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Savior Siblings in the United States: Ethical Conundrums, Legal and Regulatory Void

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Savior Siblings in the United States: Ethical Conundrums, Legal and Regulatory Void

*Zachary E. Shapiro**

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I. Introduction

Molly Rose Nash was born in Colorado, on July 4, 1994.¹ While the birth of a child is usually remembered joyously, it was immediately obvious that something was wrong with Molly, as she was only able to emit a “sickly whimper.”² Doctors soon realized that Molly had been born with a genetic condition known as Fanconi Anemia.³ Fanconi Anemia is an extremely rare genetic condition, resulting from a genetic defect in the proteins responsible for DNA repair.⁴ The condition meant that Molly’s body was unable to produce sufficient blood cells.⁵ Fanconi Anemia results in a myriad of problems, ranging from an extremely high likelihood of developing acute myelogenous leukemia, to an over 90% chance of developing bone marrow failure.⁶ People with Fanconi Anemia who manage to survive early childhood have a high incidence of esophageal, head and neck, gastrointestinal, and anal cancers.⁷ While there are treatments that can help delay bone marrow failure, the only cure is a bone marrow transplant,⁸ which is best provided by a sibling who is a match.⁹ Unfortunately, Molly was an only child.¹⁰ While the Nash family originally wanted to

1. Amanda M. Faison, *The Miracle of Molly*, 5280 (Aug. 2005), <http://www.5280.com/2005/08/the-miracle-of-molly/> (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

2. *Id.*

3. *Id.*

4. See Alan D. D’Andrea, *Susceptibility Pathways in Fanconi’s Anemia and Breast Cancer*, 362 NEW ENG. J. MEDICINE 1909, 1909–11 (2010) (explaining the cause of Fanconi’s Anemia and its rarity).

5. See Faison, *supra* note 1 (stating that Fanconi Anemia caused Molly to have an insufficient number of blood cells).

6. See D’Andrea, *supra* note 4, at 1910 (listing the symptoms and complications that come with Fanconi’s Anemia).

7. See *id.* (specifying the other types of cancer that can result from Fanconi’s Anemia).

8. See Faison, *supra* note 1 (“A bone marrow transplant . . . is the only cure for progressive bone marrow failure.”); see also D’Andrea, *supra* note 4 (stating that a bone marrow transplant is a viable treatment for Fanconi’s Anemia).

9. See *HLA Matching*, NAT’L MARROW DONOR PROGRAM, <https://bethematch.org/patients-and-families/before-transplant/find-a-donor/hla-matching/> (last visited Apr. 17, 2018) (noting that the best bone marrow donations are from siblings) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

10. Faison, *supra* note 1.

have more children, Fanconi Anemia is an inherited condition,¹¹ and once Molly was diagnosed, they knew they were both healthy carriers of the genes for the disease.¹² This meant that any additional children they had could suffer the same disease as Molly.¹³

There seemed to be no hope for the family, until doctors proposed a combination of pre-implantation genetic diagnosis (PGD) and in vitro-fertilization (IVF) that would lead to a novel concept in the field of biomedicine: that of the savior sibling.¹⁴ Using these techniques, the physicians were able to harvest ova and collect sperm from the Nashes, combine them in the laboratory, and then use PGD to screen the embryo, to ensure that it did not carry the Fanconi Anemia gene.¹⁵ After four in vitro fertilization attempts, Lisa Nash gave birth to a baby boy, named Adam.¹⁶ Adam's placenta was gathered immediately and the umbilical cord blood was saved.¹⁷ Umbilical cord blood contains stem cells that doctors then transplanted into Molly's circulatory system.¹⁸ After four weeks, Molly showed bone marrow recovery and three years later, her immune system was normal.¹⁹ The popular media termed Adam a "savior sibling," as he was born with a unique purpose: to save his older sister.²⁰

11. Giuseppe Burgio et al., *Conceiving a Hematopoietic Stem Cell Donor: Twenty-Five Years After our Decision to Save a Child*, 97 HAEMATOLOGICA 479, 479–81 (2012).

12. Faison, *supra* note 1.

13. *See id.* ("And because both [of Molly's parents] are carriers for the disease, there was a whopping 25 percent chance they would have a baby with [Franconi's Anemia].").

14. *See* Satkiran Grewal et al., *Successful Hematopoietic Stem Cell Transplantation for Fanconi Anemia from An Unaffected HLA-Genotype-Identical Sibling Selected Using Preimplantation Genetic Diagnosis*, 103 BLOOD 1147, 1147, 1150 (2004) (discussing the novelty of "savior siblings" and how it was Molly's only viable option).

15. *See id.* at 1147–48 (describing the process to create a "savior sibling").

16. Faison, *supra* note 1.

17. *Id.*

18. *See id.* (explaining that umbilical cord blood contains stem cells that are required to heal Molly).

19. Bruce Dickens, *Preimplantation Genetic Diagnosis and 'Savior Siblings'*, 88 INT'L J. GYNECOLOGY & OBSTETRICS 91, 94 (2005).

20. *See* Kirsty Horsey, *US 'Saviour Siblings' Spark Debate*, IVF.NET (May 5, 2004), <https://ivf.net/ivf/us-saviour-siblings-spark-debate-o299.html> (naming the

As the Nash family can attest, advances in reproductive technology are increasingly finding applications in fields that seem more the realm of science fiction than reality.²¹ One such application is in the treatment of individuals suffering with rare genetic diseases, who are desperately in need of some form of biological material transplantation.²²

“Savior siblings” is the term used to describe a sibling created for the purpose of providing biological material that can help treat or cure an existing terminally ill child.²³ These children are conceived through the sequential use of two reproductive technologies: pre-implantation genetic diagnosis (PGD) and in-vitro fertilization (IVF).²⁴ While these techniques were developed for other purposes, in the context of savior siblings, PGD is used to screen embryos prior to implantation in the uterus, to determine whether the embryo will be a tissue “match” to a sick child.²⁵ It is estimated that roughly one percent of PGD in the United States is used to create children that are tissue matches for their siblings.²⁶

While the process has become more common in America in recent years, meaningful discussion about savior siblings has lagged. The practice has advanced with nearly no governmental involvement, as there exists no formal regulation or professional society guidelines governing the use or creation of savior siblings.²⁷

first savior sibling “Adam”) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

21. See Alison Motluk, *Fertility Treatments: From Sci-Fi to Reality*, GLOBE & MAIL (Feb. 9, 2015), <https://www.theglobeandmail.com/life/health-and-fitness/health/a-look-inside-the-changing-world-of-fertility/article22863038/> (describing how advanced reproductive technology is today) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

22. See Horsey, *supra* note 20 (explaining that tissue transplants from “savior siblings” had been used to treat several types of leukemia and anemia).

23. See *id.* (noting that “savior siblings” are used to help treat terminally ill siblings via biological donations).

24. See Faison, *supra* note 1 (describing the process by which “savior siblings” are conceived).

25. See *id.* (explaining how PGD is used to screen embryos for a specific tissue match).

26. See BETH WHITEHOUSE, *THE MATCH: SAVIOR SIBLINGS AND ONE FAMILY’S BATTLE TO HEAL THEIR DAUGHTER* 127 (2001) (stating the percent of PGD uses that correspond with “savior siblings”).

27. See Michelle J. Bayefsky, *Comparative Preimplantation Genetic Diagnosis Policy in Europe and the USA and Its Implications for Reproductive Tourism*, 3 REPROD. BIOMEDICINE & SOC’Y ONLINE 41, 43–45 (2016) (discussing

The case of the United States stands in stark contrast to other countries, particularly the United Kingdom, where a robust regulatory framework for the use of savior siblings has risen, along with debate and discussion over the acceptability of savior siblings.²⁸

The issue of savior siblings is fraught with ethical pitfalls.²⁹ Thus, extraordinary care and planning must be invested to ensure that the process is undertaken only when absolutely necessary and is done in a way that respects the dignity of the new child.³⁰ Protection of dignity and preservation of autonomy are fundamental tenets in bioethics, and must be kept in mind, especially when dealing with a vulnerable population, such as children.³¹ Caution is paramount, as there is potential for serious ethical missteps. For instance, some hypothesize that the savior sibling may be irrevocably harmed by being a savior, if the child believes that they were not wanted for themselves, or if a child conceived for this reason enjoys a less close and loving relationship with his/her parents.³² Opponents of this practice go so far as to suggest that no matter how the parents choose to love and care for the new child, it still does not ameliorate the harm caused by the fact that this child may be aware that they were born for the purpose of saving their sibling.³³ These potential harms contrast

the lack of regulation regarding PGD in the United States).

28. See *id.* (comparing the regulation of the United Kingdom with the lack of regulation in the United States).

29. See Grewal et al., *supra* note 14 (listing several ethical issues regarding savior siblings).

30. See Thomas R. McCormick, *Principles of Bioethics*, UNIV. WASH. SCH. MED., <https://depts.washington.edu/bioethx/tools/princpl.html> (last updated Oct. 1, 2013) (describing the “[f]our commonly accepted principles of health care ethics . . . include[ing] the: principal of respect for autonomy, . . . of nonmaleficence . . . of beneficence, and . . . justice” implicated by savior siblings) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

31. See Grewal et al., *supra* note 14 (describing ethical issues regarding savior siblings).

32. See Jennifer Lahl, *My Sister’s Savior*, CBC (July 22, 2009), <http://www.cbc-network.org/2009/07/my-sisters-savior/> (describing the argument that savior siblings will be irrevocably harmed by being a savior sibling) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

33. See Alasdair Cochrane, *Undignified Bioethics*, 24 *BIOETHICS* 234, 235–38 (2010) (stating the various arguments that dignity should play a major role in bioethics).

with the therapeutic benefits that having a savior sibling can provide, both for the existing sick child, who gets to continue living, and the family unit as a whole, who not only do not have to bury a child, but now have the enjoyment of two (hopefully healthy) children. Consideration of savior siblings is a necessary endeavor for those at the intersection of law and bioethics, as this process raises a number of issues that can benefit from the input of those with an understanding, not only of bioethical principles, but of legal issues concerning child autonomy, welfare, and pediatric consent.³⁴

This Article will approach the topic of savior siblings, created using pre-implantation genetic diagnosis and in-vitro fertilization, from an ethical and legal focus. It will start with an investigation into the nature and technology surrounding the creation of savior siblings. The next section will move into a discussion about the unique ethical issues presented by savior siblings. Then, the regulatory framework (or lack thereof) that governs their use will be addressed, contrasting the lack of regulation in the United States, with the framework in the United Kingdom, where the use of savior siblings is regulated. This Article will conclude with a series of practical recommendations, including a call for regulation in the United States, in order to move the field forward ethically, and responsibly.

II. What is a savior sibling?

Most of the conditions that savior siblings are used to ameliorate are genetic in nature.³⁵ Pre-implantation genetic diagnosis (PGD) refers to the genetic profiling of embryos, and is used to screen embryos and zygotes for genetic diseases.³⁶ In PGD,

34. See generally Zachary E. Shapiro, FIELD NOTES: BIOETHICS IN THE LAW, 47 HASTINGS CTR. REP. 1 (2017).

35. See Horsey, *supra* note 20 (explaining that savior siblings are used to help treat terminally ill siblings via biological donations).

