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SAVIOR SIBLINGS, PROTECTIVE PROGENY, AND PARENTAL
DETERMINISM IN THE AGE OF CRISPR-CAS

BARBARA PFEFFER BILLAUER JD MA PHD*

Now Israel loved Joseph more than all his children, because he was the son of his old age; and he made for him [a brother with matching genes]. Genesis ch. 37, v. 3.

And when his brethren saw that their father loved Joseph more than all his brethren, they hated him, and could not speak peaceably unto him. 4. Genesis ch. 37, v. 4.

ABSTRACT

The current state of technology and law allows for creating children, called ‘savior siblings’ for the purpose of transplanting their stem cells to cure an existing, sick sibling. If both parents agree, court oversight is unnecessary—even though the procedure is risky for both children. Ethical paradigms evaluating the legitimacy of the procedure focus only on the process of savior sibling creation and ignore considerations incident to later organ transplantation, i.e., issues of consent, autonomy, dignity, and best interests of the savior child. Legal analysis, which focuses on the best interest rule, leads to counter-normative results. Recent data, e.g., that 95% of such instances require invasive bone marrow transplantation, and technological advances such as gene-editing, further confound the analysis. This essay details the contradictions and conflicts in legal and ethical paradigms in light of recent data and technological advance and proposes that societal and biological input is necessary before the law or bioethics can

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provide consistent guidelines. It also puts us on notice of ethical conundrums sure to arise—even with existing technology—that we have failed to address, a sure harbinger of things to come.

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I. THE CASE OF HONEST ABE V. MAMMY YOKUM

Abner (“Pappy”) and Pansy (“Mammy”) Yokum (fictitious names) have four children. The third, Daisy Mae Yokum, suffers from Fanconi’s Anemia. She faces a life of continued blood transfusions and intense discomfort with a poor life-span prognosis. Knowing that umbilical cord blood transfusions, or failing that, bone marrow transfusions, could cure Daisy Mae, the Yokums decide to pursue this treatment modality. Not able to find the necessary compatible blood donor,¹ they revert to a controversial procedure which involves creating a new child, a “savior sibling,” to supply the stem cells Daisy Mae needs.²

After hormonal stimulation, several eggs were retrieved from Mrs. Yokum’s uterus. Using advanced *in vitro* fertilization (“IVF”) techniques, these were fertilized in a laboratory with sperm provided by her husband. After a few days, these pre-embryos were subject to two different preimplantation genetic tests (“PGT”). Luckily, the embryologist identified one that satisfied the two criteria necessary for successful treatment:³ The tested pre-embryo blastocyst did not have genes for Fanconi’s Anemia and it was also a human leukocyte antigen (“HLA”) tissue match (or immuno-compatible) with Daisy Mae. This pre-embryo⁴ was implanted into Mrs. Yokum’s uterus. Nine months later, Mrs. Yokum gave birth to her fourth child, Tiny-Tim, who would furnish the necessary stem cells to cure his sister.

Alas, the first method of treatment choice, a rather benign procedure called umbilical cord transfusion, fails. So, one year later Daisy Mae receives a risky bone marrow transfusion from her little brother. Luckily, the bone marrow transplant cures Daisy Mae and doesn’t kill or harm Tiny-Tim. But it could have done either, or both. Such were the risks Abner and Pansy were

1. Liat Ben-Senior, *Creating a Savior Child*, PARENTS GUIDE TO CORD BLOOD FOUNDATION (Aug. 2019), <https://parentsguidecordblood.org/en/news/creating-savior-child> [<https://perma.cc/7AG3-85VD>] (Noting that the probability of finding a suitable match among family members is 30%. Among siblings, the chances of having an HLA match ranges from 13% to 51%. Most report that the odds of finding a tissue match within families are one in four.); see e.g., N R Ram, *Britain’s new preimplantation tissue typing policy: an ethical defence*, 32 J. MED. ETHICS 278–282 (2006).

2. See Willem Verpoest, *PGD and HLA matching: not a quick fix*, 23 REPROD. BIOMED. ONLINE, 271, 271 (2011).

3. See generally BETH WHITEHOUSE, *THE MATCH* 32 (2010) (recounting the true story of a family and their quest for a savior sibling to cure their existing sick child).

4. See Barbara Pfeffer Billauer, *Egg-stra, Egg-stra: Do We Care About Abandoned Pre-Embryos Created by IVF?*, TIMES OF ISRAEL (Jan. 22, 2020, 1:05 PM), [<https://perma.cc/2XA6-2XVK>] (PGT is done at the blastocyst stage, four to five days after fertilization when the zygote reaches 32 cells. The embryo state does not occur until two-weeks after zygote formation).

willing to take to save the life of Daisy Mae. Court oversight or ethics committee approval for the transplant were not triggered since both parents consented to the “treatment.”

The Yokums, like their heroes, the (real-life) Trebings⁵ and the (fictitious) Fitzgeralds,⁶ take to the press to tell their story and become media darlings. Their physicians become heroes as well—and the free press doesn’t do them any harm, either. Interestingly, only their pediatrician, focusing on the children, raises objections.

While the exact number of savior siblings created in this fashion is not known, estimates are in the hundreds.⁷ Similarly, in the United States there is no registry of how many savior siblings are subjected to risky bone marrow transplantation when the umbilical cord blood transfusion fails.⁸ We can only guess based on European studies that the number is high.⁹ The ethics of creating savior siblings was robustly dissected in medical literature between 2001 and 2004, when the matter came before the British Human Fertilization and Embryology Authority (“HFEA”).¹⁰ British and other European ethicists advocating for the procedure papered the medical press and championed its use.¹¹ By comparison, a few legal academics also sounded in—mostly in

5. See generally WHITEHOUSE, *supra* note 3 (describing the birth of the Trebings’ savior child to cure his sister, Katie).

6. See generally JODI PICOULT, *MY SISTER’S KEEPER* (2004) (a fictitious account of savior siblings, written decade before the Trebings’ experience and eerily foreshadowing those events).

7. Emily S. Jungheim, *Shared Decision Making about IVF for Savior Siblings*, 16 *AMA J. ETHICS* 24, 25 (2014) (reporting on a 2011 report about 171 couples who had undergone the IVF/PGD procedure with the intent of creating savior siblings.); G. Kakourou et al., *The Clinical Utility of PGD with HLA Matching: a collaborative multi-centre ESHRE study*, 33 *HUMAN REPROD.* 520, 524 fig.1 (Feb. 2018) [hereinafter Kakourou, *Clinical Utility*] (reporting on over a hundred cases in Europe); WHITEHOUSE, *supra* note 3, at 126–27 (as of 2010 there were 250 children so created, presumably in the US, and 1% of all PGD cases are for the purposes of savior sibling creation); but see Yury Verlinsky et al., *Over a decade of experience with preimplantation genetic diagnosis: a multicenter report*, 82 *FERTIL. & STERIL.* 292, 293 (2004), <https://www.fertstert.org/action/showPdf?pii=S0015-0282%2804%2900872-6> [<https://perma.cc/PTV9-UM87>] (“[a] total of 754 babies have been born as a result of 4,748 PGD attempts” as of 2004 in the three largest preimplantation centers since its introduction in 1990); see also Zachary E. Shapiro, *Savior Siblings in the United States: Ethical Conundrums, Legal and Regulatory Void*, 24 *WASH. & LEE J. CIV. RTS. & SOC. JUST.* 419, 422 (2018) [hereinafter Shapiro, *Ethical Conundrums*].

