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Should Parents Make Martyrs of Their Children?: An Argument for Private Regulation of Savior Siblings

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Introduction

In 1969, long before the rapid advancement of artificial reproductive technology, Kentucky courts considered whether Jerry Strunk, a 27-year-old legally incompetent individual with a mental age of approximately six years, could be compelled to donate a kidney to Tommy Strunk, Jerry's 28-year-old brother who suffered from a fatal kidney disease.[1] A majority of the Kentucky State Supreme Court deemed the transplant in the best interest of Jerry and allowed the kidney transplant to occur.[2] Judge Steinfeld issued a vigorous dissent where he noted that he was torn between "a compassion to aid an ailing young man and a duty to fully protect unfortunate members of society."[3] Despite his apprehensions, Judge Steinfeld was unwilling to hold that an organ should be removed from an incompetent at the behest of the incompetent's parents.[4] The dissenter reasoned, "[p]arents 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."[5]

In *Strunk*, Judge Steinfeld contemplated the general ability of legal guardians to permit removal of an organ of their ward for the benefit of a third party. Judge Steinfeld's moral dilemma would soon be amplified with the rapid advance of artificial reproductive technology. In 2000, genetic screening and in-vitro fertilization would allow a family in Colorado to select an

[1] Strunk v. Strunk, 445 S.W.2d 145 (Ky. 1969).
[2] *Id*. at 149.
[3] *Id.* (Steinfeld, J., dissenting).
[4] *Id.*
[5] *Id.*

embryo that was a perfect immunological match to donate body tissue to their ailing, already-existing daughter with a blood disorder.[6] That is, the Colorado family was able to use artificial reproductive technology to create a child specifically for the purposes of becoming a "martyr" for their already-existing child. This phenomenon became known as creating a "savior sibling."

Judge Steinfeld contemplated how his sympathies for a sick young man weighed against his desire to protect society's most vulnerable members.[7] This delicate balancing also applies to cases involving savior siblings. On one hand, there is deep compassion and empathy for the sick sibling, who requires medical intervention to survive. On the other hand, there is an instinct to protect the "unfortunate" members of society – including the interests of the children who do not yet exist. The precarious balance between the need to procure treatment for a sick child and the welfares of a potential donor sibling must be bracketed by comprehensive regulation in order to assure that the best interests of all parties are met.

Part I of this paper will provide a primer on the reproductive technology used to create a savior sibling. With this background, Part II will consider the various ethical implications of using reproductive technology to create a child for the purpose of providing biological material to an older sibling. Part III will outline the regulatory approaches that some European nations have taken to prevent the potential ethical pitfalls associated with the procedure of savior siblings. These approaches are contrasted with the United states' non-regulatory approach to the field of artificial reproductive technology inn Part IV. Finally, Part V proposes a solution that bypasses the difficulties associated with federal or state regulation which is private regulation led

[6] Josephine Marcotty, 'SAVIOR SIBLING' RAISES A DECADE OF QUESTIONS THE SEATTLE TIMES (2010), https://www.seattletimes.com/seattle-news/health/savior-sibling-raises-a-decade-of-questions/ (last visited Dec 16, 2020).
[7] *Strunk*, 445 S.W.2d 149 (Steinfeld, J., dissenting).

by physician professional organizations. The proposal includes content suggestions for the guidelines promulgated by these organizations.

If Judge Steinfeld is correct in his reasoning that parents are not free to make martyrs of their children before the child has reached an age to make a legal choice for themselves, it follows that parents cannot be unbounded in their discretion to create a child for the specific purpose of becoming a martyr for their older sibling.

Part I. Procedure Used to Create Savior Siblings

A. Why do Families Need Savior Siblings?

The concept of savior siblings has been popularized in books and movies.[8] However, the phenomenon of savior siblings is actually used worldwide to conceive and deliver a child who is a perfect Human Leukocyte Antigen (HLA) match to a sibling who is in need of a transplant to cure or treat an existing illness.[9] In 2000, United States physicians were able to use IVF and PGD to conceive Adam Nash, a perfect HLA match for his older sister, Molly, who was born with Fanconi's Anemia.[10] Fanconi's Anemia rendered Molly's body unable to produce enough blood cells, and her only chance of survival was for the family to find a bone marrow donor.[11] The best bone marrow match is typically a sibling, but the Nash family understood that Molly's condition was inherited so they were hesitant to have more children naturally.[12] Eventually, the Nash family's physicians were able to successfully perform PGD to conceive Adam, whose cord

[8] *See* MY SISTER'S KEEPER (New Line Cinema 2009).
[9] 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, 1016 (2006).
[10] Amanda M. Faison, THE MIRACLE OF MOLLY 5280 (2005), https://www.5280.com/2005/08/the-miracle-of-molly/ (last visited Dec 17, 2020).
[11] *Id.*
[12] *Id.*

blood was used to cure Molly's bone marrow failure.[13] Although Molly's condition is permanent, the birth of her brother saved her life.[14]

The Nash family exemplifies the typical case of why savior siblings are created. Usually, there is an already-existing life that is threatened by a blood-based illness. Without intervention in the form of blood transfusions or bone marrow transplant or cord blood transfusions or organ transplant, the already-existing child is going to die. Parents, unwilling to watch their child die, undertake to create a sibling who is not only free from disease, but also a perfect candidate to provide their sibling with life-saving treatment. While the Nash family only needed cord blood to save Molly's life, it is necessary to consider what other body tissues may be required of savior siblings down the line.

B. Technology Used to Create a Savior Sibling

The term "savior sibling" is used to refer to a sibling created for the purpose of providing biological material that can help treat or cure an existing terminally ill child.[15] Savior siblings are conceived using two consecutive artificial reproductive technology processes: (1) pre-implantation genetic diagnosis (PGD) and (2) in-vitro fertilization (IVF).[16]

PGD is a multi-step process that involves ovarian stimulation, egg extraction, IVF, cell biopsy, genetic analysis, and embryo transfer.[17] Clinicians first stimulate egg production in a woman, extract the eggs, and then fertilize the eggs with the desired sperm in a petri dish to form embryos.[18] A few days after fertilization, cells are removed from the early embryos and