36. See Molina B. Dayal et al., *Preimplantation Genetic Diagnosis*, MEDSCAPE, <https://emedicine.medscape.com/article/273415-overview> (last updated Dec. 30, 2015) (“[PGD] refers specifically to when one or both genetic parents has a known genetic abnormality and testing is performed on an embryo to determine if it also carries a genetic abnormality.”) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

a biopsy is taken from an embryo that has been artificially fertilized outside of a woman's womb.³⁷ This biopsy then undergoes genetic analysis, in order to determine genetic makeup of the embryo, with respect to the disorder in question.³⁸

Given that PGD requires a biopsy, it is an invasive procedure that carries small, but real, risks to the embryo.³⁹ While most of the risks come from improper biopsy technique, the risks are real.⁴⁰ Most medical practitioners therefore feel that PGD is only warranted if there is a necessary indication for its use.⁴¹

PGD is undertaken when creating a savior sibling for two reasons. First, it is important that the new child does not suffer the same disease as the existing child, as a sick child cannot serve as a donor, and could face the same health problem as their older sibling.⁴² Second, it is essential that the new sibling be a tissue (or HLA) match with their older sibling, so that the child can successfully donate biological material without fear of said material being rejected.⁴³ Even close relatives and siblings are often not a genetic match, meaning they would be unable to donate biological material.⁴⁴ When a donor is not a match, the recipient's

37. *Id.*

38. *See id.* (explaining that in PGD the embryo is tested to determine if it is afflicted with a genetic disorder).

39. *See Embryo Freezing (Cryopreservation)*, GENETICS IVF INST., <http://www.givf.com/fertility/embryofreezing.shtml> (last visited Apr. 17, 2018) (indicating there are risks to the embryo in performing PGD) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

40. *See Bust a Myth about PGD/PGS*, FERTILITY AUTHORITY, <http://www.fertilityauthority.com/articles/bust-myth-about-pgd-pgs> (last visited Apr. 17, 2018) (indicating that not everyone should use PGD as it contains dangers for the embryo) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

41. *See id.* (listing the most common indications for PGD's use are pregnancies in women thirty-nine and older, severe male factor infertility, two or more past miscarriages, and past IVF failures).

42. *See Merle Spriggs, Is Conceiving a Child to Benefit Another Against the Interests of the New Child?*, 31 J. MED. ETHICS 341, 341–42 (2005) (explaining that PGD can lower the odds that the savior sibling suffers from the same disease as the afflicted child).

43. *See id.* (stating that PGD can be used to tissue match the savior sibling with the afflicted child).

44. *See HLA Matching, supra* note 9 (noting that siblings only have a 25% chance of being a tissue match for each other).

immune system rejects the transplantation.⁴⁵ It is also possible for the donated biological material to “reject” the host into whom it has been transplanted, causing a serious reaction called graft vs. host disease.⁴⁶ Thus, PGD is required to ensure not only that the new child will be free from the disease, but will also be a tissue match with the sick child.

Of course, the concept of savior siblings does not necessarily require the use of in vitro fertilization, as a couple could conceive naturally.⁴⁷ Such parents would have to hope that they bear a new child who is not afflicted by the condition of their sibling, and hope that the new child will be a tissue match with the existing child.⁴⁸ In these circumstances, conceiving naturally carries a significant risk, that either the baby will be born into a life of suffering and pain, or that complications could arise during pregnancy, which could threaten the life or well-being of the mother.⁴⁹ The concept of savior siblings need not be restricted to siblings. Indeed, a child could be conceived to help cure a sick parent, relative, or other member of the family, a concept that will be discussed further below.⁵⁰ Typically, the use of in vitro fertilization and PGD is necessary for the creation of savior siblings due to the need to match donor tissue matching with the existing sick child.⁵¹

45. See *Transfusion Reaction—Hemolytic*, U.S. NAT’L LIB. MEDICINE, <https://medlineplus.gov/ency/article/001303.htm> (last visited Apr. 17, 2018) (describing how non-matching biological donations cause the host to reject the transfusion) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

46. See *Graft vs Host Disease: An Overview in Bone Marrow Transplant*, CLEV. CLINIC, <https://my.clevelandclinic.org/health/diseases/10255-graft-vs-host-disease-an-overview-in-bone-marrow-transplant> (last updated Apr. 17, 2014) (explaining that in Graft vs. Host Disease “the donated bone marrow or peripheral blood stem cells view the recipient’s body as foreign, and the donated cells/bone marrow attack the body”) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

47. Janelle Mills, *Understanding the Position of the Savior Sibling: Can We Save Lives and Protect Savior Siblings*, WAKE FOREST U. GRADUATE SCH. ARTS & SCI., at ix (Dec. 2013), https://wakespace.lib.wfu.edu/bitstream/handle/10339/39113/Mills_wfu_0248M_10493.pdf (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

48. See *id.* at 2 (discussing the risks associated with having a child naturally, specifically, that the fetus may have the same illness as the sick child).

49. *Id.*

50. See *infra* C. Slippery Slope (analyzing “slippery slope” arguments and ways in which the “savior siblings” process could be abused).

51. See generally S. Sheldon & S. Wilkinson, *Should Selecting Savior*

A. *When are savior siblings considered?*

The decision to create a savior sibling is by no means common. This section will discuss conditions for which savior siblings might be a plausible treatment, and point out ethical implications of these conditions. Consideration of savior siblings is only *biologically* appropriate under a specific set of circumstances.⁵² First of all, the disease affecting the sick individual must have some genetic component or be readily identifiable with genetic testing.⁵³ This is important because, as mentioned above, it is essential that the savior does not suffer the same condition as the sick child.⁵⁴ While pre-implantation diagnosis is an evolving and advancing field, we currently only have the ability to perform genetic testing on an embryo for a select list of genetic conditions.⁵⁵ These conditions are the only ones that we can currently ensure, through screening, will not be present in the savior embryo, prior to implantation.⁵⁶

Secondly, savior siblings should only be considered when a child is suffering from a disease that is serious enough to necessitate intervention, but which can only be treated through the use of transplantation.⁵⁷ Most savior siblings have been employed to ameliorate life-threatening conditions, both genetic

Siblings be Banned?, 30 J. MED. ETHICS 533, 537 (2004) (arguing that “the selection of saviour siblings should be permitted, especially given that prohibiting it would result in the preventable deaths of a number of existing children”).

52. Bruce Dickens, *Preimplantation Genetic Diagnosis and ‘Savior Siblings’*, 88 INT’L J. GYNECOLOGY & OBSTETRICS, 91, 92–94 (2005).

53. *See id.* (outlining the elements of pre-implantation genetic diagnosis); *see also* Dayal et al., *supra* note 36 (explaining the science behind pre-implantation genetic diagnosis).

54. *See id.* (explaining that only unaffected embryos are transplanted as to avoid replicating the genetic disorder).

55. *See PGD Testable Diseases*, THE FERTILITY INSTITUTE, <http://www.fertility-docs.com/programs-and-services/pgd-screening/genetic-diseases-tested-for-with-pgd.php> (last visited Apr. 17, 2018) (advertising the Fertility Institute’s ability to screen for over 400 hereditary diseases during the embryo stage) (on file with Washington & Lee Journal of Civil Rights & Social Justice).

56. *Id.*

57. *See* Dickens, *supra* note 52, at 93–96 (outlining the policy concerns considered by a handful of countries in the debate over the use of pre-implantation genetic diagnosis).

and otherwise.⁵⁸ This Article does not categorically suggest that savior siblings should not be used to provide transplantations for elective procedures, or procedures that will simply improve quality of life. However, if there is no life-threatening condition being suffered, it is much more difficult to ethically justify the creation of a savior child.⁵⁹ While most of my analysis focuses on savior siblings used to treat debilitating and generally fatal conditions that are not curable through other means, the potential for abuse in this regard will be discussed later, as it provides support for seeking some form of regulation of this procedure.

Savior siblings provide biological material, so any disease that could be treated through a transplant, could theoretically be treated by means of a savior sibling.⁶⁰ While transplantation immediately conjures images of organ harvesting, it can actually refer to a broad range of biological material transplantation, with organs perhaps being the rarest material harvested.⁶¹ Up to this point, savior siblings have been utilized to treat conditions that can be cured through the transplantation of hematopoietic stem cells, derived from bone marrow, umbilical cord blood, or peripheral blood.⁶² Nonetheless, this technology and practice could easily be utilized to harvest a more significant donation, such as a kidney or another organ, which would have troubling implications.⁶³

58. *See id.* (describing several high-profile uses of pre-implantation genetic diagnosis by families due to the serious and life-threatening nature of disease experienced by a child).

59. *See id.* at 95 (addressing many of the ethical issues which challenge the use of pre-implantation genetic diagnosis and other reproductive technologies).

60. *Id.*

61. *See* Todd Pesavento, *Facing Organ Donor Shortage, Patients Forced to Get Creative*, LIVESCIENCE.COM (Oct. 20, 2015), <http://www.livescience.com/52526-rarity-of-organ-donations-forcing-patients-to-get-creative.html> (reporting on the unconventional ways patients have attempted to circumvent the shortage of organ donations available for transplantation) (on file with Washington & Lee Journal of Civil Rights & Social Justice).

62. *See* Susan M. Wolf et al., *Using Preimplantation Genetic Diagnosis to Create a Stem Cell Donor: Issues, Guidelines & Limits*, 31 J. L. MED. & ETHICS 327, 329–35 (2003) (outlining the ways in which stem cells from savior siblings have provided important biological material).

63. *See id.* at 334 (recommending a framework that requires judicial review of bone marrow and solid organ transplant “to determine whether the harvest is in the best interest of the donor child”).

Hematopoietic stem cell transplant can be used to combat an evolving list of diseases, but is most often associated with fighting cancers of the blood and bone marrow.⁶⁴ These range from commonly known conditions like leukemia, Hodgkin's and Non-Hodgkin's Lymphoma, and solid tumor cancers, to certain hematologic diseases (non-cancerous blood diseases) and metabolic conditions.⁶⁵

Thirdly, consideration of a savior sibling should only occur when there is no viable tissue donor that can be found for the sick child.⁶⁶ While "transplantation from an HLA identical sibling is associated with a much higher success rate than a transplant from alternative donors,"⁶⁷ an existing tissue match renders the creation of a savior sibling unnecessary.⁶⁸ The presence of an existing donor eliminates the ethical quandaries raised by the creation of savior siblings, discussed below. Furthermore, an older, more developed person has more biological material to donate, especially when compared to a very young child who may not be fully developed in key aspects.⁶⁹

Finally, the condition that requires transplantation must not be immediately life threatening, as it can take several years for a savior sibling to be able to provide the necessary biological

64. See Ajay Perumbeti, *Hematopoietic Stem Cell Transplantation*, MEDSCAPE (Nov. 13, 2017), <http://emedicine.medscape.com/article/208954-overview> (discussing the biological mechanisms of hematopoietic stem cell transplantation (HSCT) and medical indications for HSCT treatment) (on file with Washington & Lee Journal of Civil Rights & Social Justice).

65. *Id.*

66. See G.N. Samuel et al., *Establishing the Role of Pre-Implantation Genetic Diagnosis with Human Leucocyte Antigen Typing: What Place do "Saviour Siblings" have in Paediatric Transplantation?*, 94 ARCH. DIS. CHILDHOOD 317, 318–20 (2009) ("Discussions regarding this technology may be appropriate where no suitable related donor is available and transplantation is only likely to be entertained with a matched sibling donor.").