8. Ben-Senior, *supra* note 1 (Reporting that in 2018, the European Society of Human Reproduction and Embryology published data from 15 years of PGT-HLA practice at 14 different centers. A total of 136 HLA matched babies were born, and stem cell transplants were performed in 57, of which 54 required bone marrow transplants); Kakourou, *Clinical Utility*, *supra* note 7, at 522 (United States not among participating countries in study).

9. Kakourou, *Clinical Utility*, *supra* note 7, at 525; see also *infra* footnote 76 and accompanying text.

10. Discussed *infra*.

11. See, e.g., G. Pennings et al., *Ethical Considerations on Preimplantation Genetic Diagnosis for HLA Typing to Match a Future Child as a Donor of Haematopoietic Stem Cells to a Sibling*, 17 *HUMAN REPROD.* 534, 548 (2002).

opposition. In carefully researched articles, they strenuously objected to creating savior siblings without strict legal safeguards.

Indeed, safeguards do exist—in some places. In the United Kingdom, the procedure is strictly regulated (including criminal penalties for non-compliance) and requires permission on a case-by-case basis.¹² This implicitly limits its use.¹³ As of 2009, the HFEA had granted just twelve licenses allowing “savior sibling” creation.¹⁴ As of 2010, only one bone marrow transplant had been performed in the United Kingdom.¹⁵ By that time, hundreds of donor children existed in the rest of the world¹⁶ along with scores of transplants. This is not surprising as many countries, such as the United States,¹⁷ Turkey, and Israel, do not regulate the procedure and doctors are free to perform the procedures as they wish.¹⁸ A 2018 study reported that at least thirty two centers existed for production of donor siblings in Europe alone,¹⁹ most notably in Turkey.²⁰ And although PGT-HLA testing in the US is fairly circumspect, in Israel facilities creating donor children proudly advertise their capacities.²¹

Even as the debate faded from the legal and bioethical stage in the last few years,²² data accumulation and technological advances have marched on. These new data seriously undermine early bioethical assertions supporting the procedure, while technological advances create new questions that have not yet been raised—let alone addressed. It is the impact of these

12. Malcolm Smith, *Licensing ‘saviour siblings’: Why the HFEA is right*, BIONEWS, Feb. 22 2010, https://www.bionews.org.uk/page_92174 [<https://perma.cc/8DG5-CL2A>].

13. See Quintavalle v. Hum. Fertilis. & Embryo. Auth. [2005] UKHL 28, [8] (appeal taken from EWCA) <https://publications.parliament.uk/pa/ld200405/ldjudgmt/jd050428/quint-1.htm> [<https://perma.cc/2THR-5Y7L>] (discussing one couple who was denied permission and short-circuited the process by having it done in America).

14. Ailsa Stevens, *Twin Saviour Siblings born in the UK*, BIONEWS (Aug. 17, 2009), https://www.bionews.org.uk/page_91806 [<https://perma.cc/QHP-8JYK>]; see also Smith, *supra* note 12.

15. Jay Stone, *First ‘saviour sibling’ stem cell transplant performed in UK*, BIONEWS (Jan. 10, 2011), https://www.bionews.org.uk/page_92756 [<https://perma.cc/ZJT5-DJKE>].

16. WHITEHOUSE, *supra* note 3, at 126.

17. See Zachary Shapiro, *Savior Siblings in the United States*, BILL OF HEALTH (Oct. 23, 2014), <https://blog.petrieflom.law.harvard.edu/2014/10/23/savior-siblings-in-the-united-states/> [<https://perma.cc/2VFW-27V5>] [hereinafter Shapiro, *Savior Siblings*] (noting that “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.”).

18. Called “voluntary certification”; see also Shapiro, *supra* note 7 at 144.

19. Kakourou, *Clinical Utility*, *supra* note 7, at 522.

20. Emily S. Jungheim, *Shared Decision Making about IVF for Savior Siblings*, AMA J. ETHICS (2014), <https://journalofethics.ama-assn.org/article/shared-decision-making-about-ivf-savior-siblings/2014-01> [<https://perma.cc/R672-ASQT>].

21. Alan Rosenbaum, *Advanced Procedures Bring Hope to Couples With Genetic Diseases*, JERUSALEM POST MAG. (Feb. 8, 2019), <https://www.jpost.com/magazine/advanced-procedures-bring-hope-to-couples-with-genetic-diseases-579959> [<https://perma.cc/UB7Y-VVWB>].

22. See Shapiro, *Savior Siblings*, *supra* note 17.

advances, including CRISPR-Cas gene editing and new data regarding HLA-tissue matching, to which this essay is addressed. My analysis demonstrates that the current means of analyses, legal and bioethical, are ill-equipped to address the dilemmas posed by the new technologies. This work further reveals that we, as a society, must first consider optimally desired outcomes if we wish to design consistent analytical paradigms needed to reach them. The analysis here also exposes counter-normative responses reached if existing paradigms are used for analysis. Finally, I note the lacuna in legal remedies afforded the savior child, should aspects of the procedure be performed improperly and cause damage.

Let's revisit the Yokums to explore some of these issues.

A. Creation of Protective Progeny

Assume that a decade after Tiny-Tim Yokum is born, a novel virus overtakes the country. No vaccine is in sight and highly-touted possible treatments flounder or fail. The main cause of death, it seems, is lung failure. Since it is possible for a live person to donate a lung—or at least a lobe, as long as the tissue donor is immunologically compatible—Abner and Pansy return to their IVF team with the intention of creating “protective progeny.” Their intent is that the new offspring could serve as tissue or organ donors for them—should they need a lung.²³ Or a kidney. Or bone marrow. Or a slice of liver. Or a piece of intestine or portion of pancreas—all of which can be donated by a live person.²⁴

As it happens, immediately prior to their first IVF appointment, Pappy Yokum is diagnosed with lung cancer. The diagnosis of the serious condition makes the birth of a compatible donor child even more imminent and imperative—and provides cover for the doctors in choosing to go forward. Mammy suggests that it also might be a good idea to select a potential organ-donor for her, too—just in case. Since her child-bearing years are expiring, this might be the last round of IVF for which she is eligible. Some of Mammy's doctors express reservations—but given the market such an endeavor might open, the facility agrees.²⁵

23. Lindsay Tanner, *Coronavirus survivor in US receives double lung transplant*, AP NEWS (June 11, 2020), <https://apnews.com/article/90f342e73117fe9fa7f2b0e443d40941> [<https://perma.cc/Q55W-SQM5>].