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[13] *Id.*
[14] *Id.*
[15] Zachary E. Shapiro, *Savior Siblings in the United States: Ethical Conundrums, Legal and Regulatory Void*, 24 WAS. & LEE J. CIV. RTS. & SOC. JUST. 419, 422 (2018).
[16] *Id*.
[17] Baruch, et al., *Genetic testing of embryos: practices and perspectives of US in vitro fertilization clinics*, 89 FERTILITY AND STERILITY 1053, 1054 (2008).
[18] *Id.*

analyzed.[19] The genetic analysis of the embryonic cells is used to infer the genetic makeup of the egg.[20] Typically, the desired (i.e., "healthy") embryos that are disease-free and perfect immunological matches for their older sibling are implanted into a uterus or stored for future use, while the genetically-impaired (i.e., "sick") embryos are destroyed.[21]

PGD is an artificial reproductive technology technique that was developed to detect and avoid specific disease-causing gene mutations before pregnancy.[22] PGD is used to test embryos for diseases that are highly fatal within the first few years of life, such as Tay-Sachs disease, and for severely debilitating illnesses, such as cystic fibrosis.[23] Today, the possible uses of PGD has been extended to include detection of genetic mutations leading to adult-onset disorders, such as Huntington's disease, and the detection of mutations that indicate an increased risk of developing diseases later in life. Some couples elect to use PGD to select an embryo for the presence of a disability.[24] In more controversial cases, PGD can be used to select the sex of an embryo, or a physical characteristic that satisfies the preferences of the future parents.[25]

In order to create a savior sibling, PGD is employed to both ensure that an embryo is free of the inheritable disease that plagues an older, already-existing child and ensure that the resulting child would be immunologically compatible to his or her older sibling in order to successfully donate life-saving bodily tissue.[26] It is essential that the potential embryo is free from disease because a sick child cannot serve as a donor.[27] It is equally important that the

[19] *Id.*
[20] *Id*.
[21] Shapiro, *supra* note 15, at 422.
[22] Baruch, et al., *supra* note 17, at 1054.
[23] *Id*.
[24] *Id*.
[25] *Id*. at 1055.
[26] Baruch, et al., *supra* note 17, at 1055.
[27] Shapiro, *supra* note 15, at 425.

embryo chosen will develop into a child whose white blood cells contain the same HLA pattern as their older, ailing sibling.[28] A donor must be an identical HLA match to the recipient in order to prevent the donated biological material from being rejected in the recipient sibling.[29] If a donor is not an exact match, there is a risk that the recipient sibling's immune system will reject the transplant, causing the transplant to fail and potential death in the recipient.[30] By using PGD, clinicians can simply select healthy embryos who are perfect HLA matches to their older sibling.

Part II. Ethical Issues of PGD and Savior Siblings

There are various ethical issues that arise when PGD is used to create a savior sibling for an already-existing ill child. The following discussion of such ethical considerations provides insight into the pitfalls that may occur when the process of creating savior siblings is entirely unregulated.

A. Commodification of Donor-Sibling

First, there is a persistent worry that the savior siblings would be used as a commodity rather than a person.[31] In other words, there is a concern that a child created for a specific purpose would be treated as a means rather than an end. Lord Robert Winston, one of the fertility experts who helped to develop the PGD technique, frequently criticizes the use of PGD in order to create a savior sibling because of the risk of treating the offspring to be born as a commodity.[32] Lord Winston argues that using PGD to create a savior sibling might prevent the resulting child from ever making a meaningful choice about whether to donate cells to a

[28] *Id.*
[29] *Id.*
[30] *Id.*
[31] Amy T. Lai, *To Be or Not to Be My Sister's Keeper? A Revised Legal Framework Safeguarding Savior Siblings' Welfare*, 32 J. LEGAL MED. 261, 265 (2011).
[32] Gitter, *supra* note 9, at 1016.

sibling.[33] Other commentators argue that the commodification ethical argument necessarily fails if parents intend to care for the new child for its own sake.[34] These scholars argue that the resulting child will not be commodified because the fact that parents are willing to conceive another child in order to protect the first child suggests that these parents are highly committed to the well-being of their children, thereby suggesting that these parents will value the savior sibling for its own sake as well.[35]

B. Inability of Minor Child to Consent

Related to the commodification concern is the argument that even if the donor-sibling is valued as a child independent of their ability to donate biological material, the minor might face intense familial pressure to serve as a continuing source of donations to the ill sibling.[36] A major part of the donor-sibling's identity might be intimately tied to his ability to donate biological material to his sibling. The worry that the donor child might see himself as a commodity raises serious issues about the minor child's ability to consent to donation.

From the perspective of the savior sibling, autonomy is further threatened because of the child's inability to provide consent to medical procedures.[37] For very young children, the critical element of competence is lacking.[38] The lack of competence in young children is concerning because they are generally unable to signify to medical professionals that they have the ability to make health-related decisions.[39] Additionally, it is doubtful that a young child can be informed

[33] *Id*.
[34] Lai, *supra* note 31.
[35] Gitter, *supra* note 9, at 1017.
[36] *Id*. at 1019.
[37] Giovanni Rubeis & Florian Steger, *Saving whom? The ethical challenges of harvesting tissue from savior siblings*, 103 EUR. J. OF HAEMATOLOGY 478–482 (2019).
[38] *Id*.
[39] *Id*.

about the nature, scope, and consequences of a medical procedure in an appropriate way.[40] Compounded with the possible pressure from family to provide needed body tissue to a sick sibling, the autonomy of a donor-sibling is severely threatened by the young child's inability to provide informed consent to medical providers.

C. Psychological Effects on Donor-Sibling

Another ethical concern associated with the use of PGD to create savior siblings is the potential negative psychological effects on the donor child.[41] There is little empirical evidence regarding the psychological welfare of a PGD-created donor-sibling, but the fear is that the donor child might suffer from a lack of self-confidence because the child believes her parents created her only to help provide treatments for older sibling.[42] The child may believe he would not have been born had it not been for her sibling's disease.[43] Perhaps more concerning would be the burden felt by a donor-sibling if the treatments using the donor-sibling's biological material fail and the sick sibling passes away.[44] Some scholars point out that there might be *positive* psychological benefits to a donor-sibling. Namely, the knowledge that the donor-sibling's birth saved the life of a sibling may be empowering and bolster the donor-sibling's sense of self-worth.[45]

D. Physical Effects on Donor-Sibling

There is also an ethical concern surrounding the potential physical effects on the donor child.[46] The PGD procedure involves removing cells from an embryo which may cause injury to

[40] *Id*.
[41] Gitter, *supra* note 9, at 1022.
[42] Sandra O. Samardžić, *Saviour Siblings – Current Overview, Dilemmas and Possible Solutions?*, 12 MED. L. & SOC. 89, 100 (2019).
[43] *Id.* at 99.
[44] S. Sheldon & S. Wilkinson, *Should selecting saviour siblings be banned?*, 30 J. MED. ETHICS 533, 535 (2004).
[45] Samardžić, *supra* note 42, at 101.
[46] *Id.* at 99.