67. See Katrien Devolder, *Preimplantation HLA Typing: Having Children to Save our Loved Ones*, 31 J. MED. ETHICS 582, 582 (2005) (addressing critics of pre-implantation tissue typing as a method of ensuring that potential donor children are a tissue match).

68. See *id.* at 583–88 ("The underlying reasoning is that when PGD is used to test for genetic diseases that testing is done in the best interests of the embryo or the person it will become, whereas when PGD is used solely for tissue typing, the only benefit is for the existing sick child.").

69. See generally Samuel et al., *supra* note 66.

material to the sick child.⁷⁰ The amount of time before a savior sibling can provide material to treat a child varies depending on exactly what material is needed.⁷¹ In the case where the umbilical cord would provide sufficient stem cells, the cure can be harvested immediately after birth, with no further requirement from the savior sibling.⁷² In cases where bone marrow or some other material are needed however, it can be several years before a savior sibling can function as a viable donor.⁷³

While potential for abuse exists, a strict analysis of conditions where consideration of savior siblings would be appropriate is of utmost importance. These conditions combine to make the use of savior siblings, objectively quite rare.

III. Ethics

The ethical issues raised by savior siblings vary and depend on the type of transplantation required.⁷⁴ Many believe that the ethical questions exist on a spectrum, reflecting the invasiveness of the tissue being transplanted.⁷⁵ This spectrum views non-invasive transplantation, such as the use of umbilical cord blood, as less objectionable than a more extensive procedure, such as the donation of bone marrow, and these procedures similarly being less objectionable than a permanent donation such as a kidney or another vital organ.⁷⁶ No matter the degree of invasiveness, there are a few key arguments advanced in nearly any framework dealing with savior siblings.

70. *See id.* at 319 (explaining that IVF and PGD for HLA typing with the goal of one day performing a biological material donation is only appropriate in non-urgent transplantation cases).

71. *Id.* at 319.

72. *Id.* at 319.

73. *See generally* Devolder, *supra* note 67, at 585 (noting how age is a factor in bone marrow donations).

74. *See id.* at 584 (discussing the ethical issues raised by various transplantation procedures).

75. *See id.* (discussing the range of acceptability of donor transplantations from the “widely accepted” umbilical cord blood harvest to the “not accepted” vital organ harvest).

76. *Id.*

A. Concerns about the New Child

Many of the ethical arguments against the use of savior siblings focus on the status and welfare of the newly conceived child.⁷⁷ One specific concern relates to commodification of the savior sibling. In a procedure such as tissue donation, it is difficult to argue that the savior sibling is not, in some way, being used as a means (providing a cure) to an end (curing an existing sick child).⁷⁸ Many philosophers, particularly Kantians,⁷⁹ will object on this basis. One could respond that while the savior sibling is being used a means, it is not merely a means to an end. Indeed, a savior sibling serves a much more complicated role: that of a savior, a family member, and an individual person. Of course, worries of commodification must be addressed, as without the savior sibling's role of providing biological material that allows for the curing of a sick child, it is unlikely that this specific individual would exist. This is because a great deal of effort and technology must be invested to ensure that the new child meets the specific conditions necessary to serve as a donor (namely that they are free from the disease, and are an HLA match with the existing sibling).

The commodification argument plays into the larger contention that being used as a savior sibling damages the welfare of the new child.⁸⁰ Some argue that the new child may feel like they only exist to serve their sick sibling, as a simple cog in the family machine that decided to create them.⁸¹ This could lead to feelings

77. See Sally Sheldon & Stephen Wilkinson, *'Saviour Siblings': Hashmi and Whitaker. An Unjustifiable and Misguided Distinction*, PROCHOICEFORUM (2005), http://www.prochoiceforum.org.uk/irl_rep_tech_2.asp#top (outlining the ethical controversies surrounding savior siblings as presented in two cases decided by the Human Fertilisation and Embryology Authority) (on file with author).

78. See generally Jose Silber, *Is it Ethical to Have a Child to Save a Child?*, 13 AAP GRAND ROUNDS 30, 30 (2005).

79. *Id.*

80. See Mariana Do Carmo, *Child Autonomy and the Rights to One's Own Body: PGD and Parental Decision Making*, THEBIOETHICSPROJECT (Feb. 13, 2013), <http://www.thebioethicsproject.org/essays/child-autonomy-and-the-rights-to-ones-own-body-pgd-and-parental-decision-making/> (discussing ethical considerations of savior siblings as related to the wellbeing of the child) (on file with author).

81. See, e.g., Allane Madanamoothoo, *Saviour-Sibling and the Psychological, Ethical and Judicial Issues that It Creates: Should English and French Legislators Close the Pandora's Box?*, 18 EUR. J. HEALTH L. 293, 301 (2011)

of depression and a lack of self-worth or malaise, as the child may not feel special in their own right, but rather that they are forever tied to their sibling.⁸² It has been argued that serving as a savior sibling solely benefits the parents and sick child, as the savior may be subjected to invasive, and potentially painful, procedures that provide no direct biological benefit to them as an individual.⁸³ Indeed, while many of these procedures are simple, some of them, such as bone marrow transplant, can be extremely painful.⁸⁴

These concerns become even starker when parents wish to undertake a more significant transplantation from a savior sibling.⁸⁵ While utilizing the umbilical cord that is otherwise discarded may be morally acceptable, there is greater risk if saviors were to donate biological materials such as organs or other tissues.⁸⁶ Harvesting an organ can result in a lifetime of differentiated care and health problems, including the possibility of a shortened life span.⁸⁷ With no obvious benefit to the new child,

("[T]hey may feel of having been conceived for the sole purpose of caring for their elder brother or sister.").

82. See Sally Sheldon & Stephen Wilkinson, *Should Selecting Saviour Siblings Be Banned?*, 30 J. MED. ETHICS 533, 534 (2004); see also *Savior Siblings: At What Moral Cost?*, ZENIT (Mar. 23, 2011), <http://zenit.org/articles/savior-siblings-at-what-moral-cost/> (concluding that selecting savior siblings should not be banned) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

83. See generally LORI KNOWLES & GREGORY E. KAEBNICK, *REPROGENETICS: LAW, POLICY, AND ETHICAL ISSUES* (2007) (bringing together bioethicists from the United States, Canada, and the United Kingdom to examine the ethical and policy questions created by new genetic technologies).

84. See, e.g., Martha Bebinger, *From Cheek Swab To Operating Room: What's It Really Like To Donate Bone Marrow?*, WBUR (May 13, 2014), <http://commonhealth.wbur.org/2014/05/what-its-like-to-donate-bone-marrow> (highlighting David Cavell's journey of donating bone marrow) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

85. See, e.g., *Risks Involved in Living Donation*, KIDNEYLINK, <http://www.kidneylink.org/RisksInvolvedinLivingDonation.aspx> (last visited Apr. 17, 2018) (discussing risks associated with kidney donation, including: high blood pressure, the kidney not functioning properly after recipient receives the transplant, unforeseen problems the donor may experience, body image problems from the surgical scars, and feelings of anger or anxiety) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

86. See *id.* (explaining the dangers that savior siblings face in donating certain organs).

87. See *id.* (emphasizing the long-term risks associated with savior siblings donating organs).

there seems to be a clear difference if a savior sibling is created for a donation more invasive than bone marrow, as such a process disregards the welfare of the savior, in favor of the health of the sick child and the happiness of the family unit.

Invasive donation is particularly problematic, given that the savior sibling is not afforded the same level of autonomy that a normal individual is given when deciding to consent to a transplant of biological material.⁸⁸ It is important to note that autonomy is necessary for an individual to give consent to a procedure.⁸⁹ Autonomy can be violated through coercion or pressure, which removes an individual's ability to give genuine consent, or by not providing an individual with the option of consenting.⁹⁰

Savior siblings present a unique situation with the issues of consent and autonomy for several reasons. Firstly, as the child was created specifically to serve as a donor, the individual does not have the chance to "agree" to serve as a savior sibling.⁹¹ This means that the only wishes that get expressed, when deciding whether or not to create a savior sibling, are those of the parents.⁹² Some argue that this fundamentally undermines the ability of that individual to ever give meaningful consent, as they were created for the purpose of serving as a transplant, whether they want to or not.⁹³

88. See Kimberly Strong et al., *Savior Siblings, Parenting and the Moral Valorization of Children*, 28 *BIOETHICS J.* 187, 188–90 (2014) (testing the ethical objection to savior siblings and concluding that the ethical objections rely heavily on speculative arguments and inappropriately scrutinize parental motives).

89. See K. Satyanarayana Rao, *Informed Consent: An Ethical Obligation or Legal Compulsion?*, 1 *J. CUTANEOUS AESTHETIC SURGERY* 33, 33–35 (2008) (claiming that informed consent is an ethical and legal obligation).

90. See *id.* (asserting that no one has the right to coerce the patient to act in any way, not even a doctor).

91. See Kiley Bonk, *Minors as Living Organ Donors: Protecting Minors from Martyrdom*, 28 *CHILD. LEGAL RTS. J.* 45, 45 (2008) (considering the legal safeguards in place with regard to organ donation by minors and discussing the possible side effects).

92. See *id.* (discussing the inability of savior siblings to consent to their role in the savior sibling process).

93. See Steven Ertelt, *Rescue Me: The Moral and Ethical Problems of Creating Savior Siblings*, *LIFENEWS* (Aug. 8, 2008), <http://www.lifenews.com/2008/08/08/bio-2540/> (discussing ethical issues with savior siblings and consent) (on file with Washington and Lee Journal of Civil Rights & Social Justice).

Some scholars question whether consent from the savior sibling is even factored in to the decision to harvest biological material in the first place.⁹⁴ In many cases, the child may be too young to have the capacity to offer their own consent.⁹⁵ There are several levels of concern regarding consent that relate to the invasiveness of the proposed procedure.⁹⁶ To wit, it is probably not very important that we obtain a newborn's "consent" to use their umbilical cord, which is arguably considered a part of the mother anyway, and is traditionally discarded.⁹⁷ But if the procedure involves significant pain, or a potentially life-long alteration of the savior sibling's quality of life, one would agree that then it becomes more important to have the consent of the individual.

Scholars question whether savior siblings will face undue pressure from their family unit, meaning that even if they chose to serve as donors, this may not be a genuinely autonomous choice.⁹⁸ Undue pressure can remove a normal individual's ability to consent to a procedure, to say nothing of a young child.⁹⁹ Even with supportive parents, children may feel compelled to fulfill their family's wishes, and feel a sense of responsibility for their sibling's life, which only they are able to "save."¹⁰⁰

94. See generally KNOWLES & KAEBNICK, *supra* note 83, at 187–89 (considering the benefits and risks of combining reproductive technologies).

95. See Lawrence Schlam & Joseph Wood, *Informed Consent to the Medical Treatment of Minors: Law and Practice*, 10 HEALTH MATRIX: J. LAW-MED. 141, 142 (2000) (analyzing the competence of minors and discussing the requirement of informed consent when treating minors).

96. See *id.* (discussing the different ethical questions involved in medical decisions for minors).

97. See *Donating Umbilical Cord Blood to a Public Bank*, HEALTH RESOURCES & SERVS. ADMIN., <https://bloodcell.transplant.hrsa.gov/cord/options/donating/index.html> (last visited Apr. 17, 2018) (explaining the process of donating umbilical cord blood and how the umbilical cord is typically discarded) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

98. See, e.g., Strong et al., *supra* note 88, at 187–89 (discussing the moral significance and pressures from the parents of a savior sibling).