24. *Becoming a Living Donor*, UNOS NETWORK (2020), <https://transplantliving.org/living-donation/being-a-living-donor/> [<https://perma.cc/UT2J-NGLY>].

25. Robert Winston, *IVF: Lord Winston on private fertility treatment costs*, BBC NEWS (June 16, 2011), <https://www.bbc.com/news/av/uk-politics-13795110/ivf-lord-winston-on-private-fertility-treatment-costs>. [<https://perma.cc/PR2R-GFLF>] (claiming there was “massive profiteering” by private firms involved in IVF treatment); see also Barbara Pfeffer Billauer, *The Spermator as a Public Nuisance*:

And why not? Presently, there are no laws in the United States prohibiting using PGT for HLA tissue-matching and embryo selection.²⁶

But recent data has emerged causing the Yokums to think twice.²⁷ Notwithstanding early wildly optimistic claims of a 98% success rate,²⁸ newer reports are more troubling.²⁹ The Yokums can't be sure that even with hearty doses of hormones, Mammy will produce enough eggs. Even if she does, will they be healthy—what of the impact of the hormonal stimulation on the eggs?³⁰ And even if they are healthy, will they be a tissue match? Only one

Redressing Wrongful Life and Birth Claims in New Ways (A.K.A. New Tricks for Old Torts), 42 U. ARK. LITTLE ROCK L. REV. 1, 10–11 (2019) [hereinafter Billauer, *The Sperminator*]; see also Barbara Pfeffer Billauer, *Wrongful Life in the Age of CRISPR-Cas: Using the Legal Fiction of “The Conceptual Being” to Redress Wrongful Gamete Manipulation*, 124 PENN STATE L. REV. 435, 463 (2020) [hereinafter Billauer, *Conceptual Being*].

26. See Shapiro, *Savior Siblings*, *supra* note 17 (citing 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)) (noting that other than New York., no United States jurisdiction has legislation or guidelines regarding regulation of preimplantation genetic interventions). See also Naomi Cahn & Sonia Suter, *The Art of Regulating ART*, 96 CHI.-KENT L. REV. 29 (2021).

27. Rick Weiss, *Fertility Treatment Linked to Genetic Defects*, WASH. POST, Mar. 30, 1999 (reporting on issues in animal testing resulting from ICSI (Intracytoplasmic sperm injection) and noting that while such issues are monitored in children born of IVF in Europe, no such monitoring is done in the US).

28. M. Spriggs & J. Savelscu, *Saviour Siblings*, 28 J. MED. ETHICS 289 (2002); see also REPRODUCTIVE GENETIC INNOVATIONS, <https://rgiscience.com/> [<https://perma.cc/XB27-RE9D>]; see Javier Bautista, *Higher incidence of immunological disease in donor sperm-conceived adults*, BIONEWS (Sept. 28, 2020), https://www.bionews.org.uk/page_152140 [<https://perma.cc/6T9M-RHX9>].

29. *A New Approach to IVF for 2019*, OVA (Jan. 18, 2019), (Discussing excellent pregnancy rates. Indeed, success rates for frozen embryo transfer are now the same, or higher, than those of fresh embryo transfer. Indeed, success rates for frozen embryo transfer are now the same, or higher, than those of fresh embryo transfer).

30. Vanessa Milne, *The Long-Term Effects Of IVF: What We Know—And What We Don't*, CHATELAINE (Feb. 6, 2019), <https://www.chatelaine.com/health/long-term-impact-ivf/> [<https://perma.cc/X9RS-J5PF>] (noting “the procedure [has] . . . potential links to conditions like cardiovascular disease, [and Blood clotting]). As early as 1999, the concern that one form of IVF, ICSI, or intracytoplasmic sperm injection, may prove hazardous, being linked to genetic defects in animal studies. See Rick Weiss, *Fertility treatment Linked to Genetic Defects*, WASH. POST, Mar. 30, 1999. More recently, this has been confirmed to pose riskier IVF procedure in humans. “Findings from some but not all studies suggest that ICSI is associated with an increased risk for chromosomal abnormalities, autism, intellectual disabilities, and birth defects compared with conventional IVF. These increased risks may also be due to the effects of subfertility.” See *ART and Intracytoplasmic Sperm Injection (ICSI) in the United States*, CDC, <https://www.cdc.gov/art/key-findings/icsi.html#:~:text=Findings%20from%20some%20but%20not,to%20the%20effects%20of%20subfertility> [<https://perma.cc/3ZZ8-88Y5>]. See also Javier Bautista, *Higher incidence of immunological diseases in donor sperm-conceived adults*, BIONEWS (Sept. 28, 2020), https://www.bionews.org.uk/page_152140 [<https://perma.cc/YM7L-23PM>] (noting that adults conceived through sperm donation suffered a higher incidence of immunological diseases, such as type 1 diabetes, along with thyroid disease, acute bronchitis, and environmental allergies). Another concern in the past, Dayan says, was that the hormonal surges caused by IVF may make certain cancers more likely to develop.” Although for now those fears appear to be ill-founded based on the latest tests. See also Ayla Coussa et al., *Impact of Contraception and IVF Hormones on Metabolic, Endocrine, and Inflammatory Status*, 37 J. ASSISTED REPROD. AND GENETICS 1267–1272 (2020). See also Annabel Slater, *The Health of IVF Babies: What Do We Know? What Do We Need to Find Out?*, BIONEWS (Mar. 1, 2021), (“It is known that IVF babies have altered fetal growth

in four are.³¹ And then, even if the laboratory says they match, there is some question as to laboratory accuracy. A 2006 report noted that HLA diagnoses could only be assured in 90% of the embryos.³² The only multi-center study available, done in 2018, reported complications in 23% of the transplants.³³ Worse, in a nested-cohort of that sample, significant adverse reactions occurred in 10 of 44 transplants—even with HLA-tissue matching.³⁴ Luckily, the new CRISPR technology theoretically can “tinker” with HLA genes to produce a more perfect tissue match. While CRISPR hasn’t been used before in this way, the Yokums consent to be the “test case.”