the embryo.[47] Importantly, there have been no studies conducted to determine the long-term effects that PGD has on the health of children.[48] Possible impacts on the physical health of a donor-sibling involving the actual donation of biological material could include injury from multiple procedures and the typical risks associated with organ donation, including potential death, if the ailing sibling requires an organ.[49] Organ donation is a more extreme example of how a donor-sibling may serve their sick sibling. Typically, the donor-sibling is asked to donate blood or bone marrow, especially if harvesting stem cells from the umbilical cord was unsuccessful.[50] Harvesting stem cells from the donor-sibling's umbilical cord poses no risk to the donor-sibling.[51] Harvesting bone marrow from a child involves surgery, which poses the typical risks associated with general anesthesia and the risks of bleeding and infection.[52]

E. Non-Medical Uses of PGD

A general concern with the unregulated procedure of PGD is the potential for a "slippery slope." The concern is that PGD, when unregulated, will be used for eugenic practices of creating an "ideal" child.[53] With economic gain in mind, clinics may formulate policies that encourage couples seeking certain physical characteristics for their offspring to receive PGD services with their clinicians.[54] With the current, non-regulatory state of artificial reproductive technology clinics in America, clinics have unchecked power to market and provide couples with

[47] *Id*. at 99. Samardžić cites a study done on mice subjected to PGD in the embryonic phase that revealed the resulting mice experienced excess weight and memory problems later in life.
[48] *Id*.
[49] *Id*.
[50] Samardžić, *supra* note 42, at 100.
[51] *Id.*
[52] Indranil Mallick, A LOOK AT THE DIFFERENT RISKS AND SIDE EFFECTS OF DONATING BONE MARROW, Verywell Health (2019), https://www.verywellhealth.com/the-risks-of-donating-bone-marrow-2252482 (last visited Dec 16, 2020).
[53] Gitter, *supra* note 9, at 1024.
[54] *Id.*

babies designed pursuant to the couple's preferences rather than to ensure the health of the resulting fetus.[55]

Part III. Regulatory Schemes Abroad

In order to comprehensively address the ethical concerns associated with PGD and savior siblings, many countries have decided to outline the boundaries of acceptable uses of PGD through comprehensive, national regulation. On other hand, some countries, including the United States, have decided to take an entirely hands-off approach to the field of artificial reproductive technology and PGD. Non-regulatory states provide clinicians with unbounded authority to determine when PGD is warranted. Part III discusses the regulatory schemes found in three European countries: France, the United Kingdom, and Spain. Part IV will discuss the non-regulatory approach of the United States.

A. France

France has a detailed regulatory framework for PGD.[56] The French government explicitly sanctions the use of PGD in the Code de la Santé Publique only in exceptional cases.[57] Initially, a doctor in a prenatal clinic must "certify that the couple, because of their family situation, has a high probability of giving birth to a child with a genetic disease of particular gravity recognized as incurable at the time of diagnosis."[58] A doctor needs certain evidence to certify a couple for PGD.[59] If the couple already has a child with a severe heritable illness or an immediate relative

[55] *Id.*
[56] Michelle J. Bayefsky, *Comparative preimplantation genetic diagnosis policy in Europe and the USA and its implications for reproductive tourism*, 3 REPRODUCTIVE BIOMEDICINE AND SOC. ONLINE 41, 43 (2016) [hereinafter Comparative PGD Policy].
[57] Code de la Santé Publique [C. Santé Publique] [Public Health Code] art. L2131-4 (Fr.).
[58] *Id.*
[59] *Id.*

of either individual has a severe heritable illness, these facts can serve as evidence that a couple is qualified to receive PGD.[60]

In France, the Agence de la Biomedicine is the government organization that dictates the acceptable standards of prenatal clinics as well as the necessary qualifications of providers who can perform PGD.[61] The Agence de la Biomedicine also espouses the acceptable uses of PGD that authorized PGD clinics in France are bound to follow.[62] In 2012, the Agence de la Biomedicine endorsed that PGD should be used to select potential donors for sick siblings.[63] Therefore, a French individual seeking to receive PGD for the purpose of creating a savior sibling is legally permitted to do so, if the individual is initially deemed to be at sufficient risk of having a child with an incurable heritable disease. Once that medical determination is made, then then individual can consent to PGD for the purpose of creating a savior sibling.

B. United Kingdom

In the United Kingdom, Parliament regulates PGD through the Human Fertilization and Embryology Act (the Act) of 1990.[64] Pursuant to the Act, the Human Fertilization and Embryology Authority (HFEA) is the government organization that was created to:

> (a) keep under review information about embryos and about the provision of treatment services and activities governed by this Act…(b) publicise the services provided to the public by the Authority or provided in pursuance of licenses, (c) provide, to such extent as it considers appropriate, advice and information for persons to whom licenses apply or who are receiving treatment services or providing gametes or embryos for use for the purposes of activities governed by the act or may wish to do so.[65]

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[60] Public Health Code, art. L2131-4-1 (Fr.).
[61] Michelle J. Bayefksy, *Who Should Regulate Preimplantation Genetic Diagnosis in the United States?*, 20 AMA J. OF ETHICS 1160, 1161 (2018) [hereinafter Who Should Regulate PGD*?*].
[62] *Id.*
[63] *Id.*
[64] Human Fertilisation and Embryology Act 1990 c. 37 (Eng.).
[65] *Id*. at §8.

The HFEA continues to be the primary government licensing agency for clinics in the United Kingdom that carry out IVF and donor insemination.[66] In R (on the application of Quintavalle) v. Human Fertilisation and Embryology Authority, the House of Lords decreed, "[the Act] clearly gave the HFEA the authority to honor a family's request for PGD with tissue typing if the HFEA found it proper, as well as to decline such a license on ethical or other grounds."[67] The court's holding underscores the broad authority given to the HFEA to determine whether PGD to create a savior sibling is appropriate.

