, under which the court was authorized to review the case.¹⁶² While the court published its holding in a brief, two-page per curiam opinion, and thus did not provide extensive detail regarding its analytical process, it nevertheless seemed to properly apply the best interests standard.¹⁶³ The court assessed the risk to John in donating his bone marrow and decided that “a bone marrow transplant [would] be of minimal risk to the incompetent and is the only reasonable medical alternative to save petitioner’s life.” It also assessed the potential benefits to John in donating his bone marrow and saving his brother’s life, but did not explain what these benefits were. The court merely stated that “the trial court found the evidence established to a ‘reasonable certainty’ that participation in the procedure would be in the incompetent’s best interest,” after performing a “thorough and systematic analysis of the benefits and risks.”¹⁶⁴ After reviewing the trial court’s “thorough and systematic analysis,”¹⁶⁵ the court affirmed the decision of the trial court, declaring “that the transplant would be in the incompetent’s best interests because the benefits to him of his brother’s future company and advocacy outweigh any physical and psychological risks.”¹⁶⁶

The court in *In re Pescinski*¹⁶⁷ rejected the substituted judgment standard and applied the best interests standard,¹⁶⁸ but did so in an unclear manner,¹⁶⁹ highlighting the primary criticism of the standard—that it is vague and difficult to apply.¹⁷⁰ The court was asked to determine whether a county court could order Richard Pescinski, a thirty-nine-year-old incompetent schizophrenic with the mental capacity of a twelve-year-old,¹⁷¹ to donate his kidney to his ailing sister, Elaine Jeske.¹⁷² There was no evidence that Richard ever consented to the procedure. Furthermore, there was no evidence to support that “any interests of the ward [would] be served by the transplant.”¹⁷³ The court thus concluded that “[i]n the absence of real consent on [Richard’s] part, and in a situation where no benefit to him ha[d] been established,” there was no “authority for the county court, or this court, to approve the operation.”¹⁷⁴ However, the court

cases involving donations between siblings, or other relatives, to ensure that they minimize the conflict of interest inherent in such cases. *See, e.g., id.*

¹⁶² *See id.* (“We conclude that the source of any power that a court may have to authorize an incompetent’s participation in a surgical procedure to save the life of another is confined to its *parens patriae* power; thus, such authorization may only be given if it is in the incompetent’s best interests.”).

¹⁶³ *See generally id.*

¹⁶⁴ *Id.* at 933.

¹⁶⁵ *Id.*

¹⁶⁶ *In the Matter of John Doe*, 481 N.Y.S.2d 932 (N.Y. 1984).

¹⁶⁷ *In re Pescinski*, 226 N.W.2d 180 (Wis. 1975).

¹⁶⁸ *Id.* at 182.

¹⁶⁹ *See generally id.*

¹⁷⁰ Jansen, *supra* note 147.

¹⁷¹ Cases such as *In re Pescinski*, 226 N.W.2d 180, are discussed in this article despite the fact that the potential donor may not be a minor per se because these cases involve donors who have the mental capacity of a minor and thus are parallel to cases involving potential donors who are in fact minors.

¹⁷² *Id.* at 180–81.

¹⁷³ *In re Pacinski*, 226 N.W.2d 180, 181 (Wis. 1975) (emphasis added).

¹⁷⁴ *Id.* at 182.

did not indicate precisely how it came to the conclusion that Richard would not receive any benefits from the transplant, nor did it discuss the potential risks that Richard would face if he donated his kidney.¹⁷⁵ Therefore, this decision left courts with little guidance in how to apply the best interests standard in future analogous cases.

In *Curran v. Bosze*,¹⁷⁶ “perhaps the best analysis of any case concerning the propriety of a donation by a minor,”¹⁷⁷ the court properly applied the best interests standard, after rejecting the substituted judgment standard. The case was brought before the Supreme Court of Illinois by the biological father of three-and-a-half-year-old twins. The twins’ father sought a court order, against the twins’ mother’s wishes, to compel the twins to donate bone marrow to their half-brother who suffered from leukemia.¹⁷⁸ The court determined that bone marrow donations from minors were permissible only if the child’s parents or guardian have consented to the transplant and the procedure is in the child’s best interests. A transplant would be considered in the child-donor’s best interests only if three factors were satisfied: (1) the parent or guardian who consented on behalf of the minor was well informed of the risks and benefits to the child-donor inherent in the medical procedure; (2) the parent or guardian would be able to provide adequate emotional support to the donor; and (3) there was an existing, close relationship between the donor and the recipient.¹⁷⁹

After considering the facts of the case and testimony from a number of physicians and psychologists, the court concluded that the twins’ mother would not be able to provide adequate emotional support to them during, and immediately following, the medical procedure because she was adamantly opposed to the procedure. Moreover, the court determined that the twins did not have a close relationship with their half-brother whom they had only met twice.¹⁸⁰ Accordingly, the court concluded that compelling the twins to donate their bone marrow would not be in their best interests.¹⁸¹

The detailed, articulate, and clear decision in *Curran* is the exception, not the rule. The best interests standard has been criticized time and again. First, the standard has been attacked for being vague and difficult to apply.¹⁸² While in theory it is vital to consider the best interests of the potential minor donor, in practice it is quite difficult to conclude precisely what factors should be considered in determining what is in his or her best

¹⁷⁵ See generally *id.*

¹⁷⁶ *Curran v. Bosze*, 566 N.E.2d 1319, 1320 (Ill. 1990).

¹⁷⁷ Shartle, *supra* note 12, at 458.

¹⁷⁸ *Curran*, 566 N.E.2d at 1320–21.

¹⁷⁹ *Id.* at 1343.

¹⁸⁰ See *id.* at 1344 (stating that although the twins and their half-brother shared the same biological father, “there was no evidence . . . to indicate [they were] known to each other as family”); Shartle, *supra* note 12, at 459.

¹⁸¹ *Curran*, 566 N.E.2d at 1345.

¹⁸² See Jansen, *supra* note 147 (stating that the best interests standard is difficult to apply and that it is “often unclear what interests of the donor should be taken into account when considering what is in his or her best interests”); Rosalind Ekman Ladd, *The Child as Living Donor: Parental Consent and Child Assent*, 13 CAMBRIDGE Q. HEALTHCARE ETHICS 143, 144 (2004) (stating that the best interest standard is “inherently vague and difficult to determine”).

interests.¹⁸³ Furthermore, it is entirely speculative to consider how the potential minor donor may feel in the future, following the donation procedure. Second, some argue that the standard is so broad that it enables courts to base their holdings upon moral grounds and then use the best interests standard to justify their conclusions.¹⁸⁴ Finally, some critics argue that it is inappropriate for a court to focus only on what will physically and psychologically be in the best interests of the donor and to fail to recognize a minor's personal wishes.¹⁸⁵ These critics argue that "when a minor, particularly one near majority desires to donate his organ or tissue to another, such as his sibling, the reasonable wishes of the minor should be heard and considered but should not be determinative."¹⁸⁶

2. *Substituted Judgment Standard*

The substituted judgment standard was originally introduced to guide guardians and courts in determining whether a formerly competent, now incompetent, individual would consent to a particular medical procedure.¹⁸⁷ A primary caregiver's desire to substitute what she believes would be the patient's decision regarding whether to undergo particular medical treatment if he were competent, for the decision, or lack thereof, of the incompetent patient, is permissible only if there is "clear and convincing evidence of the patient's intent, derived either from a patient's explicit expressions of intent or from knowledge of the patient's personal value system."¹⁸⁸ In assessing whether a formerly competent individual would consent to a medical procedure, the individual's primary caregiver must ascertain whether the individual ever "expressed explicit intent regarding this type of medical treatment prior to becoming incompetent."¹⁸⁹ If the individual never explicitly expressed any intentions regarding the medical procedure, then the primary caregiver may consider the "patient's personal value system" to determine what decision the incompetent individual would make.¹⁹⁰ The incompetent individual's primary caregiver may consider all of the following in an attempt to substitute a decision the now incompetent individual would make if he or she were still competent: the

¹⁸³ Jansen, *supra* note 147.