After another round of IVF, PGT identifies several healthy pre-embryo-blastocysts. Another PGT identifies one which is an HLA tissue match for Abner. As for Mammy—alas, none matched. Instead, a second blastocyst was gene-edited, using CRISPR technology, and engineered to be immunocompatible. These pre-embryos are implanted in Mammy’s womb. Nine months later, Mammy births twin boys, one who might serve as a donor for his father, named Little Abner, and the other who would serve as a tissue/organ backup for Mammy, named Honest Abe.³⁵

Ten years fly by. Pappy’s condition deteriorates and Mammy wants Little Abner to donate a lobe of his lung to save Pappy. Since parents “own” the right to make medical decisions for their minor children,³⁶ Little Abner, now ten, meekly complies. Meanwhile, Mammy has been diagnosed with

and birthweight . . . fresh transfer IVF babies continued to lose weight after birth compared to their naturally-conceived peers, but this weight gap closed by the time they reached school age. Evidence from studies of naturally-conceived children suggests that this ‘catch-up growth’ is associated with a slightly increased risk of cardiovascular and metabolic diseases in later life . . . Yet, mothers who conceive via IVF are at an even higher risk of giving birth preterm, at 55 percent, when compared to fertile mothers. Furthermore, mothers who undergo ovarian stimulation have a 45 percent increased risk . . . There was a small increase in incidence of a rare type of liver tumour and muscle tumours. Similar results were found in a Nordic study, with a small increased risk of central nervous system tumours and epithelial tumours . . .”).

31. WHITEHOUSE, *supra* note 3, at 15.

32. Ben-Senior, *supra* note 1.

33. Kakourou, *Clinical Utility*, *supra* note 7.

34. *Id.* at 527 (including graft-versus-host disease, rejection, and additional complications).

35. See Katrien Devolder, *Preimplantation HLA Typing: Having Children to Save our Loved Ones*, 31 J. MED. ETHICS 582, 582 (2005) (One father apparently did use his offspring’s umbilical cord blood in the Netherlands).

36. Susan D. Hawkins, *Protecting the Rights and Interests of Competent Minors in Litigated Medical Treatment Disputes*, 64 FORDHAM L. REV. 2075 (1996). See Garry S. Sigman & Carolyn O’Connor, *Exploration for Physicians of the Mature Minor Doctrine*, 119 J. PEDIATRICS 520, 521 (1991); Matthew S. Feigenbaum, *Minors, Medical Treatment, and Interspousal Disagreement Should Solomon Split the Child?*, 41 DEPAUL L. REV. 841, 851 (1992); Shapiro, *Ethical Conundrums*, *supra* note 7. See also Naomi Cahn, *CRISPR Parents and Informed Consent*, 23 SMU SCI & TECH L. REV. 3 (2020) (noting that while as a general matter, parents are legally entitled to deference in their decisions about their children in upbringing and care, the state can infringe these rights where there are significantly important government interests).

leukemia. She is eyeing Honest Abe's bone marrow for transplantation.³⁷ While Abe desperately loves his mother, seeing his own future written on his genes, he does not cotton to the idea. Besides, he has medical problems of his own that he suspects were occasioned by the gene-editing procedure. And so is born the case of *Honest Abe v. Mammy Yokum*. Honest Abe wants a permanent injunction preventing his mother from accessing his bodily materials—just in case. He also wants to sue for being gene-edited without his consent, and for damages he claims accrued from excessive hormonal stimulation, negligent IVF, and improper gene-editing.³⁸

Can ten-year-old Honest Abe sue for wrongful creation? Short answer: No.³⁹ Can he recover meaningful damages caused by alleged negligence in performing the IVF or gene-editing or PGT? Again, short answer: No.⁴⁰ Would he receive an injunction to prevent transplantation of his bone marrow to his mother? The answer, based on current law, likely would also be “no”, at least in virtually all of the United States.

How can this possibly be? How can we allow procedures to be conducted, such that if they are done negligently, the victims have no redress? The current legal paradigm that leads to this unfortunate result has been discussed elsewhere.⁴¹ Ethical assessments relating to transplantation from one sibling to another generally condone its use and are evaluated here. However, salient novel issues also emerge: is there a difference between creating one child to save a sibling (which is legal), versus creating a child to save an

37. See Shapiro, *Ethical Conundrums*, *supra* note 7, at 422 (noting that savior sibling tissue transplants have been used to treat leukemia).

38. See Ram, *supra* note 1 (noting that “[s]ome . . . evidence has indicated that IVF may magnify the risks for major birth defects”); see also Michele Hansen et al., *The Risk of Major Birth Defects After Intracytoplasmic Sperm Injection and In Vitro Fertilization*, 346 *NEW ENG. J. MED.* 725, 725–30 (2002), <https://www.nejm.org/doi/pdf/10.1056/NEJMoa010035> [<https://perma.cc/PML8-977T>]; see also Shapiro, *Ethical Conundrums*, *supra* note 7, at 425 (citing *Bust a Myth about PGD/PGS*, FERTILITY AUTHORITY).

39. See *Grossbaum v. Genesis Genetics Institute, LLC*, Civil Action No. 07-1359 (GEB) (D.N.J. June 10, 2011).

40. See Billauer, *The Sperminator*, *supra* note 25; Billauer, *Conceptual Being*, *supra* note 25. See also DOV FOX, *BIRTH RIGHTS AND WRONGS* (2019); cf. David Heyd, *Embryonic Injuries: Can you sue if you wouldn't have been born, or born different?*, 96 *CHI.-KENT L. REV.* 145 (2021); Lisa Cherkassky, *The Wrong Harvest: The Law on Saviour Siblings*, 29 *INT'L J. L., POL'Y & FAM.* 1, 7 (Apr. 2015) (Under Section 13(5) of the United Kingdom's HFEA, “the action would be brought by the ‘designed’ child against the HFE Authority . . . for damaging his welfare by creating him for harvest.” In *McKay v. Essex*, the Court “refused to compensate for existence,” so the damages would be nil.) In the United Kingdom, under section 13(5) of the HFEA, “the action would be brought by the ‘designed’ child against the HFE Authority . . . for damaging his welfare by creating him for harvest,” under *McKay v. Essex*, but the damages would be nil because the court in *McKay* refused to compensate for existence. See *McKay v. Essex Area Health Authority* [1982] 2 *W.L.R.* 890 (C.A.).

41. Billauer, *The Sperminator*, *supra* note 25, at 4. See also Yaniv Heled et al., *A Wrong without a Remedy: Leaving Parents and Children with a Hollow Victory in Lawsuits Against Unscrupulous Sperm Banks*, 96 *CHI.-KENT L. REV.* 115 (2021).

unrelated child or a parent, biological or otherwise (which probably isn't)? Does it matter if the child was created to save someone already ill, or as a backup organ provider?

Then, we must ask about ensuing transplantation. Presently, bone marrow (in fact, any organ) transplantation between siblings—with all its incident risks to both children (discussed *infra*)—is available, even if the savior child is but a year old. If the parents agree, no court oversight is required.⁴² By comparison, creating protective progeny for future and mutual intra-familial transplantation when the child reaches majority is condemned although enforcement mechanisms are unavailable to prevent its use. Further, given the lacuna in reporting requirements, it appears this procedure has in fact been well-utilized in some countries.⁴³ Is this the result we intend as a society, or has a systematic evaluative mechanism been preempted by eager proponents of savior siblings, leaving us with this muddled state-of-affairs?