In response to Quintavalle, Parliament amended the Act in 2008 to sanction the use of PGD with HLA-matching to create a savior sibling within certain regulatory boundaries.[68] The 2008 amendments to the Act specified:

> A license…cannot authorize the testing of an embryo, except for one or more of the following purposes…(d) in a case where a person ('the sibling') who is the child of the persons whose gametes are used to bring about the creation of the embryo (or of either of those persons) suffers from a serious medical condition which could be treated by umbilical cord blood stem cells, bone marrow or other tissue of any resulting child, establishing whether the tissue of any resulting child would be compatible with that of the sibling.[69]

The HFEA requires clinics to obtain licenses for every new genetic disease that they would like to test an embryo for using PGD.[70] By closely monitoring the uses of PGD, the HFEA is able to prevent the slippery slope of allowing PGD to be used for non-medical purposes or sex selection. The Act attaches criminal liability to a person who "provides any information for the purposes of the grant of a license, being information, which is false or misleading in a material

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[66] Gitter, *supra* note 9, at 980.
[67] *R (on the application of Quintavalle) v. Human Fertilisation and Embryology Auth*., [2005] UKHL 28 (House of Lords 2005).
[68] Lisa Cherkassky, *The Wrong Harvest: The Law on Saviour Siblings*, 29 INT J. L., POL'Y, & FAM., 1, 4 (2020).
[69] Human Fertilisation and Embryology Act 1990 c. 37, sch. 2 (Eng.).
[70] Shapiro, *supra* note 15, at 451.

particular and, either he knows the information to be false or misleading in a material particular or he provides the information recklessly…."[71] Individuals who provide false or misleading information to obtain a license in violation of the Act are subject to a fine and/or imprisonment for up to two years.[72]

C. Spain

Spanish legislators regulate the use of artificial reproductive technology through the Ley de Técnicas de Reproducción Humana Asistada.[73] On the topic of PGD, the Assisted Reproduction Procedures Law states:

> Duly authorized centers may practice preimplantation diagnostic techniques for: (a) the detection of serious hereditary diseases, of early appearance and not susceptible to post-natal curative treatment according to current scientific knowledge, with the purpose of carrying out the embryonic selection of the pre-embryos not affected for their transfer; (b) the detection of other alterations that may compromise the viability of the pre-embryo. The application of pre-implantation diagnostic techniques in these cases must be communicated to the corresponding health authority, which will inform the National Commission of Assisted Human Reproduction [CNHRA]. The application of pre-implantation diagnostic techniques for any other purpose not included in the previous section, or *when they are intended to be practiced in combination with the determination of the histocompatibility antigens of the in vitro pre-embryos for therapeutic purposes for third parties*, shall require the express authorization, case by case, of the corresponding health authority, after a favorable report from the CNHRA, which shall evaluate the clinical, therapeutic and social characteristics of each case.[74]

Unlike France and the United Kingdom, Spanish individuals wishing to use PGD for the purpose of "histocompatibility antigens…for therapeutic purposes for third parties" (i.e., for

[71] Human Fertilisation and Embryology Act 1990 c. 37, §41 (Eng.).
[72] Shapiro, *supra* note 15, at 451.
[73] Ley 14/2006, de 26 de mayo, sobre técnicas de reproduction humana asistada [Assisted Reproduction Procedures Law] (B.O.E. 2006, 126) (Spain).
[74] Assisted Reproduction Procedures Law art. XII (B.O.E. 2006, 126) (emphasis added).

savior siblings), are required to undergo individual evaluation by the corresponding health authority and receive a favorable report from the appropriate governing body, the CNHRA. Only after the authorities review the clinical, therapeutic, and social characteristics of a particular case will the individual be allowed to proceed with the PGD procedure.[75] In France and the United Kingdom, by contrast, the governing bodies exercised regulatory authority to sanction the uses of PGD for the purpose of creating a savior sibling if a clinic or individual meets certain criteria.[76] Individuals in the United Kingdom and France seeking to create savior siblings are not required to undergo vigorous case analysis as is required in Spain.

Part IV. Current Regulatory Scheme in the United States

The United States has taken a hands-off approach to federal regulation of artificial reproductive technology. The regulatory lacuna on the federal level forces states to fill in the blanks and regulate providers and clinics specializing in artificial reproductive technology. States may be in the best position to consider the specific needs and values of citizens of the state, but – like the federal government – states have largely refused to draft legislation regarding artificial reproductive technology. Because states have also neglected specific regulations regarding artificial reproductive technology, conflicts involving artificial reproductive technology care have, by default, fallen into the lap of the state judiciary. Part IV explores the current, non-regulatory framework of the United States and how conflict regarding artificial reproductive technology, and specifically PGD, is resolved.

A. Lack of Federal Regulation

[75] Samardžić, *supra* note 42, at 93.
[76] *See supra* Part III.A-B.

In the United States, there are no federal laws on the acceptable use of PGD.[77] Since the process of creating savior siblings can only be accomplished through PGD, it follows that no governmental oversight or legal guidance regarding the use of savior siblings exists.[78] The analytical quality of the tests and the qualifications of the personnel performing the tests are subject to the Clinical Laboratory Improvement Amendments (CLIA) of 1988.[79] The CLIA requirements include standards and testing to monitor laboratory performance.[80] The Center for Medicare and Medicaid Services (CMS), the federal agency that administers CLIA, has refused to establish specific proficiency testing regulations for molecular genetic testing, including the genetic analysis of preimplantation embryos.[81] Likewise, the Food and Drug Administration (FDA), which generally regulates genetic tests for analytical and clinical validity, does not espouse specific guidance regarding PGD or savior siblings.[82]

B. State Judicial Response

The regulatory gap on the federal level leaves the topic of PGD and savior siblings open to state and private regulation. The *parens patriae* power of states grants "inherent power and authority of the state to protect persons who are legally unable to act on their own behalf."[83] While there are strong constitutional protections to safeguard a parent's right to rear his children according to the parent's wishes, a state can circumvent these rights by asserting its *parens patriae* power to protect children from harm.[84] A state is therefore empowered to intervene if the

[77] Comparative PGD Policy, *supra* note 56, at 43.
[78] Shapiro, *supra* note 15, at 444.
[79] *Id.* at 445.
[80] Baruch, et al., *supra* note 17, at 1056.
[81] Shapiro, *supra* note 15, at 444.
[82] *Id.*
[83] Legal Dictionary, PARENS PATRIAE, https://legal-dictionary.thefreedictionary.com/parens+patriae (last visited Nov. 1, 2020).
[84] Marley McClean, *Children's Anatomy v. Children's Autonomy: A Precarious Balancing Act with Preimplantation Genetic Diagnosis and the Creation of "Savior Siblings,"* 43 PEPP. L. REV. 837, 851 (2016).

state "believes the child is either endangered or not receiving adequate parental care because of the child's use as a savior sibling. The state can also protect a child born as a result of PGD by requiring informed consent for medical procedures…."[85]

No state laws have been enacted specifying regulations for PGD or savior siblings.[86] There is a small amount of case law on the state level that illustrates the state responses to issues of whether donation from a minor sibling is in the best interests of both minor siblings.[87] Importantly, this case law helps courts determine whether tissue or organ donation between minors is acceptable.[88] There is, however, no case law regarding the propriety of the savior sibling procedure.