¹⁸⁴ Pentz et al., *supra* note 123, at 150. See Robert A. Crouch & Carl Elliot, *Moral Agency and the Family: The Case of Living Related Organ Transplantation*, 8 CAMBRIDGE Q. HEALTHCARE ETHICS 275, 280 (1999).

¹⁸⁵ See Curran v. Bosze, 566 N.E.2d 1319, 1320 (Ill. 1990) (discussing the decision in *In re Estate of Longeway*, 549 N.E.2d 292 (Ill. 1989) to reject the best interests standard because "it lets another make a determination of a patient's quality of life, thereby undermining the foundation of self-determination and inviolability of the person upon which the right to refuse medical treatment stands").

¹⁸⁶ Shartle, *supra* note 12, at 449. See *In re Pescinski*, 226 N.W.2d 180, 184 (Wis. 1975) (Day, J., dissenting) (stating that the best interests standard applied by the majority "would forever condemn the incompetent to always be a receiver, a taker, but never a giver," and concluding that the substituted judgment standard would enable the court to do "for the incompetent what it is sure he would do himself if he had the power to act.").

¹⁸⁷ See Curran, 566 N.E.2d at 1323; Sankoorikal, *supra* note 119, at 609 (stating that the substituted judgment standard "assumes some sort of prior decision-making capability"); WALLANDER, *supra* note 140.

¹⁸⁸ Curran, 566 N.E.2d at 1324 (citing *Longeway*, 549 N.E.2d 292).

¹⁸⁹ See *id.* (quoting *Longeway*, 549 N.E.2d 292).

¹⁹⁰ See Curran v. Bosze, 566 N.E.2d 1319, 1324 (Ill. 1990) ("Ascertainment of what the patient would decide must be based on clear and convincing evidence of the patient's intent, derived either from a patient's explicit expressions of intent or from knowledge of the patient's personal value system.").

incompetent's "philosophical, religious and moral views, life goals, values about the purpose of life and the way it should be lived, and attitudes toward sickness, medical procedures, suffering and death" ¹⁹¹

The substituted judgment standard, which has been utilized in American courts since 1844, ¹⁹² has now been extended to determine whether minor children, considered legally incompetent to make informed decisions regarding medical procedures, would consent to donating an organ or tissue. ¹⁹³ In using the substituted judgment standard in this context, the court must essentially put itself in the "shoes" of the minor patient and determine whether the minor, or incompetent, patient would choose or refuse to make an organ or tissue donation if she were fully competent to make the decision on her own. ¹⁹⁴ "The doctrine requires that the court 'substitute itself as nearly as may be for the incompetent and to act upon the same motives and considerations as would have moved' the incompetent." ¹⁹⁵

The application of the substituted judgment standard to cases involving potential minor donors has been criticized significantly. The primary criticism of this standard is that it is next to impossible to determine whether a minor child would decide to donate tissue or an organ if he or she were legally competent because the child has never been deemed legally competent, ¹⁹⁶ leaving no "clear and convincing evidence" regarding the minor's intent upon which to base a critical medical decision. ¹⁹⁷

The court in *Curran* ¹⁹⁸ discussed this criticism. Mr. Bosze argued that the court should follow the doctrine of substituted judgment in making its decision because he believed that the evidence clearly established that "the twins, if competent, would [have] consent[ed] to the bone marrow

¹⁹¹ *Id.* at 1323.

¹⁹² *Hart v. Brown*, 289 A.2d 386, 388 (Conn. Super. Ct. 1972).

¹⁹³ WALLANDER, *supra* note 140. *See Strunk v. Strunk*, 445 S.W.2d 145, 147 (Ky. 1969) (purporting to apply the substituted judgment standard to a case in which authorization of a kidney donation from a twenty-seven-year-old incompetent was sought); *Hart* 289 A.2d at 386 (purporting to apply the substituted judgment standard to a case in which authorization of a kidney donation from a seven-and-a-half-year-old minor was sought); *Little v. Little*, 576 S.W.2d 493, 493 (Tex. Civ. App. 1979) (purporting to apply the substituted judgment standard to a case in which authorization of a kidney donation from a fourteen-year-old minor with Down's Syndrome was sought).

¹⁹⁴ *See Strunk*, 445 S.W.2d at 147 ("The inherent rule in these cases is that the chancellor has the power to deal with the estate of the incompetent in the same manner as the incompetent would if he had his faculties."); *Shartle*, *supra* note 12, at 448 ("A court applying the substituted judgment in its purest form attempts to substitute itself as nearly as possible for the incompetent and to act upon the same motives and considerations that would move the incompetent but for the lack of competency.").

¹⁹⁵ *Little*, 576 S.W.2d at 497 (quoting *City Bank Farmers Trust Co. v. McGowan*, 323 U.S. 594, 599 (1945)).

¹⁹⁶ *Shartle*, *supra* note 12, at 449.

¹⁹⁷ *See James Dwyer & Elizabeth Vig, Rethinking Transplantation Between Siblings*, 25(6) HASTINGS CENTER REP. 7 (1995) ("The application of this doctrine to the case of children is quite problematic. Young children are not formerly competent adults who have lost their capacity to decide. They are young people who have never been competent, and may not have well-formed values and outlooks."). *See also* WALLANDER, *supra* note 140; *Curran v. Bosze*, 566 N.E.2d 1319, 1325-26 (Ill. 1990) (refusing to apply the substituted judgment standard because both of the potential bone marrow donors were only three-and-a-half years old and therefore had yet to have the opportunity to develop "'actual, specific express intent' or any other form of intent, with regard to serving as a bone marrow donor").