99. See, e.g., Cameron Stewart & Andrew Lynch, *Undue Influence, Consent and Medical Treatment*, 96 J. ROYAL SOC'Y MED. 598, 599 (2003) (explaining the influence of the doctor-patient relationship when consenting to medical treatment).

100. See *id.* (providing an example of a child who felt responsible for the life of their sibling).

Superimposed on the issue of consent specific to the savior sibling situation is the more general issue of informed consent in children. Young children generally lack a true understanding of medical procedures and what they entail.¹⁰¹ A full discussion of this is beyond the scope of this Article, but the issue clearly imparts an ethical consideration.

While some highlight the magnitude of such ethical pitfalls,¹⁰² other scholars argue that creating savior siblings may not lead to the negative scenarios imagined.¹⁰³ These scholars point out that, when considering ethical objections to the creation of a savior sibling, we must do our best to try to assess what effect being a savior sibling has on a child to determine whether the fears and concerns that people raise are well founded, or alarmist.¹⁰⁴

B. Available Data

While the arguments raised above seem persuasive, there is currently little direct evidence to back up claims that being a savior sibling is damaging to the welfare, psychological or emotional health of the savior sibling.¹⁰⁵ It is essential to note, that this evidence is lacking, primarily because of the novelty of the procedure, and the absence of serious, long-term investigation.¹⁰⁶

101. See *id.* at 600–04 (discussing the influence of family members on a child’s decision making abilities).

102. See, e.g., Wesley J. Smith, “Savior Siblings” Start Us Down Harrowing Ethical Path, CENTER FOR BIOETHICS & CULTURE (Mar. 3, 2011), <http://www.cbc-network.org/2011/03/savior-siblings-start-us-down-harrowing-ethical-path/> (criticizing the creation of a savior siblings) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

103. See, e.g., Guido Pennings, *Saviour Siblings: Using Preimplantation Genetic Diagnosis for Tissue Typing*, 1266 INT’L CONG. SERIES 311, 312–17 (2004) (weighing ethical concerns regarding savior siblings).

104. See *id.* (discussing the need to consider the sensibilities of the savior sibling in their creation).

105. See Sheldon & Wilkinson, *supra* note 51, at 534 (finding that arguments against the practice of savior siblings based on the welfare of the savior sibling are unfounded).

106. See *id.* at 536 (“[F]ull consideration of the issue of psychological harm would involve marshalling substantial bodies of empirical evidence (not something that we can do here).”).

Many have criticized the available quality of life studies as relying too much on self-reporting,¹⁰⁷ and for lacking objective indices about appropriate quality of life criteria.¹⁰⁸ Despite these flaws, interviews and anecdotal data suggest that many savior siblings have relatively normal, uncomplicated lives, free from philosophical concerns about their creation or place in the universe.¹⁰⁹ I argue that parents who undergo the extensive process needed to have a savior sibling are unlikely to simply disregard or treat the savior child poorly, just because their function as a donor is over. Indeed, given the extensive time, money, effort, and difficulty, involved in having a savior sibling, the process is unlikely to be undertaken by parents who are not concerned with caring for their children. It is just as likely that parents might show increased care for the savior sibling, as the savior has played an integral role in preserving the family unit.

Further, although there is some argument that psychological harm could occur if a child finds out that he or she was wanted not for himself or herself, but rather for the ulterior purpose of assisting a sibling to live, anecdotal interview data report high level of satisfaction for the savior sibling.¹¹⁰ This may be due to the fact that it seems just as likely that that child will feel pride and contentment in the knowledge that he or she is responsible for saving the life of a sibling.¹¹¹ These feelings of pride seem to extend to the knowledge that the savior was created for a specific purpose. Interviews with savior siblings also suggest that worries about commodification, and reason for birth, do not seem to produce

107. See *Self-Report Measures: Notoriously Unreliable*, INTROPSYCH, http://www.intropsych.com/ch01_psychology_and_science/self-report_measures.html (last visited Apr. 17, 2018) (noting the unreliability of studies which collect data via self-reporting) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

108. See Pedro Conceição & Romina Bandura, *Measuring Subjective Wellbeing: A Summary Review of the Literature 2–7* (United Nations Dev. Programme Dev., Working Paper No. 2, 2008) (finding flaws in the traditional method of studying quality of life).

109. Telephone Interviews by Zachary Shapiro with various hospitals and fertility clinics in the United Kingdom (2011–2012) (notes on file with author).

110. See Bonk, *supra* note 91, at 45–49 (considering the potential psychological benefits of living organ donation).

111. See *generally* Grewal et al., *supra* note 14 (providing an example of a case wherein a child received psychological benefits).

serious negative mental and emotional consequences for the savior sibling.¹¹² Many siblings report not only high levels of personal pride, and satisfaction, but also a unique feeling of connection with their sick, older sibling.¹¹³

Despite these sanguine reports, there is reason to have concerns regarding the self-reported experience of savior siblings.¹¹⁴ Self-reported happiness and quality of life studies have a long history of subjectivity, and unreliability.¹¹⁵ Given the novelty of this procedure, there is simply so little primary evidence that we cannot conclude whether the initial evidence is generalizable, or whether it is an outlier.¹¹⁶ Indeed, the absence of evidence showing harm might be meaningless if the data are not robust.¹¹⁷ Furthermore, research design, implicit bias, and researcher agenda can have a tremendous impact on social science research, as can the way in which a question is phrased or the manner the interview is conducted in.¹¹⁸ These concerns ring especially true when interviewing children.¹¹⁹

Given the limited amount of data on the savior sibling experience, it may be helpful to turn to studies of similarly situated individuals.¹²⁰ One such study, performed by MacLeod, Whitsett, Mash, and Pelletier, examined a small number of children who donated stem cells to their sibling via a painful, but not dangerous,

112. See MacLeod et al., *infra* note 120 (describing positive mental and emotional results derived by a savior sibling).

113. See *id.* (explaining that the savior sibling developed a closer relationship with his brother as a result of the experience).

114. See generally David Lipinski & Rosemary Nelson, *The Reactivity and Unreliability of Self-Recording*, 42 J. CONSULTING & CLINICAL PSYCHOL. 118 (1974) (arguing that data collected from self-recording is both reactive and unreliable).

115. See *id.* at 118–19 (summarizing various studies that have addressed the reliability of self-recording).

116. *Id.*

117. *Id.*

118. *Id.*

119. *Id.*

120. See Kendra D. MacLeod et al., *Pediatric Sibling Donors of Successful and Unsuccessful Hematopoietic Stem Cell Transplants (HSCT): A Qualitative Study of Their Psychosocial Experience*, 28 J. PEDIATRIC PSYCHOL. 223 (2003) (examining the psychological impact of pediatric hematopoietic stem cell transplants on sibling donors and emphasizing the effect on donors involved in unsuccessful transplants).

bone marrow biopsy.¹²¹ The study contrasted the effects on the children involved depending on whether the transplant was successful or unsuccessful.¹²²

There is good reason to believe that these data are meaningful for the savior sibling situation, as the process of donation is the same for savior siblings and children who donate biological material but who were not specifically conceived as savior siblings. The study found that children who had donated stem cells in a successful transplant procedure had a generally positive view of the experience.¹²³ The children reported that the process had many positive effects on their lives.¹²⁴ Crucially, investigators noted that negative feelings of anger, guilt, and blame were present amongst donors who participated in unsuccessful transplants, or if the donor child was uninformed about potential medical complications or did not receive adequate support afterwards.¹²⁵ This highlights that donation can be ethically conducted, but should involve honest discussion with the donor. Furthermore, it highlights that savior siblings, like any donor children, will need to have a well-established support network in place at home.¹²⁶

In conclusion, lack of evidence of harm to savior siblings does not mean that harm is not occurring, and further study is essential before we can draw meaningful conclusions. Study design will be key in generating effective, longitudinal data. It will be necessary to assure that the right parties are gathering the evidence, and that appropriate methodologies are employed. Of course, researchers must be careful to ensure that any large scale collection of data is conducted ethically.¹²⁷ Work should be done to

121. *Id.* at 225.

122. *Id.*

123. *See id.* at 227 (“Nearly all sibling donors who participated in a successful HSCT believed their participation had 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.”).

124. *See id.* at 227–28 (providing participants’ remarks regarding the positive impact of a successful HSCT on relationships, views of world, feelings about self and decreased helplessness, and insight into siblings’ illness).

125. *See id.* at 228 (discussing themes amongst those involved in unsuccessful HSCTs, as well as similarities between the unsuccessful and successful groups).

126. *See id.* (explaining that negative psychological effect as a result of HSCT most often occurred when the donor did not have adequate emotional support).

127. *See generally* Ben Berkman et al., *The Ethics of Large Scale Genomic*

de-identify any sensitive information, along with other appropriate steps to ensure privacy and protection of data.¹²⁸ The absence of such data should lead us to be skeptical of claims which argue that evidence should push us one way or the other, in this highly-charged field.

C. Slippery Slope

While current uses of savior siblings are limited, a number of potential troubling ethical issues have been mentioned.¹²⁹ These ethical issues may seem benign when applied to an individual case at this point, but, when taken in aggregate, could pave the road for troubling practices in the future.¹³⁰ Indeed, proponents of “slippery slope” arguments are concerned about discussions regarding savior siblings and the number of ways in which this process could be abused.¹³¹

The general question is whether any use of savior siblings paves the way for the potential utilization of savior children for purposes that society does not find acceptable. This could occur in two distinct ways. The first concern is that, although savior siblings are currently used for less invasive donations, such a process opens up the potential to one day harvest significant biological material, such as organs, limbs, or tissues, which could seriously harm the savior sibling, or lead to a compromised quality of life.¹³² As discussed above, the ethics surrounding savior siblings significantly change if the biological material being harvested will result in a lifetime of differentiated function or care for the

Research, ETHICAL REASONING IN BIG DATA: AN EXPLORATORY ANALYSIS (2015) (discussing the ethical considerations associated with big data in “biomedical research settings”).

128. *Id.*

129. *See generally* Devolder, *supra* note 67.

130. *See id.* (explaining how children do not understand the severe impact and the consequences of making a donation).

131. *See* John A. Robertson et al., *Conception to Obtain Hematopoietic Stem Cells*, 32 HASTINGS CTR. REP. 34, 34–40 (2002) (discussing concerns about the donor child’s rights and welfare).