The case law analyzing tissue or organ donation between a minor donor and a minor recipient reveals two governing legal standards: (1) the best interest standard and (2) the substituted judgment standard.[89] The best interests standard instructs courts to determine "whether allowing a child to donate tissue or organs would be in the best interest of the child and the child's needs."[90] In the context of sibling donations, courts will often look to the relationship of the siblings to determine if the siblings have a close relationship.[91] If the siblings have a close relationship, courts are likely to conclude that donor sibling would be psychologically benefited if his or her sick sibling survives because of the donation.[92]

In Curran v. Bosze, the Supreme Court of Illinois iterated that a transplant would be considered in the child-donor's best interest if:

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[85] *Id.*
[86] Shapiro, *supra* note 15, at 444.
[87] McClean, *supra* at note 84, at 852.
[88] *Id.*
[89] *Id*.
[90] *Id.* at 853.
[91] Nicole Hebert, Note, *Creating A Life To Save A Life: An Issue Inadequately Addressed By The Current Legal Framework Under Which Minors Are Permitted To Donate Tissue And Organs*, 17 S. CAL. INTERDISC. L. J. 337, 356 (2008).
[92] *Id.*

> (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 recipient.[93]

Illinois's highest court considered how to apply the standard in the context of a father who petitioned the court to compel his three-year-old twin girls to undergo compatible blood testing and potentially donate bone marrow to their half-sibling.[94] The twins' mother, who is not the mother of the ailing child and was never married to the twins' father, refused the compatibility testing for her daughters.[95] Under the standard announced by the court, the state supreme court determined that it was not in the best interest of three -year-old twins to compel compatibility testing to potentially serve as bone marrow donors for their half-brother whom they had only met twice because the donor-recipient relationship was not sufficiently close.[96]

The other legal standard used to determine the legality of organ or tissue donation from a minor is the substituted judgment standard.[97] The substituted judgment standard requires courts to essentially place themselves in the position of the minor to determine whether the minor patient would choose or refuse to make an organ or tissue donation if she were fully competent to make the decision on her own.[98] The historical use of the substituted judgment standard requires "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" in order for a primary caregiver to substitute what he believes would be the incompetent patient's

[93] Curran v. Bosze, 566 N.E.2d 1319, 1343 (Ill. 1990).
[94] *Id.* at 1321.
[95] *Id.*
[96] *Id.* at 1344.
[97] Hebert, *supra* note 91, at 360.
[98] *Id.* at 361.

decision regarding medical treatment.[99] The standard has largely been used for people who were once legally competent, but became incompetent.[100] The application of the substituted judgment standard to potential minor donors has been criticized on the ground that a child has *never* been legally competent so there is no "clear and convincing evidence" regarding what the minor's intent would be for a critical medical decision.[101]

When applying the substituted judgment standard, courts have disregarded the analysis of whether the minor child would wish to donate tissue or organs if the child were competent.[102] In Hart v. Brown, the court purported to use the substituted judgment standard to determine whether a seven-and-a-half year old child could be permitted to donate a kidney to her identical twin sister.[103] In Hart, the parents of identical twin girls brought suit against physicians treating one of their daughters with a terminal kidney illness.[104] The physicians refused to allow the parents to provide consent for their healthy child to undergo a kidney transplant for the benefit of her twin sister, so the parents filed action in state court to compel the physicians to allow for the parents' consent on behalf of the healthy child.[105] The court concluded that, under these facts, the potential donor sibling had a strong identification with her twin sister and therefore the donation would be most beneficial to the donee and would be of some benefit to the donor.[106] The court held that prohibiting the natural parents of the minor child the right to give consent in situations where there is supervision by the court and other persons in examining their judgment, would be "unjust, inequitable, and injudicious."[107] Although purporting to apply the substituted judgment

[99] *Id.* at 361.
[100] *Id*.
[101] *Id.* at 362.
[102] Hebert, *supra* at note 91, at 366.
[103] Hart v. Brown, 289 A.2d 386, 288 (Conn. Super. Ct. 1972)
[104] *Id.* at 387.
[105] *Id.*
[106] *Id.* at 389.
[107] *Id.* at 391.

standard, the Hart court concluded that the transplant was permissible based on an analysis more akin to the best interests standard.[108]

As more children are conceived using PGD for the purpose of donation for an older, sick sibling, state courts may need to grapple with the deficiencies of the current standards governing the legality of organ and tissue donation by minor children. Statutory mandates would provide the necessary standards for courts to enforce when facing issues that arise when a child is created solely for tissue and organ donation. However, these statutory mandates are unlikely to be enacted by state or federal regulation because of several challenges unique to the United States medical system.

C. Challenges in the United States to Federal or State Regulation of PGD

There are several obstacles preventing the comprehensive regulation of PGD and savior siblings in the United States. The most significant barrier is the United States' lack of government-sponsored healthcare. Unlike the United Kingdom, France, and Spain, in the United States, most citizens are covered by private insurance.[109] Some United States citizens qualify for government-sponsored healthcare programs like Medicare, Medicaid, and the Veterans Health Administration. However, none of these government-sponsored programs cover advanced fertility treatments like IVF and PGD.[110] Lack of a healthcare system largely or entirely subsidized by the government encourages a deregulatory state because the United States, by virtue of a privatized healthcare system, is not compelled to stipulate when artificial reproductive technology like PGD is permissible.[111]

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[108] Hebert, *supra* note 91, at 366; *See also* Strunk v. Strunk, 445 A.W.2d 145 (Ky. 1969); Little v. Little, 576 S.W.2d 493 (Tex. Civ. App. 1979).
[109] Comparative PGD Policy, *supra* note 56, at 44.
[110] *Id.*
[111] *Id.*

Unlike countries with government-sponsored healthcare, it is not necessary or inevitable for the United States to regulate medical practice.[112] In addition to a lack of urgency, the United States government is dissuaded from regulation of artificial reproductive technology and PGD by various interest groups.