¹⁹⁸ *Curran*, 566 N.E.2d 1319.

harvesting procedure.”¹⁹⁹ The mother argued that the court should reject the substituted judgment standard and apply the best interests standard because it was not possible to determine whether the twins would consent or refuse to donate their bone marrow if they were competent adults.²⁰⁰ The court ultimately sided with the twins’ mother and concluded that the substituted judgment standard was inadequate to serve justice in the case at bar.²⁰¹ The court reasoned that there was “no evidence by which a guardian may be guided in ascertaining whether these three-and-a-half-year-old children, if they were adults, would or would not consent to a bone marrow harvesting procedure for another child, their half-brother whom they have only met twice.”²⁰²

To take the definition of substituted judgment literally would mean that both the psychological and physical effects of the medical procedure should be irrelevant.²⁰³ However, given the difficulty in trying to determine whether a child would choose to donate an organ, most courts, in applying the substituted judgment standard, place significant emphasis on the potential benefits to the minor donor, and not much emphasis on whether the minor would have consented to the transplant if he were fully competent.²⁰⁴ Thus, as illustrated by the cases summarized below, despite the fact that courts claim that they are using the substituted judgment standard they are actually using a variation of the best interests standard.

In *Strunk v. Strunk*,²⁰⁵ the Kentucky Court of Appeals purported to apply the substituted judgment standard, but in reality applied a variation of the best interests standard,²⁰⁶ in affirming the county court’s decision to allow the removal of a kidney from Jerry Strunk, a twenty-seven-year-old incompetent with an IQ of thirty-five (the equivalent intelligence of a six-year-old), so that it could be donated to his ailing brother, Tommy.²⁰⁷ Tommy was twenty-eight years old and suffering from chronic glomerulus nephritis, a fatal kidney disease. At the time the case was presented to the court, Tommy was being kept alive by frequent treatment on his artificial kidney, but the treatments could not be continued for much longer.²⁰⁸ Jerry had been committed to a state hospital maintained for the “feeble-minded.” A number of family members were tested for blood type or tissue

¹⁹⁹ *Id.* at 1322.

²⁰⁰ *Id.*

²⁰¹ *Id.* at 1326.

²⁰² *Id.*

²⁰³ Sankoorikal, *supra* note 119, at 609.

²⁰⁴ *See* Dwyer & Vig, *supra* note 197 (“When it is not possible to use the notion of substituted judgment because the person was never competent (or because not enough is known about the preferences of the person who was once competent to yield a determinate answer), then the conventional approach turns to the idea of the person’s best interests.”); *Little v. Little*, 576 S.W.2d 493, 498 (Tex. App. 1979) (“It is clear in transplant cases that courts, whether they use the term ‘substituted judgment’ or not, will consider the benefits to the donor as a basis for permitting an incompetent to donate an organ.”).

²⁰⁵ *Strunk v. Strunk*, 445 S.W.2d 145, 145 (Ky. 1969).

²⁰⁶ *See id.* at 147 (stating that they were applying the substituted judgment standard in which “the chancellor has the power to deal with the estate of the incompetent in the same manner as the incompetent would if he had his faculties”). *But see Little*, 576 S.W.2d at 498 (stating that the court in *Strunk* based its decision on the benefits the incompetent donor would derive, not based on what the incompetent donor would decide to do if he was competent).

²⁰⁷ *Strunk*, 445 S.W.2d at 149.

²⁰⁸ *Id.* at 145.

compatibility with Tommy, but all, except Jerry, were found to be medically unacceptable as donors. Subsequently, Tommy and Jerry's mother petitioned the county court for authority to proceed with the transplant. The county court authorized the transplant after concluding that it was necessary and would be beneficial for both Tommy and Jerry.²⁰⁹ The county court's decision was ultimately appealed by Jerry's guardian ad litem who disagreed with the court's authority to "authorize the removal of an organ from the body of an incompetent who is a ward of the state."²¹⁰ The circuit court adopted the findings of the county court and the case was again appealed to the Kentucky Court of Appeals.²¹¹

While on appeal, the Kentucky Court of Appeals purported to apply the substituted judgment standard, yet it did not once reflect upon whether Jerry would want to donate his kidney to his brother if he were competent.²¹² Perhaps the court avoided discussing this critical element of the substituted judgment standard because Jerry had never been competent and therefore any determination regarding whether Jerry, if competent, would wish to donate his kidney would have been entirely speculative.²¹³ Instead, the court seemed to base its decision primarily on the fact that psychiatric testimony demonstrated that Jerry was "greatly dependent upon [his brother], emotionally and psychologically and that his well-being would be jeopardized more severely by the loss of his brother than by the removal of a kidney."²¹⁴

In *Little v. Little*²¹⁵ the court applied a variation of the substituted judgment standard similar to that applied in *Strunk*, despite the fact that it acknowledged that prior judicial decisions, including *Strunk*, had inappropriately applied the standard.²¹⁶ The Texas Court of Appeals approved a kidney donation from Anne Little, a fourteen-year-old minor with Down's Syndrome, to her ailing brother, Stephen.²¹⁷ Stephen was suffering from endstage kidney disease and evidence demonstrated that for Stephen to survive his illness he would need to be placed on dialysis or receive a kidney transplant. Anne had been declared to be of unsound mind and was the only living related donor with acceptable matching characteristics. After finding out that Anne was a compatible donor for Stephen, Anne's mother filed a petition with the county court to authorize

²⁰⁹ *Id.* at 146.

²¹⁰ *See id.* at 146-47.

²¹¹ *See Strunk v. Strunk*, 445 S.W.2d 146, 146 (Ky. 1969).

²¹² *See generally id.*

²¹³ *See* Louise Harmon, *Falling Off The Vine: Legal Fictions And The Doctrine Of Substituted Judgment*, 100 YALE L.J. 1, 34-35 (1990) (stating that since Jerry Strunk was born "mentally retarded" he was never competent; therefore, the court had nothing upon which to base a determination of whether he would have wished to donate his kidney if he had been competent and it had "unfettered discretion" to determine whether the kidney donation could be compelled).

²¹⁴ *Strunk*, 445 S.W.2d at 146.

²¹⁵ *Little v. Little*, 576 S.W.2d 493, 493 (Tex. Civ. App. 1979).

²¹⁶ *See Little*, 576 S.W.2d at 498 ("Although in *Strunk* the Kentucky Court discussed the substituted judgment doctrine in some detail, the conclusion of the majority there was based on the benefits that the incompetent donor would derive, rather than on the theory that the incompetent would have consented to the transplant if he were competent."); Shartle, *supra* note 12, at 454.

²¹⁷ *Little*, 576 S.W.2d at 500.

the transplant operation. The county court authorized the transplant, but Anne's guardian ad litem appealed the decision.²¹⁸

In determining what standard to apply to the case at bar, the Texas Court of Appeals stated:

It is clear in transplant cases that courts, whether they use the term 'substituted judgment' or not, will consider the benefits to the donors as a basis for permitting an incompetent to donate an organ. Although in *Strunk* the Kentucky Court discussed the substituted judgment doctrine in some detail, the conclusion of the majority there was based on the benefits that the incompetent donor would derive, rather than on the theory that the incompetent would have consented to the transplant if he were competent. We adopt this approach.

Thus, the court proceeded to apply what it considered to be the substituted judgment standard, not the traditional standard. In reality, by considering the benefits a minor would receive from being a donor, the court applied a standard akin to the best interests standard.