132. *See* David King, *Why We Should Not Permit Embryos to be Selected as Tissue Donors*, in BIOETHICS: AN ANTHOLOGY 158, 158–61 (Helga Kuhse & Peter Singer eds., 2006) (stating that allowing child donors presents the risk of these children being treated as objects).

savior.¹³³ Indeed, donation of any organ, from a kidney, to an eye, to a lung, would cause a form of permanent harm to the savior child,¹³⁴ and might be wholly unacceptable to our society. While savior siblings are currently primarily used for umbilical cord blood and bone marrow donations, we must keep in mind this potential for abuse, so we can safeguard against more intrusive donations.¹³⁵

The other slippery slope argument questions whether the recipients of the donations will one day change, from sick siblings today to perhaps a parent, elderly family member, or even someone outside the family unit.¹³⁶ The prospect of parents using this mechanism to provide themselves, or other relatives or friends, with biological material, is rightfully troubling, even to the most ardent supporters of the savior sibling model.¹³⁷

Such scenarios raise significant ethical red flags, as this situation would involve harming a new child, solely for the benefit of another individual, who lacks the direct connection with the savior that a sick brother or sister would share. The motivation behind the decision would also be twisted, as this could present a scenario where parents decide to have a savior child to save their own life, or the life of others without an immediate family connection, complicating our notions of parental decision-making and autonomy.¹³⁸

Other objections focus on the notion that IVF and PGD could be used to usher in a new age of eugenics, as advances allow parents to select certain traits and favor select characteristics over

133. See Devolder, *supra* note 67, at 584–85 (discussing how umbilical cord blood harvest and bone marrow donations are accepted procedures but that harvesting vital organs is not).

134. See Lainie Friedman Ross & J. Richard Thistlethwaite, *Minors as Living Solid-Organ Donors*, 122 PEDIATRICS 454, 455–57 (2008) (examining potential psychological, medical, and long-term risks to the child donor).

135. See Devolder, *supra* note 67, at 584 (noting that while umbilical cord blood harvest and bone marrow donations are widely accepted, the harvesting of vital organs is not).

136. See *id.* at 585 (“The second concern of opponents of PGD/HLA typing to create a donor child is whether this technique should be available when the intended recipient is someone other than a sibling.”).

137. See *id.* (discussing a family in the Netherlands, where a father used his daughter’s umbilical cord blood).

138. See generally King, *supra* note 132.

others.¹³⁹ While there is limited evidence at this juncture, given the scientific community's history of problematic utilization,¹⁴⁰ such objections should not be dismissed lightly.¹⁴¹ Recognition of the issues raised in these "slippery slope" arguments should not lead to a ban on the procedure. They instead argue for the importance of creating a robust regulatory framework to guide, and monitor, decision making in this area.

D. Regulation and Decision Making Regarding Savior Siblings

Given the ethical pitfalls discussed above, and the genuine potential for abuse, the question of who gets to make the decision about whether to have a savior sibling is complicated. Such a debate pits traditional arguments of parental rights and autonomy against arguments concerning the welfare of the savior sibling.¹⁴² Ultimately, this leads to the question of whether there is a role for some form of governmental regulation.

There is a long-standing tradition in the Western World of allowing parents be the ultimate arbiter of medical and family planning decisions for their individual family unit.¹⁴³ These ideals clash with arguments about the welfare of the child, if there is a perception that the family is either disregarding a child in a

139. See generally Armand Marie Leroi, *The Future of Neo-Eugenics. Now That Many People Approve the Elimination of Certain Genetically Defective Fetuses, Is Society Closer to Screening All Fetuses for All Known Mutations?*, 7 EMBO REP. 1184, 1184–85 (2006) (arguing that there might be less resistance in the future to more sophisticated methods of eugenic selection).

140. See generally Michael J. Malinowski, *Choosing the Genetic Makeup of Children: Our Eugenics Past-Present, and Future?*, 36 CONN. L. REV. 125, 134–49 (2003) (discussing the origins of eugenics, how the Nazi state used it as a rationalization for selective breeding, sterilization, and human experimentation, and the history of the development of eugenics in the United States).

141. See Hilary White, *Eugenics Threat Growing in IVF Industry: British fertility expert*, LIFESITENEWS (Apr. 8, 2013), <https://www.lifesitenews.com/news/eugenics-threat-growing-in-ivf-industry-british-fertility-expert> (quoting Lord Robert Winston as saying that “[w]e may find that people well want to modify their children, enhance their intelligence, their strength and their beauty and all the other so-called desirable traits”) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

142. See Do Carmo, *supra* note 80 (discussing the tension between a potential savior child's rights and parental rights).

143. *Id.*

harmful way, or making a decision that flies in the face of traditional notions of morality.¹⁴⁴ Both of these fears are present when discussing savior siblings, as not only do many believe that the procedure disregards (and is perhaps, contrary to) the welfare of the savior sibling, but also the process seems to eschew traditional conceptions of family morality and planning.¹⁴⁵ Indeed, rarely are the reasons behind having a second child as transparent and tangible as they are in the case of savior siblings.

Regarding objections concerning the motivation of parents who decide to have a savior sibling, there are a myriad of motives commonly accepted as acceptable for family planning.¹⁴⁶ While they may not be as transparent as the decision to have a savior sibling, they often come with far less genuine good as a result. Parents have children to create an heir, continue a legacy, serve as a playmate for a child, strengthen a relationship (or even save a marriage), or to fulfill another, inherently selfish, desire of the parents.¹⁴⁷ While a variety of these decisions may be frowned upon, there is no suggestion that parenting should be restricted only to those who have a “good reason” to conceive.¹⁴⁸

Contrasting these cases with the decision to create a savior sibling, there is actually a great deal of genuine good that comes in the latter case, as an existing child is able to continue living, and the family unit does not have to suffer the devastating consequences of losing a child.¹⁴⁹ While it is newer, creating a savior sibling may not be a “worse” reason for having a child than our traditionally selfish motives.¹⁵⁰ Furthermore, questioning birth motives could open up Pandora’s Box concerning whether society, or governments, should have a role in deciding which reasons are acceptable for birth, and which are not.

The case of savior siblings is one in which the upmost caution is warranted, making it difficult to argue that there should be no

144. *Id.*

145. *Id.*

146. *See* Devolder, *supra* note 67, at 583–84 (listing the various motivations for having a child).

147. *Id.*

148. *Id.*

149. *See* MacLeod et al., *supra* note 120, at 227 (“[S]aving my brother’s life was a really tight thing . . . [W]e now have closer relations in the family.”).

150. *See generally* Devolder, *supra* note 67, at 584–85.

regulation or oversight of any sort.¹⁵¹ While many might agree that there are certain, limited circumstances where creating a savior sibling is ethically defensible, others point out the genuine potential for abuse in a myriad of avenues.¹⁵² As mentioned above, the ethical calculus for savior siblings changes, depending on factors such as what disease is being treated, what donation is being sought, how many procedures the savior will be subjected to, who is being saved, and other factors.¹⁵³ The answer to these questions might change the ethical acceptability of creating a savior sibling. Leaving this decision to the sole discretion of the parents or a given fertility clinic is problematic. Such a situation could allow disparate outcomes for similarly situated individuals, to say nothing of the potential for harm and abuse for the savior child.

IV. Regulatory Issues in the United States

Many of the ethical concerns detailed above play out in the larger debate over whether, and to what extent, society should seek to regulate the decision-making and issues that arise surrounding the creation of savior siblings.¹⁵⁴ Examining the status of savior siblings in the U.S. reveals that there is little to no governmental regulation, nor are there any robust guidelines, standards, or licensing procedures steering professional organizations that are involved in the creation of savior siblings.¹⁵⁵

151. See Malinowski, *supra* note 140 (analyzing the history of eugenics and discussing its abuses).

152. See generally Leroi, *supra* note 139 (discussing the use of abortion as a eugenic practice).

153. See generally Devolder, *supra* note 67.

154. See Aaron R. Fahrenkrog, *A Comparison of International Regulation of Preimplantation Genetic Diagnosis and A Regulatory Suggestion for the United States*, 15 *TRANSNAT'L L. & CONTEMP. PROBS.* 757, 762–68 (2006) (comparing pre-implantation genetic diagnosis regulation in Germany, the United Kingdom, Japan, and the United States).

155. See *id.* at 768 (“At present, no U.S. jurisdiction has issued legislation or guidelines for the regulation of PGD with the exception of New York.”).

A. Formal and Informal Regulation

There is no governmental regulation or specific legal guidance on the topic of savior siblings in the U.S.¹⁵⁶ Indeed, there are no federal regulations in the U.S. that deal explicitly with the use of PGD.¹⁵⁷ Because of this, uses of PGD, such as the creation of a savior sibling, are currently left to the discretion of providers and patients.¹⁵⁸

This lack of regulation avoids governmental interference in personal choices related to birth, ultimately enabling the scientific community to continue without guidance or oversight. Scholars describe this scheme of regulation as “voluntary certification.”¹⁵⁹ While the CDC developed a model certification template program for assisted reproduction clinics and laboratories¹⁶⁰ in accordance with the Fertility Clinic Success Rate and Certification Act of 1992 (Fertility Act),¹⁶¹ discretion was left to individual states as to whether or not they implement the scheme.¹⁶² Partially due to this flexibility, no state has fully adopted the model program, and scholars maintain that the sector has been mostly left to self-police.¹⁶³ The guidance does not consider savior children.

Indeed, the only governmental action that may be described as “regulation” is the ban on federal funding for embryo-related research.¹⁶⁴ Funding is currently only approved for research conducted on cells derived from embryos less than two weeks old,

156. *Id.*

157. *Id.*

158. *Id.*

159. *See* Malinowski, *supra* note 140, at 182 (“The United States federal regulatory scheme for ART clinics can be summarized as voluntary certification.”).

160. Implementation of the Fertility Clinic Success Rate and Certification Act of 1992-A Model Program for the Certification of Embryo Laboratories, 64 Fed. Reg. 39374 (July 21, 1999).

161. Fertility Clinic Success Rate and Certification Act of 1992, Pub. L. No. 102-493, 106 Stat. 3146 (codified at 42 U.S.C. § 201 (1992)).

162. Malinowski, *supra* note 140, at 182.

163. *See id.* (“No state has fully adopted the model program, and the CDC has contractually outsourced implementation to SART, meaning that the sector has been left to self-police.”).

164. *See id.* at 183–84 (“As a clinical service, ART escapes the FDA’s product groupings, and the federal government has long abstained from funding embryonic research—thereby further castigating ART to the private sector.”).

that are left over from infertility treatment, have been frozen and would otherwise be destroyed, or cells derived from frozen embryos without destroying the embryos.¹⁶⁵ As a result, this means that the U.S. government does not play a significant role in the process and regulation of IVF, PGD, or decisions regarding savior siblings.¹⁶⁶

While there is no formal government funding, the government does have a part to play in the complex cycle of assisted reproduction clinics and therapies.¹⁶⁷ For instance, the Center for Medicare and Medicaid Services (CMS) governs the quality of laboratories and laboratory personnel.¹⁶⁸ The Food and Drug Administration (FDA) generally regulates genetic tests for analytical and clinical validity.¹⁶⁹ These regulatory bodies do not have specific guidance regarding savior siblings.¹⁷⁰

165. See Comm. on Pediatric Research & Comm. on Bioethics, *Human Embryo Research*, 108 AAP NEWS & J. 813, 814, <http://pediatrics.aappublications.org/content/108/3/813> (last updated Nov. 1, 2001) (“Some individuals who go through the process of in vitro fertilization (potential donors) choose not to undergo additional embryo transfers and do not wish to have their embryos donated to other individuals. Such individuals or donors may be willing to donate their embryos for research.”) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

166. See Meena Lal, *The Role of the Federal Government in Assisted Reproductive Technologies*, 13 SANTA CLARA HIGH TECH. L. J. 517, 534 (1997) (“[T]he ACT fails to protect the interested parties of IVF because the Secretary does not have any power to establish any regulation, standard, or requirement that has the effect of exercising supervision or control over the practice of medicine in assisted reproductive technology programs.”).