First, physician trade groups are likely to see any regulatory body arising from the government as a "significant and unprecedent intrusion into private medical practice."[113] Private practitioners believe that because the government does not provide any funding, the government lacks the power to regulate their medical practice.[114]

Second, interest groups within the right-to-life and pro-choice movements have created a divisive backdrop for embryo politics in the United States. Fertility treatment often involves discarding excess embryos, and the legal rights of the destroyed embryo are hotly contested.[115] This highly polarizing political issue has resulted in the federal government distancing itself from the issue at large.[116] Legislation regarding PGD and savior siblings would involve the United States government to stake a position on the controversies of embryo politics. In order to safeguard political interests, legislators have consistently refused to implement policies regarding the whole field of artificial reproductive technology, including PGD and savior siblings.[117]

Lastly, disability rights advocacy groups frequently argue that PGD will cause increased injustice, stigmatization, and discrimination against people with disabilities.[118] This argument is grounded in the theory that PGD will be "misused by putting pressure on people to select against

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[112] *Id.*
[113] McClean, *supra* at note 84, at 871.
[114] Comparative PGD Policy, *supra* note 56, at 44.
[115] *Id.*
[116] *Id.* at 45.
[117] *Id.*
[118] T. S. Petersen, *Just diagnosis? Preimplantation genetic diagnosis and injustices to disabled people*, 31 J. MED. ETHICS 231 (2005).

embryos that do not have a severe genetic disease."[119] This pressure might alter the narrative surrounding disabilities and bolster injustice, stigma, and discrimination against disabled people.[120] Some commentators suggest that certain government regulations may send a message to the disabled community that legislators have collectively decided that they do not value people living with disabilities to the extent of "normal" people.[121] It is not clear to what extent these groups have had an impact on the United States government's "hands-off" approach to regulation of PGD.

D. Consequences of Lack of Governmental Regulation

Certain dangers arise out of the government's persistent refusal to regulate PGD in the context of savior siblings. First, there are no formal mechanisms in place to ensure that the best interests of a donor sibling are able to be met. Clinics performing PGD with the goal of creating savior siblings have an unchecked power to make their own decisions about what is best morally and ethically for their patients.[122] Second, because clinics are not operating under a standardized mandate regarding the limits on the savior sibling procedure, similarly situated individuals may have vastly different options available to them depending on the individual policies of the clinics performing PGD in their area.[123] Third, the lack of any centralized funding restricts data-gathering and information regarding use and prevalence of savior siblings.[124] Barriers to comprehensive data collection lead to difficulties in monitoring the long-term outcomes for

[119] *Id.*
[120] *Id.*
[121] Isabel Karpin & Roxanne Mykitiuk, *Reimagining disability: the screening of donor gametes and embryos in IVF*, 2020 JOURNAL OF LAW AND THE BIOSCIENCES 1, 16 (2020).
[122] Shapiro, *supra* note 15, at 446.
[123] *Id.*
[124] *Id.*

savior siblings, ensuring that the children are being respected and cared for, and ensuring that the children do not face lifetime burdens because of their status or biology.[125]

As discussed, there are significant sociocultural obstacles to comprehensive government regulation of PGD in the United States. Despite the potentially harmful consequences of non-regulation, the United States government has consistently refused to stake a position on the field of artificial reproductive technology. This leaves little hope for any near-future regulation regarding the welfare of children involved in the savior sibling process.

E. Professional Self-Regulation of PGD

Professional societies and private advocacy groups are the only groups drafting American policy addressing artificial reproductive technology.[126] Of the groups addressing artificial reproductive technology as a whole, only a handful have addressed PGD directly. The American Society for Reproductive Medicine (ASRM) has issued guidelines for laboratory conditions and accreditation of clinics performing PGD.[127] The ASRM Ethics Committee has also issued positions on PGD screening procedures related to sex selection.[128] Other private advocacy groups, including the PGD International Society (PGDIS) have issued practice guidelines for PGD.[129] The ASRM and other professional groups like the American College of Obstetricians and Gynecologists (ACOF) lobby Congress extensively for broader insurance coverage, minimal government regulation of artificial reproductive technology, and maximum access for patients

[125] *Id.* at 453.
[126] Robin E. Sosnow, *Genetic Material Girl: Embryonic Screening, the Donor Child, and the Need for Statutory Reform*, 7 J. HEALTH & BIOMEDICAL L. 609, 622 (2012)l.
[127] *Id.*
[128] *Id.*
[129] Nicole C. Schuppner, *Preimplantation Genetic Diagnosis: A Call for Public Sector Implementation of Private Advocacy Regulation*, 14 MICH. ST. U. J. MED. & L. 443, 452 (2010).

seeking treatment for infertility.[130] Traditionally, physicians follow the guidelines promulgated by professional organizations to the maximum extent due to state licensing and malpractice concerns.[131] While the procedural guidelines may be somewhat set by professional organizations through self-regulation, substantive decisions regarding the ethical acceptability of certain practices largely fall within the physician's own medical judgment.[132]

V. Proposal

Because of the potential dangers that arise when the process of savior siblings is unregulated, Part V proposes a solution that avoids the barriers associated with government regulation and serves as a first step toward comprehensive regulation ensuring the welfare of savior siblings and families. Physician professional organizations should consider promulgating guidelines that outline the acceptable uses of PGD, including guidelines for creating a savior sibling. I offer that a specific physician-led group can be created using the models of the HFEA in the United Kingdom, the Agence in France, and the CNHRA in Spain. The guidelines that the physician groups promulgate should encompass a "best-interests" approach to ensure the welfare of all children involved and the consent of the minor child to determine when tissue donation from a savior sibling is appropriate.

A. Physician Professional Organizations

The significant barriers to comprehensive federal regulation make private regulation through physician professional organizations the most viable option for regulation of PGD and savior siblings. Historically, the United States government has left the regulation of medical

[130] *Id.* at 449.
[131] *Id*. at 450.
[132] *Id*.

practice to the states.[133] While no states have enacted laws pertaining to PGD, a state-by-state regulation mosaic would be undesirable.[134]

Divergent laws among states will create a type of reproductive tourism intra-nationally. Individuals who live in states with harsher laws regarding PGD and savior siblings may travel within the country to find a clinic in a state with more relaxed laws. Reproductive tourism can pose certain health risks to patients and the resulting offspring.[135] Patients who travelled a great distance may feel pressure to transfer multiple embryos at once, which leads to greater risks of morbidity and mortality associated with pregnancy of multiples.[136] Additionally, clinics in the patient's home state may be reluctant to treat patients who become pregnant abroad as a result of prohibited treatment, making it difficult to perform monitoring and follow-up after IVF and PGD to ensure a healthy pregnancy and live birth.[137] Lastly, patients may fear legal or social backlash in their home state and feel pressured to withhold certain medical information about their child's conception.[138] The cost of travel and out-of-pocket expenses for the procedure may also foster inequalities in access to PGD and savior siblings.[139] Because of the significant medical and social challenges, state-by-state regulation of PGD and savior siblings is currently undesirable.