The court reviewed the evidence presented at the county court level to consider the benefits that Anne would receive if she were to donate her kidney to Stephen. A number of psychologists and physicians testified to the physical risks and the potential psychological benefits to Anne if she donated her kidney. The medical experts stated that "Anne would experience pain and discomfort, but they all referred to it as minimal" and there was evidence to demonstrate that "Anne ha[d] a high pain threshold." However, they also testified that due to Anne's "limited intellectual development" she "may be less able to understand the transplant procedures or to adapt to the unfamiliar surroundings of the hospital, so that her ordeal may be more burdensome than that of a normal adult."²¹⁹ Psychologists presented testimony that the court believed "conclusively establishe[d] the existence of a close relationship between Anne and Stephen, a genuine concern by each for the welfare of the other and, at the very least, an awareness by Anne of the fact that she [was] in a position to ameliorate Stephen's burden."²²⁰ The court conceded that "the testimony of psychiatrists and psychologists must still be classified as speculative," but nevertheless concluded that the speculative nature of psychological testimony was not a sufficient reason to justify "judicial rejection of the value of such testimony."²²¹ The court then went on to state that there was "such strong evidence to the effect that [Anne] would receive substantial psychological benefits" from donating her kidney to her ailing brother.²²²

The psychological evidence that the court in *Little* relied upon to make its decision seemed entirely too speculative to base such a critical medical decision upon. The court acknowledged that Anne probably did not have the mental capacity to understand death, but that she did understand the concept of absence and that "she is unhappy on the occasions when [her

²¹⁸ *Id.* at 494.

²¹⁹ *Id.* at 499.

²²⁰ *Id.* at 498.

²²¹ *Little v. Little*, 576 S.W.2d 493, 499 (Tex. Civ. App. 1979).

²²² *Id.* at 500.

brother] must leave home for hours when he journeys to San Antonio for dialysis.” This fact, in conjunction with the evidence that demonstrated that Anne and her brother had a close relationship, led the court to conclude that if Anne did not donate her kidney, and her brother subsequently died, she would experience significant psychological trauma.²²³ The court also stated that, “Studies of persons who have donated kidneys reveal resulting positive benefits such as heightened self-esteem, enhanced status in the family, renewed meaning in life, and other positive feelings. . . .”²²⁴ Relying upon this speculative psychological testimony, and the fact that the organ donation posed minimal risk to Anne, the court concluded that the kidney donation would be in Anne’s best interests and therefore authorized the donation.²²⁵

The decision in *Hart v. Brown*²²⁶ is yet another illustration of the difficulty courts face in applying the traditional substituted judgment standard. In this case, the court assessed whether Margaret Hart, a seven-and-a-half-year-old identical twin, could be permitted to donate a kidney to her ailing twin sister, Kathleen. At the time this case was reviewed by the court, Kathleen was in the hospital waiting for a kidney transplant. The evidence demonstrated that she would die if she did not receive a kidney transplant soon.²²⁷

In making its decision, the court purported to use the substituted judgment standard.²²⁸ Yet, like the court in *Strunk*, the court did not once consider whether Margaret would wish to donate her kidney if she were competent.²²⁹ Instead, the court relied, in part, on the following testimony from a psychiatrist: “[T]he donor has a strong identification with her twin sister . . . [and] if the expected successful results are achieved they would be of immense benefit to the donor in that the donor would be better off in a family that was happy than in a family that was distressed and in that it would be a very great loss to the donor if the donee were to die from her illness.”²³⁰ While the court declared that the value of the psychological testimony was limited given the young age of Margaret and her sister, it nevertheless went on to conclude that the donation would be “most beneficial to the donee . . . and . . . [would] be of *some* benefit to the donor” and declared the transplant permissible.²³¹ The court’s ultimate conclusion appears to be based primarily upon the benefits that Margaret would receive if she were to donate her kidney, not upon what Margaret would decide in regards to the donation if she were competent. In doing so, the court applied an analytical framework more similar to the best interests standard than the substituted judgment standard to conclude that the transplant was permissible.

²²³ See *id.* at 498–99.

²²⁴ *Id.* at 499.

²²⁵ See *id.* at 498–500.

²²⁶ *Hart v. Brown*, 289 A.2d 386, 388 (Conn. Super. Ct. 1972).

²²⁷ *Id.*

²²⁸ *Id.* at 391.

²²⁹ See generally *id.*

²³⁰ *Id.* at 389 (emphasis added) (stating that the “psychiatric testimony is of limited value only because of the ages of the minors”).

²³¹ *Id.* (emphasis added).

As illustrated by the cases discussed in this Part, a minor's wishes regarding whether to donate tissue or organs are given very little weight in determining whether organ donations from minors are permissible.²³² The wishes of a minor are generally only considered if the minor explicitly and vehemently states that she does not want to donate tissue or an organ, in which case no doctor or court would approve the donation. Of course, if a minor consents to the organ donation the court will take her consent into consideration, but it is not a determinative factor in concluding whether the donation is permissible. However, under the current framework, if a minor does consent to donation, the court makes little effort to consider the very likely possibility that the minor may have been coerced into making that decision. As more children are conceived primarily to be donors, the probability that parents may coerce their children to consent to donation will increase significantly.²³³

V. COGNITIVE DEVELOPMENT THEORIES

In an effort to protect children from being coerced into donating tissue or organs, legislative standards²³⁴ should be put in place requiring a child-donor's informed consent before any donation may be permitted. Yet, mandating that a child-donor's informed consent be obtained before a tissue or organ donation is permitted raises a thorny issue—at what age is a child able to provide adequately informed consent?

Ascertaining whether or not a potential donor is giving truly informed consent entails a sequence of complex assumptions. In asking a child to consent to a procedure, one recognizes his right to significant decision-making power. But implicit in the application of this rightful claim must be the finding that the child has the capacity to represent his own interest. The challenge is to determine when a child is cognitively, morally, and emotionally competent to provide truly informed consent or refusal for such a procedure.²³⁵

Legislative standards should be put in place to require a minor's informed consent to a proposed tissue or organ donation, but should only permit donations when the potential child-donor is at an age at which she can fully comprehend the risks entailed in the tissue or organ harvesting procedure.

In order to determine the age at which a child is capable of making informed medical decisions, it is vitally important to look to cognitive development findings. Cognitive development is the study of how thought and knowledge processes develop in children and adolescents.²³⁶ Studies in this area of psychology focus on how children become more efficient and effective in their understanding of the world and decision-making processes

²³² See discussion *supra* Part IV.

²³³ See discussion *supra* Part III.A.

²³⁴ Because the state has a fundamental interest in protecting the health of minors “the state may constitutionally enact legislation to regulate, including prohibit, living organ and tissue donation by minors.” Shartle, *supra* note 12, at 446.

²³⁵ Sheldon, *Children as Organ Donors*, *supra* note 129, at 113 (quoting Melvin D. Levine, B.M. Camitta, D. Nathan & W.J. Curran, *The Medical Ethics of Bone Marrow Transplantation in Childhood*, 86 J. PEDIATRICS 145 (1975)).

²³⁶ LISA OAKLEY, COGNITIVE DEVELOPMENT 2 (2004).

over time.²³⁷ Cognitive development findings should therefore play a critical role in concluding the age at which a child is able to make adequately informed medical decisions, particularly the decision whether to donate tissues or an organ.