167. Gutman, *infra* note 169. See generally *Clinical Laboratory Improvement Amendments (CLIA)*, CTR. FOR MEDICARE & MEDICAID SERV. [hereinafter *Clinical Laboratory*], <https://www.cms.gov/Regulations-and-Guidance/Legislation/CLIA/index.html?redirect=/Clia> (last updated Apr. 5, 2017) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

168. See generally *Clinical Laboratory*, *supra* note 167.

169. See Steven Gutman, *The Role of Food and Drug Administration Regulation of In Vitro Diagnostic Devices—Application to Genetics Testing*, CLINICAL CHEMISTRY (May 1999), <http://clinchem.aaccjnls.org/content/45/5/746> (“[G]enetic tests are received and reviewed by the FDA.”) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

170. See Michelle J. Bayefsky, *Comparative Preimplantation Genetic Diagnosis Policy in Europe and the USA and its Implications for Reproductive Tourism*, 3 REPROD. BIOMEDICINE & SOC’Y ONLINE 41, 41 (2016), [http://www.rbmsociety.com/article/S2405-6618\(17\)30004-7/pdf](http://www.rbmsociety.com/article/S2405-6618(17)30004-7/pdf) (“[T]he USA has no regulations concerning the use of preimplantation genetic diagnosis . . . a technique employed . . . for a variety of controversial purposes, including . . . [the] selection [of] ‘saviour siblings’ who can serve as tissue donors for sick relatives.”)

The lack of formal funding, and governmental regulation, has several consequences. First, disallowing funding restricts the gathering of data and information regarding the use and prevalence of savior siblings.¹⁷¹ The absence of monitoring means that any harm that could be happening to savior children may currently go unreported, as there is no system in place to follow-up on savior families, or chart their long term emotional and physical health.¹⁷² Furthermore, not having formal regulation results in increased authority for clinics performing PGD to make their own decisions on the moral and ethical issues discussed above.¹⁷³ Because each clinic is able to make their own policies, similarly situated individuals in different locations may have vastly different options available to them.

B. Professional Guidelines

Given the absence of regulatory schema in the U.S., professional guidelines, issued by organizations that might be expected to consider the status and welfare of savior siblings, can reveal expert opinion and professional attitudes. While professional guidelines can give a glimpse into informal rules and regulations that may influence opinion amongst those who are informed of the risks and benefits, review of current guidelines reveal a serious lack of consideration regarding savior siblings as a whole.¹⁷⁴

(on file with Washington & Lee Journal of Civil Rights & Social Justice).

171. See R.M.L. Winston, *Does Government Regulation Inhibit Embryonic Stem Cell Research and Can It Be Effective?*, 1 CELL STEM CELL 27, 31–32 (2007) <https://www.sciencedirect.com/science/article/pii/S1934590907000124>

(“[F]inancing this work by private initiatives or commercial interests raises substantial concerns.”) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

172. *Id.*

173. See *id.* at 32. (“Thirdly, there is anxiety that, with commercial pressure, clinical translation of basic science work could be undertaken too soon and without adequate safeguards.”).

174. Ilan Tur-Kaspa & Roohi Jeelani, *Clinical Guidelines for IVF with PGD for HLA Matching*, 30 REPROD. BIOMEDICINE ONLINE 115, 118 (2015), [http://www.rbmojournal.com/article/S14726483\(14\)00582-3/pdf](http://www.rbmojournal.com/article/S14726483(14)00582-3/pdf) (“[I]n many IVF centers, no set guidelines have been established, and most healthcare providers are still unaware of such options or how to introduce them to patients.”) (on file with the

Groups like the American Society for Reproductive Medicine, American Congress of Obstetricians and Gynecologists, and American College of Medical Genetics, which create guidelines concerning IVF, PGD and other aspects of reproductive medicine offer little of relevance.¹⁷⁵ Their guidelines do not take strong stances on contested ethical topics. Crucially, these organizations have yet to take an official stance on savior siblings, and, as a result, their guidance documents do not address savior siblings in a robust way.

A non-medical organization that might offer insight is the Council on Ethical and Judicial Affairs (CEJA).¹⁷⁶ While the CEJA discusses organ donation in general, its analysis concerning “un-emancipated minors and legally incompetent adults” donating organs can apply to savior siblings.¹⁷⁷ The CEJA determined that even though these populations should normally not be considered as possible organ donors, minors who are capable of understanding may be considered, provided that they share an emotional

Washington & Lee Journal of Civil Rights & Social Justice).

175. See *Preimplantation Genetic Diagnosis: A Discussion of Challenges, Concerns, and Preliminary Policy Options Related to the Genetic Testing of Human Embryos*, GENETICS & PUB. POL’Y CTR. (2004), <https://jscholarship.library.jhu.edu/bitstream/handle/1774.2/978/PGDDiscussionChallengesConcerns.pdf?sequence=1&isAllowed=y> (“Professional guidelines are traditionally voluntary, although they sometimes are viewed as the standard of care. Guidelines are more useful when some enforcement mechanism is contemplated.”) (on file with the Washington & Lee Journal of Civil Rights & Social Justice); see generally Michelle J. Bayefsky, *Comparative Preimplantation Genetic Diagnosis Policy in Europe and the USA and its Implications for Reproductive Tourism*, 3 REPROD. BIOMEDICINE & SOC’Y ONLINE 41, 41–47 (Dec. 2016), <https://www.sciencedirect.com/science/article/pii/S2405661817300047> (discussing the lack of oversight and regulation in the United States in comparison to Europe and the consequences that could result from continued lack of regulation) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

176. See generally *About the Council on Ethical & Judicial Affairs (CEJA)*, AM. MED. ASS’N, <https://www.ama-assn.org/about-us/about-council-ethical-judicial-affairs-ceja> (last visited Apr. 17, 2018) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

177. JOHN W. MCMAHON, NONSIMULTANEOUS, ALTRUISTIC ORGAN DONATION: CEJA Report 6-I-10, at 5 (2010), <https://www.ama-assn.org/sites/default/files/media-browser/public/aboutama/councils/Council%20Reports/council-on-ethics-and-judicial-affairs/i10-ceja-nonsimultaneous-altruistic-organ-donation.pdf> (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

connection with the recipient, and have the consent of their guardian.¹⁷⁸

In addition to the minor having cognitive capability, the CEJA points out that because the parent or guardian providing informed consent is emotionally attached to the recipient, precautions, such as obtaining a second opinion from an independent ethics committee, should be taken.¹⁷⁹ The CEJA further states that living organ donors should consult independent physicians, who are able to make decisions reflecting their best interests.¹⁸⁰ An independent doctor is especially important in the case of a savior sibling, in order to help ensure that the child is adequately prepared for what is to come.¹⁸¹ Such planning will affect how the donor perceives their situation, both before and after a procedure. Unfortunately, it does not seem like current mechanisms are in place to ensure that these criteria are met, before a savior sibling donates biological material.

V. Savior Siblings in the United Kingdom

The lack of regulation in the U.S. stands in stark contrast to regulatory schemes found in other countries, in particular the United Kingdom. In the UK, the government regulates PGD by requiring a clinic to obtain a license before they can perform the procedures that create a savior sibling.¹⁸² This is not surprising,

178. *See id.* at 5 (“[M]inors with substantial decision making capability who agree to serve as donors, with the informed consent of their legal guardians, may be considered for donation to recipients with whom they are emotionally connected.”).

179. *See id.* (“Since minors’ guardians may be emotionally connected to the organ recipient, when an unemancipated minor agrees to donate, it may be appropriate to seek advice from another adult trusted by the minor or an independent body, such as consultation with an ethics committee, pastoral service, or other counseling resource.”).

180. *See id.* at 4 (“[E]very donor should be assigned an advocate team that includes a physician . . . this team ideally should be as independent as possible from those caring for the recipient. This can help avoid actual or perceived conflicts of interest between donors and recipients.”).

181. *See id.* (“[T]his team ideally should be as independent as possible from those caring for the recipient. This can help avoid actual or perceived conflicts of interest between donors and recipients.”).

182. *See* Bayeski, *supra* note 170 (“License committees determine whether new conditions qualify as appropriate medical uses of PGD after reviewing an

given that the UK has a long history of governmental regulation of the medical field.¹⁸³ This results in significant government involvement in many aspects of medical technology, and medical decision-making. As a result, UK regulators have considered the position of savior siblings for some time now.¹⁸⁴

In the UK, PGD is regulated by the Human Fertilization and Embryology Act (HFEA).¹⁸⁵ This Act¹⁸⁶ was enacted in 1990, and allows for PGD to be performed in order to test for severe genetic diseases and perform tissue type matching for savior siblings under strict criteria.¹⁸⁷ PGD is allowed for medical purposes only.¹⁸⁸ To determine whether PGD may be allowed, the government provides a list of criteria. These include that:

- (1) the condition of the affected child should be severe or life-threatening, of a sufficient seriousness to justify the use of PGD;
- (2) the embryos conceived in the course of this treatment should themselves be at risk from the condition by which the existing child is affected;
- (3) all other possibilities of treatment and sources of tissue for the

application submitted by a fertility clinic on behalf of a patient.”).

183. See John H. Raach, *English Medical Licensing in the Early Seventeenth Century*, 16 *YALE J. BIOL. MED.* 267, 270 (1944) (“In the early years of the reign of Henry VIII, two statutes were passed which had a profound effect on English medicine and its control for more than three centuries. The first of these statutes [was] passed in 1511.”).

184. See MacKenna Roberts, *UK Parliament Legislates ‘Saviour Sibling’ Treatment*, *BIONEW* (May 27, 2008), http://www.bionews.org.uk/page_13399.asp (“UK regulation of ‘saviour siblings’ has a conflicted record since the first UK application in 2001.”) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

185. 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, 987 (2006) (“[T]he HFEA . . . review[s] both the issue of using PGD and the additional step of tissue typing to determine if an embryo has tissue compatible with an existing sibling.”).