I begin the next section by discussing the medical aspects of the procedure. Part II recounts the ethical conundrums and discusses whether current considerations amply address the broader issues. Part III evaluates whether current legal analysis adequately addresses issues relating to “protective progeny,” and raises for discussion the unintended consequences of the present decision-making paradigms. In the conclusion in Part IV, I demonstrate that one panacea often raised in the context of similar issues—namely regulation as presently envisioned—will not have the desired effect here if our objective is to allow the process, while simultaneously protecting the interests of these savior children.

B. The Science and History of Savior Siblings

The advent of IVF in the 1990s has allowed for testing of genetic integrity of pre-embryos (“morulas” or “blastocysts”). Initially, these tests examined aberrations at the chromosomal level (Preimplantation Genetic Screening, or “PGS”).⁴⁴ Later, the process evolved to include evaluating genetic anomalies identifying specific diseases (Preimplantation Genetic Diagnosis, or “PGD”),⁴⁵ such as sickle cell disease or cystic fibrosis; the purpose being to avoid their uterine implantation and prevent the need for aborting a child

42. WHITEHOUSE, *supra* note 3, at 126–9.

43. Kakourou, *Clinical Utility*, *supra* note 7.

44. Paul R. Brezina et al., *Preimplantation Genetic Screening: A Practical Guide*, 7 *CLINICAL MED. INSIGHTS REPROD. HEALTH.* 37, 38 (2013), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3888082/> [<https://perma.cc/9K3C-D3E8>].

45. Robert Boyle & Julian Savulescu, *Ethics of using preimplantation genetic diagnosis to select a stem cell donor for an existing person*, 323 *BRIT. MED. J.* 1240, 1240 (2001), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1121702/pdf/1240.pdf> [<https://perma.cc/HPP8-PA2A>].

with a congenital or genetic disease.⁴⁶ The current scientific convention is to amalgamate both terms under one umbrella phrase, called Preimplantation Genetic Testing (“PGT”).⁴⁷ Initially, these tests were used where there was a family history of genetic disease, where the mother was older or suffered recurrent miscarriage, or had a history of multiple failed fertility treatments.⁴⁸

While this technology may prevent future diseased children from being born, it does little to address treatment needs of existing sick children. In diseases where the body produces red blood cells unable to carry fully oxygenated blood, the child faces a shorter life span⁴⁹ punctuated by painful treatments and transfusions. One panacea exists: transplantation of stem cells from a normal donor. In this modality, transplanted umbilical cord blood or bone marrow replaces the child’s damaged red-blood-cell-producing machinery with the normal variety.⁵⁰ A host of diseases are amenable to this procedure including Fanconi’s Anemia,⁵¹ thalassemias,⁵² various leukemias, and Diamond-Blackfan anemia.⁵³

Also, over time, uses of PGT have expanded.⁵⁴ We can now both screen out embryos bearing genes coding for disease, as well as identify those which are HLA-matches; in other words, immune-compatible with a diseased

46. Brezina, *supra* note 44, at 38.

47. *Preimplantation genetic testing (including preimplantation genetic diagnosis and preimplantation genetic screening)*, AM. SOC’Y REPROD. MED. (2014), https://www.reproductivefacts.org/globalassets/rf/news-and-publications/bookletsfact-sheets/english-fact-sheets-and-info-booklets/preimplantation_genetic_testing_pgt_factsheet.pdf [<https://perma.cc/7T6R-MC5K>]; *see also* Santiago Munné, *Status of preimplantation genetic testing and embryo selection*, 37 REPROD. BIOMED. ONLINE 393–396 (2018) (“Since last year, preimplantation genetic screening (PGS) and diagnosis (PGD) were re-termed preimplantation genetic testing (PGT)”).

48. Munné, *supra* note 47; Brezina, *supra* note 44, at 38.

49. Spriggs & Savulescu, *supra* note 28, at 289; Susan M. Wolf et al., *Using Preimplantation Genetic Diagnosis to Create a Stem Cell Donor: Issues, Guidelines & Limits*, 31 J. L., MED. & ETHICS 327 (2003).

50. Wolf, *supra* note 49.

51. E. Glucman et al., *Hematopoietic Reconstitution in a Patient with Fanconi’s Anemia by Means of Umbilical-Cord From HLA-Identical Sibling*, 321 NEW ENG. J. MED., 1174–1178 (1989); *see also* Yury Verlinsky et al., *Preimplantation Diagnosis for Fanconi Anemia Combined With HLA Matching*, 285 JAMA 3130, 3130 (2001), <https://jamanetwork.com/journals/jama/fullarticle/193944> [<https://perma.cc/GX9V-527R>].

52. Verlinsky, *supra* note 51, at 3133.

53. *Diamond-Blackfan anemia*, GENETICS HOME PAGE REFERENCE, <https://ghr.nlm.nih.gov/condition/diamond-blackfan-anemia> [<https://perma.cc/DW8E-7SVU>] (a malfunction of the bone marrow where the body fails to produce sufficient red blood cells (anemia) depriving the body of required oxygen).

54. Yury Verlinsky et al., *Preimplantation Diagnosis for p53 Tumour Suppressor Gene Mutations* 2 REPROD. BIOMED. ONLINE, 102, 102–105 (2001), [https://www.rbmojournal.com/article/S1472-6483\(10\)62233-X/pdf](https://www.rbmojournal.com/article/S1472-6483(10)62233-X/pdf) [<https://perma.cc/SA7J-S4HD>] (Discussing PGT for inherited cancer predisposition (susceptibility) determined by p53 tumor suppressor mutations).

sibling, making them perfect candidates for donating tissue or organ for transplantation.

In 2001, the first use of IVF to create one child for the purposes of saving another was reported.⁵⁵ The procedure produced an HLA-tissue-matched child who was also disease-free. However, HLA-matched does not mean HLA-identical—and significant genetic variations can exist even in HLA-matched pairs—leading to untoward results in the recipient.⁵⁶ These include host-graft and graft-host rejection.⁵⁷ Here, the normal immune system detects—and rejects (or destroys) foreign bodies (or vice-versa), including transplanted ones).⁵⁸ Perhaps for this reason matched tissue from siblings yields superior results to matched tissues from others.⁵⁹ Even tissue-matching from siblings is not perfect, however, and rejection occurs in supposedly well-matched cases,⁶⁰ including siblings. This suggests that tinkering with HLA genes via gene-editing might provide better matching than “ready-made” matched tissue identified by PGT.⁶¹ The use of CRISPR gene-editing to enhance the accuracy and availability of donor organs will likely broaden the use and market for savior children, raising additional questions.

55. *Id.* at 105.