One of the most noted theories of the cognitive development of children and adolescents was formulated by Jean Piaget.²³⁸ Classic Piagetian theory postulates that there are four stages in the development of a child's cognition.²³⁹ The first stage of cognitive development has been coined the sensorimotor stage and lasts from when a child is born until she is approximately two years old. The second stage is the preoperational stage and occurs when a child is between the ages of two and seven. During this stage a child lacks the ability to think into the future and needs explicit, concrete examples in order to comprehend difficult concepts. "A child's thinking at this stage is also highly egocentric, and even in conversation, he or she will fail to recognize any duality in the exchange of information and certainly will fail to comprehend any perspective other than their own."²⁴⁰

Between the ages of seven and eleven children progress through the third stage, known as the concrete operational stage. In this stage a child can think about her environment from more than one perspective and thus the egocentric thought processes decline.²⁴¹ Children in this stage are capable of abstract thought, but may need previous experience with a concept in order to comprehend it.²⁴²

The final stage in the Piagetian theory of cognitive development, which begins when a child is approximately eleven years old, is the formal operational stage. In this stage, a child will initially revert to egocentric thinking, but will ultimately achieve a much broader perspective and be able to think about other individuals. Generally, children in this stage are able to think abstractly about truth, morality, justice, and the nature of existence.²⁴³ Most importantly, children between the ages of eleven and fifteen are able to "judge the merits of an act such as donation on its ability to help others and can make decisions about research not designed to have any direct, therapeutic benefit."²⁴⁴ Furthermore, "[m]inors at the formal operations stage exhibit an adult ability to address a problem and may be

²³⁷ See *id.*

²³⁸ See Stacey T. Lutz & William G. Huitt, *Connecting Cognitive Development and Constructivism: Implications from Theory for Instruction and Assessment*, 9(1) CONSTRUCTIVISM HUM. SCI. 67, 2 (2004), available at <http://chiron.valdosta.edu/whuitt/brilstar/chapters/cogdev.doc> (last visited Jan. 17, 200) (pagination supplied for online version). Jean Piaget was a Swiss biologist, philosopher, and behavioral scientist. His theory of child cognitive development was widely accepted in the 1960s and 1970s. *Id.*

²³⁹ Driggs, *supra* note 150, at 703. See Lutz & Huitt, *supra* note 238, at 2.

²⁴⁰ See *id.* at 3–4.

²⁴¹ See *id.*

²⁴² Susan Zinner, *Cognitive Development and Pediatric Consent to Organ Donation*, 13 CAMBRIDGE Q. OF HEALTHCARE ETHICS 125, 126 (2004).

²⁴³ Lutz & Huitt, *supra* note 238, at 4.

²⁴⁴ Zinner, *supra* note 242 at 128.

capable of providing informed consent despite their chronological age.”²⁴⁵
By the age of fifteen, a child is essentially able to think like an adult.²⁴⁶

Piagetian theory has been criticized and expanded upon, yet continues to have a significant impact on the study of cognitive development.²⁴⁷ Some critics have claimed that Piaget’s theory does not account for the effect of other people, the environment, and culture on the child. More specifically, they argue that dividing child cognitive development into rigid stages does not take into account that “[d]ifferences in each child’s abilities at any given age may occur due to personality, specific demands upon the child, or their individual conceptual knowledge at the time.”²⁴⁸ Others have argued that “Piagetian theory fails to account for how and why a child passes from one stage to another, and . . . to provide a systematic description of the conceptual structures possessed by the child at each stage.”²⁴⁹

Nevertheless, Piagetian theory “continues to validly describe the process of mental change” in children.²⁵⁰ Moreover, despite the fact that some researchers have added to and expanded upon classic Piagetian theory, the revised models of cognitive development theory have retained the “spirit” of Piaget’s original work.

Most studies conducted to explore the age at which children possess the requisite skills to make informed medical decisions have occurred in the context of medical research studies. These studies have assessed the age at which children are able to adequately consent to participating in medical research. Participating in a medical research study is akin to donating tissue or an organ in the sense that a child in both cases is not likely to receive a direct physical benefit. Therefore, the conclusions drawn in these studies are applicable to cases involving tissue and organ donations from minors.

Lois Weithorn conducted a ground-breaking study to determine when children are capable of making informed medical decisions. She discovered that when children were presented with complex scenarios, performance by the nine-year-old participants did not differ significantly from the fourteen-year-old, eighteen-year-old, and twenty-one-year-old participants. Most importantly, Weithorn found that the decision-making process of the fourteen-year-old participants was not markedly different from that of adult participants.²⁵¹

The combination of classic Piagetian theory and the results of Weithorn’s study indicate that children above the age of nine are able to grapple with complex scenarios and that children above the age of fourteen

²⁴⁵ *Id.* at 126.

²⁴⁶ See Driggs, *supra* note 150, at 703 (stating that Piagetian theory posits that at the age of fifteen a “child is in a mature state that includes a mature thinking process”).

²⁴⁷ Lutz & Huitt, *supra* note 238, at 4.

²⁴⁸ Driggs, *supra* note 150, at 703.

²⁴⁹ Lutz & Huitt, *supra* note 238, at 4 (quoting Kagan, as cited in W. Stanton, *A Cognitive Development Framework*, 12(1) CURRENT PSYCHOL. 26 (1993)).

²⁵⁰ *Id.*

²⁵¹ Zinner, *supra* note 242, at 127. However, it should be noted that, “[r]esearch indicates that even some adults have difficulty demonstrating knowledge sufficient to provide informed consent” and “[e]xpecting younger minors to meet this standard may be unrealistic.” *Id.* at 128.

are essentially able to think like adults when making important medical decisions. These conclusions about the ages at which children are able to adequately make informed medical decisions form the basis for the proposed restructuring of the current legal framework under which minors are permitted to donate tissue and organs.

VI. PROPOSAL FOR RESTRUCTURING THE CURRENT LEGAL FRAMEWORK UNDER WHICH MINORS ARE PERMITTED TO DONATE TISSUE AND ORGANS

Given that regulation of the conception of child-donors, with or without assistive reproductive techniques like PGD with HLA-matching, is virtually impossible, and the likelihood that PGD will be used more extensively in the future to conceive child-donors, reform of the current legal framework under which minors are permitted to donate tissue and organs is crucial. The legislative standards proposed in this Note advocate bright line age requirements, thereby prohibiting tissue and organ donation from minors below a certain age, but in no way promote a complete ban on tissue and organ donations by minors to blood relatives. The proposed legislative standards do, however, promote a complete ban on tissue and organ donations by minors to non-relatives.

While the proposed standards may be more stringent than those that have been proposed in the past,²⁵² they are nevertheless necessary to provide much needed guidance to the courts in approving organ donations from minors,²⁵³ and most importantly to protect the interests of our nation's children. The legislative standards proposed, if properly implemented, would ensure that children who are conceived to be donors are significantly protected from the psychological and physical risks discussed in Part III.