186. Human Fertilisation and Embryology Act 1990, c. 37 (Eng.).

187. See Gitter, *supra* note 185, at 989 (“[T]he HFEA also agreed . . . to permit PGD with tissue typing.”).

188. See *Clinical Commissioning Policy: Pre-implantation Genetic Diagnosis*, NHS COMMISSIONING BOARD (Apr. 2013), <https://www.england.nhs.uk/wp-content/uploads/2013/04/e01-p-a.pdf> (“The following uses of the PGD technology are excluded from this policy: Non medical gender selection e.g. for the purpose of family balancing. This is illegal in the United Kingdom.”) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

affected child should have been explored; (4) the techniques should not be available where the intended recipient is a parent; (5) the intention should be to take only cord blood for the purposes of treatment, and not other tissues or organs; (6) appropriate implications counseling should be a requirement for couples undergoing this type of treatment; (7) families should be encouraged to participate in follow-up studies and, as with PGD, clinics should provide detailed information about treatment cycles and their outcomes.¹⁸⁹

In 2004, fertility regulators in a specialized court ruled that the HFEA allows parents to use modern reproductive techniques to create a savior sibling.¹⁹⁰ The existence of this regulation is particularly significant. Indeed, there is tremendous difficulty in creating regulation of any topic that is as charged and controversial as birth.¹⁹¹ The UK tackled this problem by basing this decision on the product of close consultations between various groups of stakeholders.¹⁹² Discussions with fertility clinics and bioethicists in the UK, reveal that, when initially considering policy regarding savior siblings, lawyers, ethicists, scientists, sociologists, religious leaders, and law makers, were consulted.¹⁹³ These diverse stakeholders devised commonsense policy on a controversial topic, which ended up being acceptable to a broad

189. *HFEA Confirms That HLA Tissue Typing May Only Take Place When PGD is Required to Avoid a Serious Genetic Disorder*, HUM. FERTILISATION & EMBRYOLOGY AUTHORITY (Aug. 1, 2002), <http://hfearchive.uksouth.cloudapp.azure.com/www.hfea.gov.uk/935.html> (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

190. See Andy Coghlan, *Saviour Sibling Babies Get Green Light*, DAILY NEWS (July 22, 2004), <https://www.newscientist.com/article/dn6195-saviour-sibling-babies-get-green-light/> (“Fertility regulators in the UK have ruled that families can pre-select embryos which could potentially save ill siblings.”) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

191. See “*Medicine Babies*” or *Savior Siblings Ethical Debate*, KENNEDY INST. ETHICS, <https://bioethics.georgetown.edu/2016/05/medicine-babies-or-saviour-siblings-ethical-debate/> (last visited on Apr. 23, 2018) (highlighting the controversies associated in the savior sibling debate) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

192. Telephone Interviews by Zachary Shapiro with IVF Clinics in London, Manchester, and Essex (2011–2012) (notes on file with author); Telephone Interviews by Zachary Shapiro with Fertility Regulators and Lawyers in the UK involved in the creation of regulations concerning savior siblings (2011–2012) [hereinafter Telephone Interviews].

193. *Id.*

swath of the population.¹⁹⁴ This allowed lay people to feel that the government was appropriately balancing the welfare of children (both saviors and sick siblings), as well as the values of parental autonomy and choice.¹⁹⁵ Those interviewed suggested that the interdisciplinary nature of the committees was a major factor that allowed regulation to be promulgated, even when no national consensus existed.¹⁹⁶

To give the regulation teeth, the HFEA provides for enforcement of these rules by requiring clinics to apply for a new license for every new genetic disease that they would like to test an embryo for.¹⁹⁷ This not only allows regulators to monitor clinics that perform IVF,¹⁹⁸ but also enables regulation of embryo-centered research and PGD.¹⁹⁹ The law is given force by attaching criminal liability to any person who knowingly or recklessly provides false or misleading information to obtain a license.²⁰⁰ Punishments for such violations of the Act range from a fine to imprisonment for up to two years.²⁰¹

Such regulation provides clear guidelines while making it easier to study, and control, the use of savior siblings.²⁰² It also

194. *Id.*

195. *Id.*

196. *Id.*

197. See Alicia Ouellette et al., *Lessons Across the Pond: Assisted Reproductive Technology in the United Kingdom and the United States*, 31 AM. J. L. & MED. 419, 428 (2005) (“Section 1 of Schedule 2 specifies that clinics require a license to create embryos in vitro, store embryos, use human gametes, test embryos before implantation, implant embryos in a woman, test sperm viability, or conduct research on human embryos or gametes.”).

198. See Human Fertilisation & Embryology Authority, *Fact Sheet 2: About the HFEA*, http://hfearchive.uksouth.cloudapp.azure.com/www.hfea.gov.uk/docs/ToftFactSheet2_AboutHFEA.pdf (last visited on Apr. 5, 2018) (providing a basic summary of the Human Fertilisation & Embryology Act and outlining its framework for decision making) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

199. See generally *id.* (explaining how FHEA facilitates further embryo research).

200. Human Fertilisation and Embryology Act 1990, c. 37, § 3 (Eng.).

201. *Id.* at § 41(3).

202. Zachary E. Shapiro, *Savior Siblings in the United States*, HARV. L. BILL OF HEALTH (Oct. 23, 2014), <http://blogs.harvard.edu/billofhealth/2014/10/23/savior-siblings-in-the-united-states/> (advocating further discussion of savior siblings and the need for regulation) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

raises difficult questions about the role of governments in the birthing and family decisions of their citizens. While there exists genuine dispute as to whether it is fair to leave such important and contested questions in the hands of legislators and regulators, especially when there are no clear or universally accepted answers regarding these difficult questions, the interdisciplinary approach to creating the regulation helped build public approval.

VI. *Conclusions and Recommendations*

The close regulation of savior siblings in the UK offers a stark contrast to the situation in the U.S.²⁰³ In the U.S., the relative novelty of the procedure, its rarity, the lack of governmental consideration and regulation, and the divergence in opinions regarding the fundamental ethical questions that surround it, help explain why the issue of savior siblings has remained largely in the shadows, unexamined by the government, or the public at large.²⁰⁴ Despite this general disregard, certain commonsense steps could be taken to better understand and deal with the unique ethical dilemmas surrounding savior siblings.

A. *The U.S. Can Learn from the Regulatory Framework in the UK*

The UK has demonstrated that meaningful regulation regarding savior siblings is possible, without restricting other values, such as parental and familial autonomy and dignity, even in a diverse, pluralistic society, where individuals may not agree with each other.²⁰⁵ The U.S. should learn from this example, and seek to emulate it, to the extent feasible. As discussed, the need for regulation in the U.S. is pressing, given that important ethical decisions regarding savior siblings are currently left to the

203. *See id.* (“This stands in stark contrast to other countries, particularly England, France, and Australia, where a regulatory framework for the use of savior siblings has arisen along with debate over their acceptability.”).

204. *See id.* (“There has been little meaningful discussion about savior siblings in bioethical or legal circles, and there is no formal regulation governing their use or creation in the United States.”).

205. *See* Roberts, *supra* note 184 (explaining how UK’s legislation treats savior siblings).

discretion of individual parents and health care providers.²⁰⁶ Indeed, given the lack of regulation in the U.S., the only true barrier for access is the policies of the particular clinic selected. This means that adequately resourced parents are able to select clinics that allow whatever procedures they desire.²⁰⁷

The absence of regulation in the U.S. creates a number of particularly problematic scenarios for savior siblings. First, it allows potential harm to savior siblings, by not requiring that savior children are only utilized in specific scenarios.²⁰⁸ Without regulation, it is possible that savors will be utilized for some of the more problematic scenarios discussed above, such as for more invasive donations, or to serve as donors to non-immediate family members. Second, in the absence of regulation, it is difficult to monitor the long-term outcomes for savior children, to ensure that they are respected and cared for, and do not face lifetime burdens due to their biology or status. Indeed, savior children issues can go unnoticed, as there is no central monitoring system. Even the most ardent defenders of a free-market system can understand the desire for some form of regulation, in order to protect the welfare of these children, who are especially vulnerable.

Governmental regulation, informed by legislative guidance, is therefore necessary, both to develop workable policy, and to identify, document, and ameliorate current harms. While courts have certain checks on these outcomes, the need for a parent (or child) to bring an actual suit, as well as the uncertainty and subjectivity inherent in the current judicial standards, mean that courts are not an ideal mechanism to regulate this kind of practice. The lack of regulation also creates a situation where, given the

206. See Fahrenkrog, *supra* notes 154–158 and accompanying text (exploring the lack of regulation in the U.S. and the issues that arise as a result of it).

207. See James F. Smith, *Socioeconomic Disparities in the Use and Success of Fertility Treatments: Analysis of Data from a Prospective Cohort in the United States*, 96 FERTILITY & STERILITY 95, 99–100 (July 2011), [http://www.fertstert.org/article/S0015-0282\(11\)00667-4/pdf](http://www.fertstert.org/article/S0015-0282(11)00667-4/pdf) (studying how income effects the availability and success rates of fertility services) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

208. See Maura Dickey, *Who Will Save the Savior Siblings?*, HUFFPOST (May 15, 2015), https://www.huffingtonpost.com/maura-dickey/who-will-save-the-savior-_b_7276688.html (explaining that without further regulation, savior siblings could be used in an ethically questionable manner) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

great variety of state law and cultural attitudes towards a practice like savior siblings, similarly situated individuals in different geographic contexts may have vastly different outcomes and access.²⁰⁹ Indigent individuals in states with few IVF clinics may find themselves unable to undertake desired procedures, because they cannot access clinics with policies that permit the creation of savior children.²¹⁰ This creates harm if those individuals have children suffering rare genetic diseases, where a savior sibling may be the only viable option.²¹¹ Conversely, rich individuals are able to “shop around” skirting any local clinic policy by traveling to whichever clinic is willing to perform the desired procedure.²¹²

This is not to say that there will not be challenges. The lack of direct governmental involvement in healthcare, and IVF, will make it difficult for the government to begin the arduous task of carving out a regulatory space. The question of whether any potential regulation should be left to individual States will be a difficult one and is beyond the scope of this Article. Additionally, it will be difficult to truly ascertain parental motive in many instances of assisted reproduction, as parents could easily obscure the true motive behind seeking IVF and PGD, to skirt any formal regulation regarding savior children.

Current lack of consensus on the controversial issues related to birth and pediatric donation significantly complicates any national push on this issue.²¹³ Given the general political gridlock and the specific divisiveness of issues associated with reproduction, it is difficult to imagine politicians working together to put forth a truly bi-partisan regulatory scheme. As the UK has

209. See Alexandra Sifferlin, *Millions of Women Don't Have Access to Fertility Treatments in the U.S.*, TIME (Mar. 14, 2017), <http://time.com/4701023/fertility-treatments-ivf/> (explaining that forty percent of women in the United States do not have access to certain fertility treatments) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

210. See generally *Smith*, supra note 207.

211. See generally *id.*

212. See *id.* at 99 (“In the present study, higher income and college-educated women were much more likely to choose more expensive treatment path-ways.”).

213. See generally *Democrats, Republicans Offer Competing Birth Control Bills*, CBSNEWS (June 9, 2015), <https://www.cbsnews.com/news/democrats-republicans-offer-competing-birth-control-bills/> (illustrating the current lack of consensus between the two political parties regarding birth control) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

demonstrated, it is essential that any regulation reflect the input of many diverse stakeholders (from doctors, to bioethicists, to lawyers, to disability rights advocates, to clergy, to sociologists) to ensure that the broad range of views on this issue are addressed and respected.²¹⁴ While no regulatory framework will please everyone, this should not be the goal, especially for a novel procedure where cultural and scientific attitudes are still evolving. However, by consulting interdisciplinary stakeholders from a variety of political and religious affiliations regulators can put forth the best possible plan, for the unique situation in the U.S.

B. Research

Efforts to advance a discussion on savior siblings are hampered by the lack of robust data on this issue. We do not know what the true effects, if any, are of the decision to have a savior sibling on the ill child, the savior sibling, or the family dynamic. To properly consider this dilemma, researchers must focus on these questions and begin to gather data regarding savior siblings.²¹⁵ Such research must examine both longitudinal psychological and physical effects so that we can get the full picture of what it is to be a savior sibling. Researchers must develop a multi-factorial approach to examining the status of savior siblings. This will involve studying families prior to initiation of the process, so we can better understand what factors into the decision to have a savior sibling. Research should continue, not just throughout the donation process, but also in a longitudinal manner to investigate whether there are long-term complications or effects from being a savior sibling. Data must be gathered, so the fears discussed above can be confirmed, or disproved. Of course, ethical concerns arise when gathering large sets of data, especially if the data reveals potentially sensitive health information, or puts individuals at risk for harm.²¹⁶ However, I am confident that, with proper planning

214. Telephone Interviews, *supra* note 192.

215. Susan M. Wolf et al., *Using Preimplantation Genetic Diagnosis to Create a Stem Cell Donor: Issues, Guidelines & Limits*, 31 J.L. MED. & ETHICS 327, 331–32 (2003).