56. See Michelle Roberts, *Stem cell transplant death – what went wrong*, BBC (Nov. 24, 2014), <https://www.bbc.com/news/health-30194504> [<https://perma.cc/F2KA-NVMT>] (reporting on four children’s deaths); see also The JAMA Network Journals, *Frailty among young bone marrow transplant survivors increases risk of death*, SCIENCE DAILY (June 2, 2016), <https://www.sciencedaily.com/releases/2016/06/160602121818.htm> [<https://perma.cc/98ZK-CDBN>] (noting that “[t]he prevalence of frailty in young bone marrow transplant survivors is similar to . . . the elderly . . . and . . . is associated with an increased risk of subsequent death,” citing Mukta Arora et al., *Physiologic Frailty in Nonelderly Hematopoietic Cell Transplantation Patients: Results From the Bone Marrow Transplant Survivor Study*, 2 JAMA ONCOLOGY (2016), and noting that HSCT “to cure or control blood cancers exposes patients to high-intensity chemotherapy, radiation and immunosuppression. These exposures can damage normal tissues.”); see Savannah Koplun, *Researcher finds risk of later death after donor blood, marrow transplant in childhood*, MEDICALXPRES (July 30, 2018), <https://medicalxpress.com/news/2018-07-death-donor-blood-marrow-transplant.html> [<https://perma.cc/TY9D-TA39>]; Paul J. Martin, *Life Expectancy in Patients Surviving More Than 5 Years After Hematopoietic Cell Transplantation*, 28 J. CLIN. ONCOL. 1011 (2010).

57. See Shapiro, *Ethical Conundrums*, *supra* note 7 at 426.

58. See Sally Sheldon & Stephen Wilkinson, *Should selecting saviour siblings be banned?*, 30 J. MED. ETHICS 533 (2004).

59. Kakourou, *Clinical Utility*, *supra* note 7, at 521 (citing R.P. Gale & M. Eapen, *Who is the best alternative allotransplant donor?*, BONE MARROW TRANSPLANT (2015) and T.L. Kindwall-Keller & K.K. Ballen, *Alternative donor graft sources for adults with hematologic malignancies: a donor for all patients in 2017*, ONCOLOGIST (2017)) (human stem cell transplants (“HSCT”) “with a matched related donor is associated with fewer complications, higher survival rates and better outcomes . . . even in comparison to HSCT with a matched unrelated donor.”).

60. *Id.* at 530 (stating that “[i]n 44 children transplanted with stem cells from savior sibling, even with matched HLA, immune issues were reported in ten: graft-versus-host disease was reported in one, rejection was reported in one and additional complications were reported in eight (18.2%)”).

61. *Id.* at 529.

II: THE ETHICS OF CREATING SAVIOR SIBLINGS

In the United Kingdom, the HFEA regulates infertility treatment.⁶² The HFEA initially allowed the procedure,⁶³ via application, in cases where a preimplantation testing was done to rule out genetic diseases—subject to strict oversight—and only to save a sibling with a severe disease (subjectively determined).⁶⁴ According to the then-chairman of the HFEA, “[w]here PGD is already being undertaken we can see how the use of tissue typing to save the life of a sibling could be justified.”⁶⁵ Acceptance of the tripartite technology—combining IVF, diagnostic PGT, and PGT-HLA-tissue matching—came three years later, and only after the couple seeking permission was rejected, and went to the U.S. for the procedure as reproductive tourists.⁶⁶

In response, United Kingdom bioethicists sounded in, championing the procedure, and establishing a paradigm for analysis. Their analytical method focused, laser-like, only on the HLA-tissue matching aspect of the procedure. As for using bone marrow transplants from donor siblings when umbilical cord transfusions fail, this additional practice (commonly required)⁶⁷ is ignored—either overtly or covertly.⁶⁸ The few legal scholars involved were more reserved,⁶⁹ perhaps because they recognized the importance of assessing the future risks in store for the donor child.⁷⁰

62. Human Fertilisation and Embryology Act 1990, c.37 (UK).

63. *HFEA to allow tissue typing in conjunction with preimplantation genetic diagnosis* (December 13, 2001), https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/235223/0315.pdf [<https://perma.cc/G6KA-NXYD>].

64. Spriggs & Savulescu, *supra*, note 28, at 289.

65. *Id.*

66. See *Quintavalle v. Hum. Fertilis. & Embryo. Auth.* [2005] UKHL 28, [8] (appeal taken from EWCA) <https://publications.parliament.uk/pa/ld200405/ldjudgmt/jd050428/quint-1.htm>.

67. See Kakourou, *Clinical Utility*, *supra* note 7.

68. Sheldon & Wilkinson, *supra* note 58 (“Our focus throughout is on cases where doctors plan just to use umbilical cord tissue, as opposed to those in which the use of non-renewable solid organs (such as kidneys) is intended, and we concede from the outset that the latter raise additional objections that (for reasons of space) we do not consider here.”).

69. See, e.g., Victoria Chico, *Saviour Siblings: Trauma and Tort Law*, 14 MED. LAW REV. 180, 184–85 (2006) (addressing damages the savior sibling might suffer.); see also Arthur L. Caplan, *Am I My Brother's Keeper?*, 27 SUFFOLK U. L. REV. 1195 (1993).

70. See also Janet L. Dolgin, *Method, Mediations, and the Moral Dimensions of Preimplantation Genetic Diagnosis*, 35 CUMB. L. REV. 519, 538 (2004) (particularly noting the psychological effects on both children).

A. Evaluating the Ethical Paradigm

One paradigm to evaluate these issues proffered by these United Kingdom bioethicist-advocates dissects potential harms into two categories: harm to the child and harm to society—again focusing only on the HLA-tissue matching aspect. Bifurcating the issue neatly in this fashion allows certain real concerns to evaporate.

Insofar as harms to the donor-child are concerned, Boyle and Savulescu consider them identical to the diagnostic PGT procedure used to rule out disease. They focus on risks of the biopsy weighed against the potential benefit (which accrues to the sick sibling, not the donor).⁷¹ They, and others, including UK's HFEA, then conclude that the benefits of PGT outweigh any dangers.⁷² Their analysis is myopic and narrow, as it does not include evaluating the risks of bone marrow transplantation, which is the ultimate result of most HLA-PGT procedures.

Another approach favored by savior sibling proponents trifurcates the concerns *ex ante*. The methodology frames the objections into three categories, which are then systematically dismantled. First, “that saviour [sic] siblings would be wrongfully instrumentalized [sic], treated as mere means rather than ends-in-themselves, or as commodities.”⁷³ Second, that creation of savior siblings would either cause or constitute a move towards the creation of “designer babies.”⁷⁴ Finally, there are arguments focusing on the welfare of savior siblings “according to which saviour [sic] siblings will be physically and/or psychologically harmed.”⁷⁵

A review of these arguments and counterarguments discloses the fallacies of these approaches.