Federal and state regulation alike are impracticable. Private regulation through physician-led organizations is therefore preferable. It is clear that physicians and primary care providers are in the best position to balance the needs of their patients against the larger, ethical backdrop of PGD and savior siblings. These health professionals are often the most familiar with patients and the most equipped to ask the necessary questions to determine the bona fide intent of their

[133] Who Should Regulate PGD?, *supra* note 61, at 1163.
[134] *Id.*
[135] Comparative PGD Policy, *supra* note 56, at 45.
[136] *Id.*
[137] *Id.*
[138] *Id.*
[139] *Id.*

patients.[140] Similarly, as health professionals are necessary to the PGD process, they are in the best position to consider the individual considerations of a certain patient's case with the limitations of PGD, genetic testing, and the possibility of new medical developments.[141]

There are certain limitations to professional self-regulation of PGD. First, allowing medical professionals to determine the breadth of allowable PGD use may induce clinicians to promulgate overly broad rules and guidelines in their own self-interest or bias.[142] To mitigate this risk, there should be multiple stakeholders, including patient advocacy groups, involved in the promulgation of guidelines.

Another limitation to relying on professional organizations to govern the uses of PGD and savior siblings would be that these guidelines would not be as enforceable as a state or federal mandate.[143] However, while self-imposed professional guidelines are not legally binding, they often make up the baseline "standard of care" required when treating a patient.[144] Physicians that fail to follow the standard of care set by the industry often experience scrutiny from peers and patients, are vulnerable to litigation, and may be at risk for losing their professional licenses.[145] From a business perspective, physicians who fail to follow professional guidelines may also face severe scrutiny from potential patients, who may decide to take their healthcare needs to a more professional medical facility.

There are several already-existing physician professional groups who could take on the role of promulgating guidelines regarding the use of PGD and savior siblings. These organizations include the ASRM, ACOG, the American College of Medical Genetics and

[140] William D. White, *Professional Self-Regulation in Medicine*, 16 VIRTUAL MENTOR 275 (2014).
[141] Who Should Regulate PGD?, *supra* note 61, at 1163.
[142] *Id.* at 1164.
[143] *Id*.
[144] *Id.*
[145] *Id.*

Genomics, and others.[146] The ASRM is particularly fit to promulgate guidelines regarding the use of PGD for savior siblings because it already has an ethics committee and various subcommittees that issue opinions and guidance to clinics performing artificial reproductive techniques. Further, the ASRM is a "multidisciplinary organization dedicated to the advancement of the science and practice of reproductive medicine."[147] Basic and clinical scientists, nurses, technologists, mental health care associates, practice managers, OB/GYNs, urologists, psychiatrists, and psychologists are all included in ASRM's membership.[148]

The ASRM has promulgated guidelines that encompass a range of clinical practice and ethical issues.[149] However, the ASRM has only issued guidelines addressing the use of PGD for sex selection, but not the use of PGD for HLA-matching.[150] The ASRM is therefore sitting on a wealth of first-hand knowledge of PGD (and, perhaps, some knowledge of PGD for the use of savior siblings) but has thus far failed to address the ethical implications and provide guidelines. While ASRM does issue these lengthy guidelines to members including fertility clinics and sperm banks, it does not sanction those who are in violation of guidelines.[151] Other professional organizations, like the American Medical Association (AMA), direct individuals to file grievances against a medical professional with their state's medical licensing board if the

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[146] Joe L. Simpson, et al., *Professional self-regulation for preimplantation genetic diagnosis: experience of the American Society for Reproductive Medicine and other professional societies*, 85 FERTILITY AND STERILITY 1653 (2006).
[147] American Society for Reproductive Medicine, HISTORY OF ASRM, https://www.asrm.org/about-us/history-of-asrm/ (last accessed November 1, 2020).
[148] Simpson et al., *supra* note 146.
[149] *Id.*
[150] Lai, *supra* note 31, at 264.
[151] Pew, STATES NOT EAGER TO REGULATE FERTILITY INDUSTRY, https://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2015/3/18/states-not-eager-to-regulate-fertility-industry (last accessed December 16, 2020).

individual believes a medical professional or facility is acting unethically or failing to provide a certain standard of care.[152]

I maintain that the ASRM is a viable option to promulgate guidelines for United States clinics to use regarding PGD and savior siblings. The ASRM is sufficiently analogous a weaker, "private" version of the United Kingdom's HFEA, France's Agence de la Biomedicine, and Spain's CRHNA. The similarities between the ASRM, the HFEA, the Agence, and the CRNHA demonstrate that the ASRM can serve as a functioning regulatory body, even if it operates outside of the United States government. Additionally, the ASRM can adopt certain procedures from the French, English, and Spanish models to emulate the comprehensive regulatory schemes found in the European Union.

B. Models in the European Union

The French Agence de la Biomedicine oversees PGD by announcing appropriate uses of the procedure.[153] Clinics are then responsible for following the Public Health Code to ensure that an individual seeking PGD meets certain criteria *and* the individual is utilizing PGD for purposes sanctioned by the Agence de la Biomedicine.[154] While there is no legislative equivalent to the Public Health Code regarding artificial reproductive technology in the United States, a private organization like the ASRM can absorb the responsibilities of the Agence de la Biomedicine and agree to promulgate guidelines regarding the appropriate uses of PGD, including the boundaries of using PGD to create savior siblings. Further, the ASRM could direct clinics to consider individual candidates for PGD within a certain set of criteria. These criteria do not have to be binding for the individual to receive the procedure (like it is in France) but it could orient clinics

[152] American Medical Association, FREQUENTLY ASKED QUESTIONS ON ETHICS, https://www.ama-assn.org/about/publications-newsletters/frequently-asked-questions-ethics (last accessed December 17, 2020)
[153] *See supra* Part III.A.
[154] *See supra* Part III.A.

towards the best candidates for PGD and avoid ethical pitfalls. For example, the ASRM can direct clinics to accept only candidates seeking PGD for a medical purpose, and reject candidates seeking PGD for sex selection. There would be no complementary enforcement mechanisms, as there are in France, but the guidelines will assert pressure over ASRM membership to conform to the professional standard of care.