216. See generally Ben Berkman et al., *supra* note 127.

and consideration, research into savior siblings can be designed and conducted in an ethical manor.

Because this is a rare situation and not many savior siblings currently exist or are created annually, it will take a long time to generate statistically valid results. Although the population size places a burden on getting useful information, it is likely that the demand for this procedure will only increase in coming years. As demand grows, there will be increased attention paid to savior siblings, which will allow more robust research. Since no one institution is likely to have significant numbers of subjects, cooperative inter-institutional (or NIH) databases will be important for data collection. Such efforts will ultimately provide insight into ethical qualms that are currently theoretical.

C. Cord Banking

Umbilical cord blood has a very high concentration of hematopoietic stem cells, which, as discussed above, can be extremely helpful in fighting a wide range of conditions.²¹⁷ Most savior siblings are initially conceived to provide the life-saving cells that come from umbilical cord blood and tissue.²¹⁸ If cord blood were more readily available, it would not be as necessary for parents to create a savior sibling. If an appropriate match is available, using banked cord blood could be preferable to creating savior siblings, given the difficulty, cost, and time requirements of the procedure. Expanding the availability of cord blood could create an option for families who can't afford (financially, emotionally or due to the urgency of their sick child's condition) to go through the savior sibling process. Thus, there are numerous clear benefits to cord blood banking.

Cord blood banks function similarly to regular blood banks, but they are specifically for umbilical cord blood.²¹⁹ The blood is

217. *Hematopoietic Stem Cells*, NAT'L INSTITUTES HEALTH (June 17, 2001), <https://stemcells.nih.gov/info/2001report/chapter5.htm> (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

218. Renece Waller-Wise, *Umbilical Cord Blood: Information for Childbirth Educators*, U.S. NAT'L LIB. MEDICINE (2011), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3209739/> (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

219. *Id.*

collected by a doctor following certain protocols and is then sent to a bank where it is typed, tested, and stored for future use.²²⁰ This information is stored, so that those in need of stem cells can be connected with HLA matched donors.²²¹

There are currently two options for cord blood banking: public or private.²²² Public banks are free, regulated by the FDA, and the blood is HLA typed upon arrival.²²³ This allows quick action whenever there is a request, and allows the blood to be available for anyone to access.²²⁴ Private cord blood banks in contrast, can be quite expensive, as parents pay an initial fee and a yearly charge for storage.²²⁵ This service means that the blood is only available for the family who banked it. Any cord blood from a child who is eventually diagnosed with a genetic disease, inborn error of metabolism, or leukemia, will not be useful in treating that child, because the necessary cells will have the same mutation.²²⁶

Both public and private banking come with the benefit of enabling significant research, on the nature of umbilical cords, and the hematopoietic stem cells they contain. In order for cord blood

220. See *Cord Blood Banking for Potential Future Transplantation*, 119 PEDIATRICS 166, 167 (Jan. 2007), <http://pediatrics.aappublications.org/content/pediatrics/119/1/165.full.pdf> (explaining the procedure associated with cord blood banking and collection) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

221. *Id.*

222. Comm. on Genetics and Comm. on Obstetric Practice, *Committee Opinion No. 648: Umbilical Cord Blood Banking*, AM. C. OBSTETRICIANS & GYNECOLOGISTS (Dec. 2015), <https://www.acog.org/-/media/Committee-Opinions/Committee-on-Genetics/co648.pdf?dmc=1&ts=20180130T1703512685> (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

223. See generally Merlin G. Butler & Jay E. Menitove, *Umbilical Cord Blood Banking: An Update*, 28 J. ASSISTED REPROD. & GENETICS 669 (2011), <https://link.springer.com/article/10.1007/s10815-011-9577-x> (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

224. See *Umbilical Cord Blood Banking*, TEX. MED. ASS'N (Mar. 26, 2014), <https://www.texmed.org/Template.aspx?id=30321> (discussing advantages of donating to a public cord blood bank) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

225. See R. Morgan Griffin, *Banking Your Baby's Cord Blood: The Pros and Cons, Costs, and Reasons Behind Saving your Newborn's Umbilical Cord Blood*, WEBMD, <http://www.webmd.com/parenting/baby/features/banking-your-babys-cord-blood> (last visited on Apr. 17, 2018) (listing the three types of cord blood banks and explaining that the private option is the most expensive) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

226. *Id.*

banking to offer a viable option as an approach to genetic diseases, many people with diverse HLA types must donate. Given that this current bounty is unrealized, it is understandable why twenty states have passed laws that support a policy requiring physicians to provide information to expecting parents regarding cord blood options with different provisions.²²⁷

Increased cord banking can be accomplished while respecting the rights and autonomy of the parents who decide to donate. One step is requiring the primary physician of expectant parents to discuss the available options for banking of cord blood before the third trimester of pregnancy. Requiring the information be given prior to the third trimester acts a precaution, while giving parents time to consider the reasons why it makes sense to bank their cord blood. It is important to give parents time to make an informed decision regarding the practice before the birth of their child. If the practice of banking cord blood becomes common, the availability of cord blood for fighting future illnesses and research will greatly increase and could reduce the need for savior siblings.

Cord blood banking is a particularly powerful tool, as currently, most umbilical cords are simply discarded.²²⁸ This means the medical community is throwing away a potentially powerful tool in the battle against many rare diseases and conditions. Furthermore, hematopoietic stem cells are free from the contentious debate surrounding other forms of stem cells, because they are harvested with no harm to any living person, embryo, or fetus.

D. New Technological Advances

As medicine and medical technology advances, the hope is that living donors will become less important. The best option for this

227. See *US Regulations*, PARENT'S GUIDE TO CORD BLOOD FOUND., <https://parentsguidecordblood.org/en/regulations> (last visited on Apr. 17, 2018) (providing an overview of the states that have passed legislation encouraging physicians to provide expecting parents information on the value and options regarding cord blood, such as cord blood banking) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

228. See *Donating Umbilical Cord Blood to a Public Bank*, *supra* note 97 (“After your baby is born, the umbilical cord and placenta are usually thrown away.”).

is through research leading to the discovery of more advanced therapeutics. New treatments that target and treat the underlying condition are always preferable to utilizing a living donor.

Other future directions are more fraught with potential ethical and legal implications. Expanding our understanding and utilization of stem cell therapies could be another way to cure debilitating conditions, which presently require transplantation.²²⁹ Other potential future approaches include the development of technologies like 3D Organ Printing,²³⁰ mechanical organs,²³¹ or the use of cross species transplantation.²³² Potentially, advances in human cloning could allow scientists to replicate unique biological material, entirely without the need for any individual, other than the sick person, to serve as a donor. Although these possibilities raise significant ethical issues in their own right, they could make the need for a savior sibling obsolete.

E. Final Thoughts

Few topics raise as many ethical concerns as does the debate over the acceptability of savior siblings. Indeed, the issue of savior

229. Robert Sparrow & David Cram, *Saviour Embryos? Preimplantation Genetic Diagnosis as a Therapeutic Technology*, 20 REPROD. BIOMEDICINE ONLINE 667, 667–68 (2010), [http://www.rbmojournal.com/article/S1472-6483\(09\)00292-2/pdf](http://www.rbmojournal.com/article/S1472-6483(09)00292-2/pdf) (explaining that new advances in stem cell research have expanded to embryonic stem cells) (on file with the Washington & Lee Journal of Civil Rights & Social Justice); see generally Kazutoshi Takahashi et al., *Induction of Pluripotent Stem Cells from Adult Human Fibroblasts by Defined Factors*, 131 CELL 861–72 (2007), [http://www.cell.com/cell/pdf/S0092-8674\(07\)01471-7.pdf](http://www.cell.com/cell/pdf/S0092-8674(07)01471-7.pdf) (discussing the potential uses of pluripotent stem cells) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

230. Tim Lewis, *Could 3D Printing Solve the Organ Transplant Shortage?*, GUARDIAN (July 30, 2017), <https://www.theguardian.com/technology/2017/jul/30/will-3d-printing-solve-the-organ-transplant-shortage> (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

231. Matthew Shaer, *Soon, Your Doctor Could Print a Human Organ on Demand*, SMITHSONIAN MAG. (May 2015), <https://www.smithsonianmag.com/innovation/soon-doctor-print-human-organ-on-demand-180954951/> (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

232. See generally David K. C. Cooper, *A Brief History of Cross-Species Organ Transplantation*, 25 BAYLOR U. MED. CTR. PROC. 49 (2012), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3246856/pdf/bumc0025-0049.pdf> (explaining the history of cross-species implantation) (on file with the Washington & Lee Journal of Civil Rights & Social Justice).

siblings seems to be an almost perfect storm, where values of autonomy, consent, familial rights, and medical technology, intersect in uncertain, and potentially problematic, ways.

It is important to remember that, in most cases, savior siblings allow a sick child to extend their life, free from illness. This has untold positive consequences, not just for the child, but for the whole family unit. When considering the ethical conundrums, the saving of a child's life must be given weight in any ethical analysis. Of course, we cannot turn a blind eye towards the potential for abuse, or the ease with which this procedure could be misused, to rapidly move in a direction that society is not comfortable with, ethically or practically.

While the field has moved forward in the U.S. without any guidance or regulation, the example of the UK shows that a regulatory scheme is possible, and can succeed,²³³ even in a society where the underlying issues are still contested. Such regulation does not mean that progress will be halted, or that science and autonomy will be irrevocably restricted. Rather, commonsense regulation allows the genuine good to proceed, while protecting children, and ensuring, to the greatest extent possible, that undue harm is not occurring.

While the aim of this Article is not to develop specific regulatory recommendations, a few elements stand out as essential to any meaningful effort to allay concerns that the issue of savior siblings will quickly devolve into unethical directions. First, it makes fundamental sense to limit savior siblings' donations to biological material short of organs. Indeed, the issues of consent, harm, and autonomy, caution against allowing any child to serve as an organ donor at a very young age, unless they can persuasively demonstrate an understanding of the procedure. Second, restricting savior child donation to immediate family members can help address fears that families might make improper decisions regarding who can be "saved" by a savior child. Third, in order to ensure compliance, IVF clinics should report to a monitoring body, with a special filing for families who want to conceive, or are likely candidates to have, a savior child. This will help ensure that uses can be documented, and that data can be collected.

233. Telephone Interviews, *supra* note 192.

While these are preliminary suggestions, guidelines such as these, if adopted, monitored, and enforced, can prevent the situation from advancing in a more troubling direction. Furthermore, regulatory efforts will begin to standardize care and practice availability, so that different clinics do not offer wildly different options to similarly situated individuals. Guidelines will also allow uniform data to be gathered, permitting meaningful assessment of savior siblings in the United States.

There is no question that savior siblings touch on a wide range of difficult topics, from cultural and social attitudes about sickness, birth, and family, to deeply held beliefs about medical technology, the role of family, and tissue donation. Silence on the matter will not lead to resolution. Efforts such as those discussed above, can begin to change the situation of savior siblings in the United States, so that the field can ethically proceed in a manner that respects and protects savior siblings and their families.