A. PROPOSED LEGISLATIVE STANDARD FOR UMBILICAL CORD BLOOD DONATIONS FROM INFANTS TO BLOOD RELATIVES

The following legislative standard is proposed to regulate umbilical cord blood donations from infants to blood relatives:

No umbilical cord blood may be donated from an infant to a blood relative unless the following requirements are met:

1. Both of the potential donor's parents, or guardian, must provide informed consent on behalf of the infant; and
 - a. If one of the infant's parents is no longer living or will not play an active role in the infant's life then the informed consent of one parent is sufficient.
 - b. If the infant's parents disagree about whether to consent to an umbilical cord blood donation on behalf

²⁵² See Sankoorikal, *supra* note 119, at 613–16; Shartle, *supra* note 12, at 459–71.

²⁵³ See discussion *supra* Part IV.C; Shartle, *supra* note 12, at 463.

of the infant then they must file a petition with the court for review.

- i. The court will then determine whether the donation would be unnecessarily risky for the infant.
2. Physicians who would play a role in the procedures involved in umbilical cord blood harvesting and transplanting must approve of the donation after concluding that the procedure would not be unnecessarily risky for the infant.

The proposed legislative standard is premised on the fact that, as previously mentioned, the risks to an infant who donates umbilical cord blood are generally insignificant. Regardless of whether an infant is going to donate cord blood, the umbilical cord is removed from a child and typically discarded upon birth.²⁵⁴

²⁵⁴ See *supra* text accompanying notes 83–86. However, cord blood banks have been established to store umbilical cord blood. When parents elect to have their infant's cord blood stored at birth, the blood is removed from the cord before the umbilical cord is discarded, and then frozen and stored in a bank. Then, the child or another family member may use the blood should the need for a tissue transplant ever arise. See ViaCord, The Cord Blood Banking Process Overview, <http://www.viacord.com/cord-blood-banking-process.htm> (last visited Mar. 18, 2007). Some may argue that donating an infant's cord blood to a sibling and not storing it in an umbilical cord blood bank may harm the infant in the future. Due to current technology, a typical cord blood harvest collects enough stem cells to transplant to a child or a small adult who weighs approximately 100 pounds. Parent's Guide to Cord Blood Foundation, Motivations for Banking Cord Blood, <http://www.parentsguidecordblood.com/content/usa/medical/medmotiv.shtml?navid=20> (last visited Oct. 23, 2007). In light of this fact, some may argue that when parents choose to donate their infant's cord blood to another individual, whether it is a sibling or another relative, that they may end up harming their infant in the future if she ever needs a stem cell transplant because there will be no perfectly matched stem cells preserved for her in a blood bank. However, the probability that a child will need a stem cell transplant before the age of twenty is approximately four in 10,000. *What Is the Likelihood that My Child Will Need Her Cord Blood?*, A PARENT'S GUIDE TO CORD BLOOD BANKS, <http://parentsguidecordblood.org/content/usa/medical/medmotiv.shtml> (citing to F. Leonard Johnson, *Ask the doctor . . .*, *BLOOD & MARROW TRANSPLANT NEWSLETTER (BMT InfoNet, Highland Park, Ill.)*, Oct. 1998, Issue 43, Vol. 9, No. 3) (last visited Jan. 7, 2008). Between the ages of twenty and seventy this probability increases significantly to one in 450. *Id.* (citing to Marcelo C. Pasquini, Brent R. Logan, Frances Verter, Mary M. Horowitz & J.J. Nietfeld, *The Likelihood of Hematopoietic Stem Cell Transplantation (HCT) in the United States: Implications for Umbilical Cord Blood Storage*, 106 *BLOOD (ASH ANNUAL MEETING ABSTRACTS)* 1330 (2005)). However, the likelihood that the infant will weigh approximately 100 pounds as an adult and therefore receive enough stem cells is very low. See Pediatrics, *What Is the Average Weight for an Adult Man?* ABOUT.COM, http://pediatrics.about.com/cs/growthcharts2/f/avg_wt_male.htm (last visited Oct. 23, 2007) (stating that a National Health and Nutrition Examination Survey conducted from 1999–2002 found that the average weight for an adult male in the United States is 189.8 pounds); Pediatrics, *What Is the Average Weight for an Adult Woman?*, ABOUT.COM, http://pediatrics.about.com/cs/growthcharts2/f/avg_wt_female.htm (last visited Oct. 23, 2007) (stating that a National Health and Nutrition Examination Survey conducted from 1999–2002 found that the average weight for an adult female in the United States is 162.9 pounds). Furthermore, storing an infant's umbilical cord blood is currently very expensive and there are only a small number of institutions which can store cord blood at no cost to the parents. See *If Cord Blood Is So Great, Why Doesn't Everyone Bank It?*, A PARENT'S GUIDE TO CORD BLOOD BANKS, <http://parentsguidecordblood.org/content/usa/medical/medmotiv.shtml> (last visited Jan. 7, 2008). Therefore, the argument that parents may possibly be harming their infant in the future by failing to store her cord blood and instead donating it to another family member is not compelling, at least not at present.

1. *Informed Parental Consent*

An umbilical cord donation from an infant to a blood relative will only be permitted if both parents, or the infant's guardian, consent to the donation after being informed of all of the medical risks associated with the medical procedure. By requiring the informed consent from both of the infant's parents, or guardian, this proposed legislative standard seeks to protect the best interests of the minor and to minimize family tension that could potentially arise when parents or guardians must decide whether an infant should be compelled to donate umbilical cord blood. However, if one of the parents is no longer living or active in the infant's life, the informed consent of the active parent will be sufficient to permit the donation.

If parents disagree about whether to donate the infant's umbilical cord blood, they must file a petition with the court for review.²⁵⁵ The court should then assess whether the donation would be unnecessarily risky for the infant.²⁵⁶ The proposed legislative standard calls for the court to consider only the risks to the infant because it would be virtually impossible to apply a best interests or substituted judgment standard. The infant's personal wishes regarding donation cannot be ascertained, and it would be impossible to hypothesize the quality of the infant's future relationship with the potential recipient. Therefore, any possible "benefits" to the infant in compelling her to donate umbilical cord blood to a blood relative would be based entirely upon speculation. In light of the fact that the risks to the infant in donating umbilical cord blood are essentially nonexistent, courts will generally approve such donations.

2. *Physician Approval*

Approval from all physicians who will assist with the birth of the infant, harvesting of the umbilical cord blood, and transplanting the cord blood to the recipient is required. The physicians must review all pertinent medical facts and determine whether the umbilical cord blood donation would be unnecessarily risky for the infant. If all of the physicians conclude that there would be no significant risks to the infant and approve the medical procedure, then the umbilical cord blood donation will be permissible.

²⁵⁵ If the parents disagree about whether to donate the infant's umbilical cord blood at the time of the infant's birth and did not disagree prior to its birth, then, if possible, the umbilical cord blood should be collected and stored in a blood bank until a petition has been filed with the court and the court has determined whether the donation is in the infant's best interests. Once the court has come to a conclusion, the parent who was on the opposing side of whatever the court decided will be responsible for paying the cord blood storage fees from the date of the infant's birth until the date of the court's decision.

²⁵⁶ See generally Shartle, *supra* note 12, at 470 (stating that "the court should proceed to adjudicate the best interests of the minor without a presumption in favor of either parent's choice" in cases when parents disagree about whether to consent on behalf of their minor child to donate regenerative tissue).