The ASRM, or a similar professional organization, might also look to the United Kingdom's HFEA for guidance regarding how to enact recommendations regarding the use of the PGD procedure to create savior siblings. In a similar manner to the French Agence de la Biomedicine, the HFEA issues binding guidance regarding the appropriate uses of PGD.[155] The HFEA, pursuant to its broad authority granted by the Human Fertilization and Embryology Acts, requires clinics to obtain licenses for every new genetic disease that they would like to test an embryo for using PGD.[156] Once the clinic is granted a license for a specific procedure, they are permitted to perform the procedure within limitations provided by law.[157]

The UK model would work well for an organization like the ASRM because the multidisciplinary membership of the ASRM is ideal to lay out acceptable uses and limitations of using the procedure to create savior siblings. With an organization like ASRM, every stakeholder can be represented in the discussions regarding best practices of using PGD to create savior siblings. The ASRM does not have the authority to issue licenses, as the HFEA does, but it is possible that the state-based professional licensing agency would adopt the ASRM's recommendations as mandatory requirements for clinics to follow as a prerequisite to become

[155] *See supra* Part III.B.
[156] *See supra* Part III.B.
[157] *See supra* Part III.B.

licensed to perform PGD in the state.[158] Further, the ASRM can offer certain accreditations that bolster a clinic's credibility, even if they are not necessary.

Spain's system of review for determining when PGD is appropriate to create a savior sibling may be too rigorous to be duly applied in the United States. In Spain, clinics and independent groups must evaluate individuals seeking to use PGD to create savior siblings on a case-by-case basis.[159] The governing body, the CNHRA, must then issue a favorable report.[160] The sheer administrative burden would probably be sufficient to conclude that this system would not work in the United States. Additionally, the notions of autonomy and privacy among American individuals and medical professionals may be offended if individuals seeking a certain procedure are required to undergo vigorous analysis before the procedure.

For these reasons, broad guidelines for clinicians to follow that are similar to the regulatory system in the United Kingdom and France would be ideal as they would not hamper reproductive rights. If an individual believes that they were wrongfully rejected for the procedure under the guidelines promulgated by the ASRM, they have recourse in the state court system. A family can also seek recourse in state courts if they believe a clinic is wrongfully refusing to follow the professional standard of care as laid out by physician-led organizations. Therefore, guidelines from professional physician organizations combined with the availability of judicial review can provide robust protections for families seeking to utilize PGD for the purpose of creating a savior sibling. These processes can also provide robust protection for the interest of the potential donor child.

C. Best-Interests of the Child

[158] Simpson et al., *supra* note 146.
[159] *See supra* Part III.C.
[160] *See supra* Part III.C.

The best-interests standard should be incorporated into the ASRM's guidelines regarding when clinics should perform PGD in order to create savior siblings. The proposal does not endorse assigning judicial functions to private bodies. Instead, the best-interests standard should be folded into the general guidelines promulgated by private organizations for medical professionals to follow. In other words, private organizations will not be judging individuals seeking PGD on a case-by-case basis, as is the case in Spain. Rather, the legal tests should serve as one of several bases for the general guidelines suggested by private, physician-led organizations that medical providers are expected to follow. Along with other content that the physician-led organization deems appropriate, the legal standard generally set out by courts to guide physician practice should be incorporated into these guidelines.

The best-interests standard already has a footing in American jurisprudence. For example, in Curran v. Bosze, the Illinois Supreme Court laid out an easily applied test to determine when an organ or tissue transplant would be in a donor child's best-interest. The procedure will be considered in the best interest of the donor child if:

> (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 recipient.[161]

Aspects of the Curran best-interest test should be incorporated into guidelines promulgated by physician professional organizations. The ASRM should assert that clinics are to perform PGD in order to create savior siblings must consider the parent or guardian's ability to provide adequate emotional support to the donor such that the donor child will be well-provided for if created. Additionally, parents of a potential donor child should be able to understand the

[161] *Curran*, 566 N.E.2d at 1343.

risks and benefits to a potential donor-child. If a parent cannot sufficiently articulate an understanding of the effects on the well-being of a potential child, they should not be able to use PGD to create a savior sibling. The guidelines will serve to steer clinics towards the right result ethically and legally.

D. Reporting Requirements

The ASRM may be the superior vehicle to promulgate guidelines regarding savior siblings even after the PGD process is complete because of the organization's ability to mandate reporting requirements when a clinic undergoes PGD for the purpose of creating a savior sibling. The data collected by the ASRM and any follow-up data that clinics collect regarding the well-being of the donor-child and family can by synthesized into one database controlled by the ASRM, or a similar organization. This data could be used to further refine the ASRM guidelines and any guidelines promulgated by other medical professional organizations regarding the well-being of donor-siblings.

In sum, a private organization like the ASRM could follow the government-led models in the UK and France when deciding how to regulate PGD for the use of savior siblings. The ASRM could lay out appropriate uses of PGD, including savior siblings, and lay down standards under which clinics could evaluate a specific case. These standards should fold in the legal standards as a guide for the behavior of clinicians providing PGD. These physician-promulgated guidelines will eventually become the baseline standard-of-care and any clinic that fails to follow these guidelines would face criticism and potential litigation.

Conclusion

"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."[162] Judge Steinfeld wrote these words in 1969, unaware of the vast potential of artificial reproductive technology. The decades since Judge Steinfeld's dissenting opinion have brought unprecedented growth in artificial reproductive technology. With regard to a minor child's ability to consent to medical procedures, the question American society now faces is: are we going to allow parents and clinicians to have unfettered discretion to determine under what circumstances a child should be created for the purpose of healing an ailing older sibling?

I argue that because of the potential ethical pitfalls, regulators should cabin parents' and clinicians' unfettered discretion in order to account for the best interests of the family and the potential donor-child. Given substantial political obstacles, the most effective way to enact these regulations is privately, through professional physician organizations. Organizations like the ASRM can work off of the structure of already-existing regulatory bodies in Europe to determine how to promulgate guidelines regarding the use of PGD to create savior siblings. Further, these organizations should enact guidelines that advance the best interests of a minor donor-child, and account for the informed consent of a minor child who is able to provide such consent. The private organization that takes on the task of promulgating guidelines regarding the use of PGD for savior siblings should also keep a robust data set that tracks the well-being of donor-children over many years.

Private self-regulation is a substantial first step to creating significant safeguards for potential donor-children. Regulation through professional medical organizations protects the autonomy of medical professionals and individuals while maintaining a careful consideration of the potential dangers to a donor-child. Since parents should not compel their children to be

[162] *Strunk*, 445 S.W.2d at 149 (Steinfeld, J., dissenting).

martyrs for the sake of saving an already-existing older child, the medical profession must step in to ensure that all potential human interests are accounted for.