1. Commodification

In opposing the procedure, fertility expert Dr. Lord Robert Winston⁷⁶ describes creating children to provide cells for another, as “using an unborn child as a commodity,”⁷⁷ and says that it is wrong to bring children into

71. Boyle & Savulescu, *supra* note 45, at 1241.

72. Michele Hansen et al., *The risk of major birth defects after intracytoplasmic sperm injection and in vitro fertilization*, 346 NEW ENG. J. MED. 725 (2002).

73. Sheldon & Wilkinson, *supra* note 58; *see also* FIRST DO NO HARM: LAW, ETHICS AND HEALTHCARE 398 (Sheila A. M. McLean ed., 2006).

74. Spriggs & Savulescu, *supra* note 28, at 289.

75. Sheldon & Wilkinson, *supra* note 58, at 533.

76. *About Robert Winston*, PROFESSOR ROBERT WINSTON, <http://www.robertwinston.org.uk/about-robert-winston/> [<https://perma.cc/ZFV9-UW5U>]; *see also* Boyle & Savulescu, *supra* note 45, at 1241.

77. Boyle & Savulescu, *supra* note 45, at 1241.

existence “conditionally,”⁷⁸ or for the purposes of providing stem cells for an existing person, which would result in children not being valued in their own right.⁷⁹ In other words, “the wrongness of tissue typing stems from the fact that it is a procedure undertaken simply for the benefit of another,”⁸⁰ i.e., bringing a human being into the world simply as a means to an end.⁸¹ These arguments are premised on a Kantian view “that you use humanity . . . always . . . as an end, never simply as a means.”⁸²

Those opposing this view claim that this is a misreading of Kant—who, they say, would approve of a dual use if used *both* as an end and as a means.⁸³ Citing anecdotal reports that parents who seek this procedure *say* they wanted another child anyway,⁸⁴ Savulescu and confrères craft the speculative argument⁸⁵ that “parents willing to go to such extraordinary lengths to save their existing sick child, are *likely* to be the sort of parents who would care deeply for each of their children in their own right.”⁸⁶ Certainly, all publicized cases report the parents *claim* they would have had another child anyway.⁸⁷ But given the controversy surrounding the procedure, what else would they say?

Not only is there no evidence to support Savulescu’s assertion or sustain the purity of the parent’s motives, there is evidence to the contrary. A 1994 article reported on 32 parents who attempted to create savior siblings the old-fashioned way, without PGT-sorting and screening. In two cases, the couples aborted healthy fetuses which were not immune-compatible.⁸⁸

78. *Id.*

79. Shapiro, *Ethical Conundrums*, *supra* note 7, at 441 (“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.”).

80. Ram, *supra* note 1, at 279.

81. Sheldon & Wilkinson, *supra* note 58, at 534.

82. *Id.* (From the Kantian view, only creating a child *solely* to advance some further end is objectionable. For example, it would be wrong to create a saviour sibling and then just to discard him or her once it had “served the purpose.”).

83. Spriggs & Savelescu, *supra* note 28, (Male’s criticisms reflects a lack of appreciation for the distinction between using someone as a means to an end and using someone simply as a means to an end).

84. WHITEHOUSE, *supra* note 3.

85. Spriggs and Savulescu couch their arguments with “Indeed, it is reasonable to believe” or “It is not true of necessity, however, that parents seeking tissue typing PGD will have such simplistic motives.” Indeed, it would be surprising if parents, attacked in the media, by their friends, and relatives, would say anything else. Spriggs & Salvelsecu, *supra* note 28.

86. P. Ranscombe. *Creation of designer babies for treatment is lawful, rule Lords*, THE SCOTSMAN (Apr. 29, 2005), www.thescotsman.scotsman.com/index.cfm?id=456522005 [https://perma.cc/HAS4-TDXP], a trap into which lawyer Shapiro, cited *supra* falls.

87. See WHITEHOUSE, *supra* note 3, at 80.

88. A.D. Auerbach, *Umbilical Cord Transplants for Genetic Disease: Diagnostic and Ethical Issues in Fetal Studies*, 20 BLOOD CELLS 303, 307 (1994); see also WHITEHOUSE, *supra* note 3, at 41

But the questions become more pointed: What happens if the HLA procedure is successful, a matched tissue child is born, and the ill child needs a risky bone marrow transfusion?⁸⁹ How will the parent decide which child's needs take pre-eminence? Every reported actual case reflects that when the benign umbilical cord transfusion doesn't work (which, according to a 2018 multi-center European study, is 95% of the time), the parents subject the savior sibling to the risky bone marrow transplant.⁹⁰ Indeed, after going to such lengths to insure the ill child's survival, is it unreasonable to surmise a parent would abandon their quest midway—even if another child's life or health is endangered?

2. Designer Babies and Discrimination

Another argument claims that allowing creation of savior siblings will lead to the creation of full-fledged designer babies.⁹¹ In other words, “the new technique is a dangerous first step towards allowing parents to use embryo testing to choose other characteristics⁹² . . . such as eye colour [sic] and

(noting that “[a]ccording to . . . the International Fanconi Registry, . . . while some parents who used the natural method did go on to birth the child even though not an HLA match, some aborted.”).

89. Severe adverse events, such as pulmonary emboli and deep venous thrombosis, and even deaths, while rare, have been reported for both bone marrow and peripheral blood transfusions used for hematopoietic stem cell donations even in both adults and children, and adverse events of a less severe variety are “frequent”; see, e.g., Joerg Halter et al., *Severe Events in Donors After Allogeneic Hematopoietic Stem Cell Donation*, 94 HAEMATOLOGICA 94, 96, 99 (2009) (reporting on 1 in 10,000 deaths, 1 in 1,500 severe complications and 1 in 3,000 malignancies).

90. Kakourou, *Clinical Utility*, *supra* note 7, 521–22 (reporting on the “the first multi-centre cohort study attempting to define how often PGD-HLA achieves the ultimate clinical utility, which is to cure a sick child.” Out of 136 HLA-matched babies born of 600 attempts, only 57 underwent stem cell transplantation). It is not clear why some many did not. One speculation is that there was not enough umbilical cord blood and these parents declined to proceed with bone marrow transplants, of which 54 included bone-marrow transplants. Genetic intervention for repair of the disease itself is eclipsing use of donor blood, precisely because of the complications generated by that modality of treatment; see e.g. William Wan, *Gene Therapy Cures Infants Suffering From ‘Bubble Boy’ Immune Disease*, WASH. POST (April 17, 2019, 5:00 PM), https://www.washingtonpost.com/national/health-science/gene-therapy-cures-infants-with-bubble-boy-immune-disease/2019/04/17/ec4b131e-60ff-11e9-bfad-36a7eb36cb60_story.html [<https://perma.cc/WBK8-EVCR>].