B. PROPOSED LEGISLATIVE STANDARD FOR BONE MARROW AND OTHER TISSUE DONATIONS FROM MINORS TO BLOOD RELATIVES

The following legislative standard is proposed to regulate bone marrow and other tissue donations from minors to blood relatives:

1. No bone marrow or other tissue donation shall be permitted from any living minor under the age of nine to any blood relative under any circumstances.
2. No bone marrow or other tissue donation shall be permitted from any living minor over the age of nine to a blood relative unless the following requirements are met:
 - a. The living minor must provide informed consent to the tissue or bone marrow donation;
 - b. Both of the living minor's parents, or guardian, must provide informed consent to the tissue or bone marrow donation; and
 - i. If one of the minor's parents is no longer living or playing an active role in the minor's life then the informed consent of one parent is sufficient.
 - ii. If the minor's parents disagree about whether to consent to a tissue or bone marrow donation from the minor to a blood relative then they must file a petition with the court for review.
 1. The court must then determine whether the donation is in the best interests of the minor.
 - c. An independent medical physician must be appointed to assess the possible effects of the harvesting procedure on the potential minor donor and must approve of the procedure after concluding that the donation would not be unnecessarily risky for the minor.

1. *Informed Consent from Minor*

Given the inherent conflict of interest that many parents experience in cases involving donations between siblings and other blood relatives, parental consent on behalf of a minor donor alone should never be sufficient to permit a tissue donation (aside from cord blood) from a child.²⁵⁷

²⁵⁷ See discussion *supra* Part IV.B.

Children younger than nine years of age should not be permitted to consent to tissue or bone marrow donation because they are generally incapable of making informed medical decisions. As discussed previously, cognitive development research indicates that before the age of seven a child has a difficult time grasping complex concepts, such as organ donation, and generally thinks about things in a very egocentric manner. Therefore, before the age of seven a child cannot make adequately informed medical decisions, particularly about procedures that entail complicated risks that the child may not understand. However, children between the ages of seven and eleven begin to comprehend more complex issues and their egocentric thinking declines. Consequently, by the age of nine, when a child is halfway through what Piaget has termed the concrete operational stage, most children are able to comprehend the implications and risks inherent in donating tissue and bone marrow and thus will generally be capable of making an informed decision regarding whether to be a donor.²⁵⁸ Therefore, once a child has reached the age of nine she should be permitted to consent to tissue or bone marrow donation.

2. *Informed Parental Consent*

The minor's informed consent must be accompanied by informed consent from both parents. Requiring the consent of both parents guarantees that there is limited amount of tension within the family. If the minor is permitted to donate tissue or bone marrow, this requirement will ensure that most, if not all, family members agree with and support the minor's decision to donate, which will in turn make it relatively certain that the minor will receive the necessary emotional support throughout the potentially traumatic procedure of donating tissue.

If the parents of the potential minor-donor disagree about whether to consent to the tissue or bone marrow donation they must petition to the court for review. During its review, the court must consider more than the potential risks to the donor. The court must assess whether the tissue donation would be in the minor's best interests by considering the following: the risks to the potential donor, the benefits to the potential donor, the relationship between the potential donor and the organ recipient (including quality and length), the urgency of the recipient's medical need for the donation, and the probable strength of emotional support the donor will receive from her immediate family members if she is permitted to donate an organ.²⁵⁹ The legislative standard advocates the use of the best interests standard because of the difficulty inherent in applying the substituted judgment standard.²⁶⁰

3. *Independent Physician Approval*

The minor must be appointed an independent medical physician who will have the primary responsibility of considering all of the possible

²⁵⁸ See discussion *supra* Part V.

²⁵⁹ Shartle, *supra* note 12, at 464. See discussion *supra* Part IV.C.1.

²⁶⁰ See discussion *supra* Part IV.C.2.

effects of the proposed medical procedure on the potential donor. This requirement has been proposed to protect the minor from making an uninformed, rash, and potentially coerced decision about tissue or bone marrow donation. Furthermore, the appointment of an independent physician who is not responsible for caring for the potential tissue or bone marrow recipient is of the utmost importance to guarantee that the medical authorization for the procedure is not completely biased in favor of the transplant.

C. PROPOSED LEGISLATIVE STANDARD FOR ORGAN DONATIONS FROM MINORS TO BLOOD RELATIVES

The following legislative standard is proposed to regulate living organ donations from minors to blood relatives:

1. No organ donation shall be permitted from any living minor under the age of fourteen to any blood relative under any circumstances.
2. No organ donation shall be permitted from any living minor over the age of fourteen to a blood relative unless the following requirements are met:
 - a. The living minor must provide informed consent to the organ donation;
 - b. Both of the living minor's parents, or guardian, must provide informed consent to the organ donation; and
 - i. If one of the minor's parents is no longer living or playing an active role in the minor's life then the informed consent of one parent is sufficient.
 - c. An independent medical physician must be appointed to assess the possible effects of the harvesting procedure on the potential minor donor and approve of the procedure after concluding that the donation would not be unnecessarily risky for the minor.
 - d. The living minor's parents or guardian must file a petition with the court for review.
 - i. During the court review process an attorney must be appointed to represent the potential minor donor and oppose the organ donation during an adversarial proceeding;
 - ii. And the court must determine whether the donation is in the best interests of the minor.
 1. In determining whether a donation is in the best interests of the minor, the court should consider the following:

- a. The risks to the potential donor;
- b. The benefits to the potential donor;
- c. The relationship between the potential donor and the organ recipient (including quality and length);
- d. The urgency of the recipient's medical need for the donation; and
- e. The probable strength of emotional support the donor will receive from her immediate family members if she is permitted to donate an organ.

1. *Informed Consent from Minor*

Similar to the bright line rule proposed for bone marrow and tissue donations, mere parental consent to organ donation on behalf of a minor donor in and of itself should not be permitted due to the inherent conflict of interest parents face in cases involving an organ donation between siblings, or other blood relatives.²⁶¹

A bright line age requirement akin to that proposed for tissue and bone marrow donations from minors is advocated for organ donations from minors. This rule is proposed to minimize the risk of coercion and to ensure that minors have the opportunity to make the critically important decision of whether to donate an organ on their own at a point in their cognitive development when they are able to make truly informed medical decisions. As Piaget and Weithorn's findings suggest, children at the age of fourteen are able to make complex decisions regarding medical treatment in much the same fashion as adults.²⁶² The age requirement for minors to be permitted to consent to organ donations has been set at fourteen years old, higher than that for tissue and bone marrow donations, because the risks of donating an organ are more significant than those of donating tissue or bone marrow.²⁶³ Setting the age requirement for organ donations from minors to fourteen years of age is an attempt at accommodating possible differences in cognitive development of minors that may be caused by other individuals, the environment, and culture.²⁶⁴ The age requirement would thereby adequately ensure that most children, once they meet the age requirement, are able to fully comprehend all of the risks and implications of donating an organ, which are potentially more significant than those involved in donating bone marrow or tissue, and are able to give informed consent.

²⁶¹ See discussion *supra* Part IV.B.

²⁶² See discussion *supra* Part V.

²⁶³ See discussion *supra* Part III.B.

²⁶⁴ See discussion *supra* Part V.

2. *Informed Parental Consent*

Akin to the proposed legislative standard for tissue and bone marrow donations from a minor to blood relatives, this proposed legislative standard also requires informed consent from both of the minors' parents or guardian for the same reasons aforementioned.²⁶⁵

3. *Independent Physician Approval*

The proposed legislative standard also mandates that an independent physician be appointed to consider all of the possible effects of the organ donation on the potential minor donor. This requirement is necessary, as mentioned previously, to provide the minor with unbiased medical representation and to make sure that the organ donation would not be unnecessarily harmful for the minor.²⁶⁶

4. *Court Review Process*

Under this proposed legislative standard, court review of each individual case is necessary, as it has been under American common law,²⁶⁷ to protect the interests of the minor and to ensure that the minor is not being coerced into consenting to the organ donation. Court review is mandated under this standard and not under the bone marrow and other tissue donation standard due to the fact that the risks to the minor from donating an organ are more significant than those posed by donating bone marrow or other tissue.²⁶⁸

a. *Appointment of Attorney to Represent Minor*

Pursuant to the proposed legislative standard, the court must appoint an attorney to represent the interests of the prospective minor donor. The attorney's primary responsibility will be to advocate against the donation. Thus, the attorney will be responsible for presenting testimony by medical practitioners and psychologists, when relevant, to demonstrate the possible physical and psychological risks to the potential minor donor. The appointment of an attorney will thereby guarantee that the court considers both the potential benefits and risks to the potential child-donor if organ donation is permitted.²⁶⁹ Exploring the potential risks and benefits to the potential minor-donor in an adversarial setting ultimately protects the minor from being coerced into volunteering to donate an organ to an ailing family member and ensures that the proposed transplant is relatively safe for her.

b. *Application of Best Interests Standard*

In order for an organ donation from a minor to a blood relative to be permissible, a court must review all of the pertinent facts of the case,

²⁶⁵ See discussion *supra* Part VI.B.2.

²⁶⁶ See discussion *supra* Part VI.B.3.

²⁶⁷ See discussion *supra* Part IV.C.

²⁶⁸ See discussion *supra* Part III.B.

²⁶⁹ See Shartle, *supra* note 12, at 465.

conclude that the organ donation would be in the potential minor donor's best interests, and ultimately approve the donation. In so doing, the court should apply the best interests standard and consider the following: the risks to the potential donor, the benefits to the potential donor, the relationship between the potential donor and the organ recipient (including quality and length), the urgency of the recipient's medical need for the donation, and the probable strength of emotional support the donor will receive from her immediate family members if she is permitted to donate an organ.²⁷⁰

This requirement of the proposed legislative standard addresses some of the aforementioned criticisms of the best interests standard²⁷¹ and modifies the standard accordingly. To address the concern that the current best interests standard is too vague and difficult to apply, the proposed legislative standard specifically lists the factors that the court should consider. Furthermore, by listing these factors, the standard is an attempt to reign in courts that may otherwise have been inclined to use the current broad best interests standard to legally justify a decision that has in actuality been based on moral, not legal, reasoning. Finally, by requiring that potential minor donors over the age of fourteen consent to the organ donation before the requisite court review process even begins, the legislative standard addresses the third concern with regards to the best interests standard by guaranteeing that the minor's personal wishes in regard to whether to donate her organ are considered and relevant.

VII. CONCLUSION

In response to the proposed legislative standards, some may argue that a bright line rule barring tissue and organ donations from minors under particular ages is completely arbitrary. However, as aforementioned, cognitive development research strongly supports the fact that children below certain ages are not able to make adequately informed medical choices.²⁷² Moreover, bright line rules are frequently drawn in regards to children, despite the fact that they may seem arbitrary. The age of majority is a poignant example of such an arbitrary, bright line rule.²⁷³

Others may argue that a bright line rule does not respect a child's right to make autonomous decisions. Yet, the American legal system deems children incompetent²⁷⁴ and there are many paternalistic laws that do not allow children the freedom to make purely autonomous decisions.²⁷⁵

²⁷⁰ *Id.* at 464. See discussion *supra* part IV.C.1.

²⁷¹ See discussion *supra* Part IV.C.1.

²⁷² See discussion *supra* Part V.

²⁷³ Dufault, *supra* note 120, at 219.

²⁷⁴ Driggs, *supra* note 150, at 689.

²⁷⁵ See Dufault, *supra* note 120, at 214 (discussing the history of paternalism in America in regards to children and stating that, "[p]aternalism has long been embraced where children are concerned . . ."). Children have been deemed to have rights under the United States Constitution. See *In re Gault*, 387 U.S. 1, 13 (1967) (holding that children, not just adults, are entitled to protection under the Fourteenth Amendment and the Bill of Rights); *Tinker v. Des Moines Indep. Cmty. Sch. Dist.*, 393 U.S. 503, 511 (1969) (granting minors the right to free speech); *Planned Parenthood of Cent. Mo. v. Danforth*, 428 U.S. 52, 74 (1976) (granting minors the right to abortion); *Carey v. Population Servs. Int'l*, 431 U.S. 678, 694 (1977) (granting minors the right to contraception); *Bellotti v. Baird*, 443 U.S. 622, 650 (1979)

Furthermore, as previously discussed, making informed consent from a potential minor-donor over a certain age a prerequisite for tissue or organ donation actually protects children from coercion and gives them more freedom to make purely autonomous decisions.²⁷⁶

In addition, some may argue that a bright line rule unfairly prohibits parents from making decisions on behalf of their children that they have the right to make.²⁷⁷ Nevertheless, as previously highlighted, there exists a conflict of interest in cases involving tissue or organ donation between siblings or between a child and another blood relative. As much as parents might try to put the best interests of the minor-donor before the interests of their ailing child or other family member, such a feat is rarely ever possible.²⁷⁸ Therefore, parental consent to organ or tissue donation on behalf of a minor alone should never be sufficient to approve a donation. Parental consent should only be adequate when combined with all of the guidelines set forth in this Note. Only then will the result that is truly in the best interests of the minor be achieved.

As technology rapidly progresses, more children are going to be conceived to be organ donors for their ailing siblings. The legal framework established during the infancy of tissue and organ donation techniques is confusing and inadequate to protect child-donors. While regulation of the use of assistive reproductive techniques to conceive child-donors is unlikely in the near future, we can, and must, put legislation in place to protect child-donors from being coerced into donating tissue and organs throughout their life.

(granting minors the right to abortion). Despite the rights accorded to minors, “deeply rooted notions of paternalism have been difficult to overcome.” Dufault, *supra* note 120, at 216.

²⁷⁶ See discussion *supra* Part V.

²⁷⁷ See Morley, *supra* note 10, at 1232–1233 (“Parent-guardians enjoy a constitutionally protected zone of discretion in determining what is in their charges’ best interest, within which the decision to tender proxy consent for organ donation squarely falls.”).

²⁷⁸ See discussion *supra* Part IV.B.