91. Sheldon & Wilkinson, *supra* note 58, at 148.

92. Other concerns falling under this heading will not be discussed here, as they are not unique to creating savior siblings. These include giving prospective parents “the right to shun a disabled child” which verges on “reproductive discrimination,” that the resulting child “would have a ‘closed’ future, or that this is “a form of selective breeding.” The latter as discussed in Megan Tesene, *Propagating Privilege: An Analysis of the Marketing and Consumption of Donor Sperm*, Sections 4.8, 4.10 (2019) (Dissertation, Georgia State University). See also Wybo Dondorp & Guido de Wert, *Refining the Ethics of Pre-implantation Genetic Diagnosis: A Plea for Contextualized Proportionality*, 33 BIOETHICS 294–301 (2019).

See also “[A]ttitudes may be fostered that promote discrimination against the sick or disabled because they were not ‘designed’ properly prior to birth.” See generally Sagit Mor, *infra* note 175 (discussing the impact on the disabled community).

sex.”⁹³ This slippery slope argument is refuted by Savulescu and confrères because, per the HFEA, “HLA tissue typing may only take place when pre-implantation genetic diagnosis is required to avoid a serious genetic disorder,”⁹⁴ and that testing for conditions such as sex selection, which are “not associated with disability or a serious medical condition,” would not be acceptable.⁹⁵ But what about countries which are not regulated (such as the United States or Israel where unlimited rounds of IVF allow for two children per couple)?⁹⁶ Nor do the proponents address the question of reproductive tourism, as happened when the United Kingdom couple denied permission for the procedure went to the United States to have it done.⁹⁷

Proponents also argue that creating savior siblings is no different from the accepted, single-use PGT to exclude genetic disease because “the explicit purpose of the treatment is to cure a (particular) condition that already exists, not to eradicate the condition from the gene pool.”⁹⁸ This is a gross mischaracterization. Single-use PGT is used to select *against* children with genetic damage. In HLA-tissue matching, we are selecting *for* certain traits.⁹⁹ As noted by the Court of Appeal in *Quintavalle v. Hum. Fertilis. & Embryo. Auth.*:¹⁰⁰ “Screening out genetic abnormalities is one thing. Screening out certain normal characteristics is another. The crucial distinction has been put as being between ‘screening out abnormalities’ and ‘screening in preferences.’”¹⁰¹ HLA-tissue matching rejects embryos that are healthy but do not conform to preferred specifications. How, one asks, is this different from selecting for traits such as sex or eye color? Furthermore, where does one draw the line between medical intervention and enhancement? To confound the analysis further, what if HLA-typing includes a CRISPR component,

93. Sheldon & Wilkinson, *supra* note 58, at 534.

94. Press Release, HFEA, Approved PGT-Mand PTT Conditions (Aug. 1, 2002), <http://www.hfea.gov.uk/treatments/embryo-testing-and-treatments-for-disease/approved-pgd-and-ptt-conditions/> [<https://perma.cc/N3Q4-5NCS>].

95. J. Savulescu, *Sex Selection: the case for*, 171 MED J AUST. 373, 373–5 (1999). *But see* Sarah M. Capelouto et al., *Sex Selection for Non-Medical Indications: A Survey of Current Pre-Implantation Genetic Screening Practices Among U.S. ART Clinics*, 35 J. ASSISTED REPROD. & GENETICS 409 (noting that 72.7% of ART clinics offer sex selection).

96. Meaning a divorced couple with two children who get remarried are each entitled to two more children with their new spouses.

97. *Quintavalle v. Hum. Fertilis. & Embryo. Auth.* [2005] UKHL 28, [8] (appeal taken from EWCA) <https://publications.parliament.uk/pa/ld200405/ldjudgmt/jd050428/quint-1.htm>.

98. Sheldon & Wilkinson, *supra* note 58, at 533.

99. *Id.*; *Quintavalle*, [2005] UKHL 28, [17].

100. *See Quintavalle*, [2005] UKHL 28, [5], [22]. *See also* Rosamund Scott, *Choosing Between Possible Lives: Legal and Ethical Issues in Preimplantation Genetic Diagnosis*, 26 OXFORD J. L. STUDIES 153–178 (2006).

101. Sheldon & Wilkinson, *supra* note 58 (quoting the *Quintavalle* Ct. of Appeals 2 Op.cit., n. 3, per Mance L.J. at para. 134. at 149).

whose purpose is to repair one of the 200 genes encoding for the HLA Complex.¹⁰² In this case, the procedure undoubtedly would be therapeutic. Does it make a difference?

3. The Welfare of the Savior Child

a. Physical Harm and Best Interests

The HFEA's original policy primarily addresses concerns about the safety of children conceived with HLA-Matching,¹⁰³ and states "that the best interests of the child produced by assisted reproduction must be paramount."¹⁰⁴ As discussed below, the "best interest test" used by the British authorities is somewhat different from the legal tests used by American courts—which have been construed broadly¹⁰⁵ and surely are involved in determining whether a minor child can be compelled to donate tissue or organs, generating confusion in designing a decision-making paradigm.¹⁰⁶

Moreover, in the minds of the procedure's proponents, it is not clear whose physical safety is paramount when the interests of the two children diverge: the existing sick child, or the one whose existence is enabled for the purpose of saving that child?¹⁰⁷ Recognizing that there must be concern for the savior sibling, but nevertheless intent on favoring the ill child, Sheldon and Wilkinson frame the problem through a different—and skewed—lens. They claim that because PGT does not harm the savior sibling and might help his sibling, it is ethically justified.¹⁰⁸ They formulate the issue as a simple risk-benefit analysis done at a singular point in time: the savior sibling's creation, and hence assert that "for a given embryo, the harms and benefits of selection are equal in tissue typing PGD and disease testing PGD."¹⁰⁹ This formulation enables them to argue (convincingly according to some,¹¹⁰ preposterously according to others)¹¹¹ that concerns "about the physical safety

102. *The major histocompatibility complex and its functions*, in IMMUNOBIOLOGY: THE IMMUNE SYSTEM IN HEALTH AND DISEASE (5th ed., 2001).

103. Boyle & Savulescu, *supra* note 45, at 1241.

104. *Id.*

105. See generally, Adrian E. Alvarez, *Enabling the Best Interests Factors*, 2 ARIZ. STATE L.J. ONLINE 90 (2020).

106. See *infra* discussion on Curran case.

107. Tissue typing PGT differs from this model in that the primary benefits of the procedure fall to the sibling in need of a tissue transplant rather than to the future child.

108. Sheldon & Wilkinson, *supra* note 58, at 535.

109. *Id.*

110. *Id.*

111. Such as myself.

of children created through PGD may not be sufficient to prohibit the use of PGD for tissue typing.”¹¹²

This characterization again focuses with narrow intensity on one aspect of the procedure—the child’s creation—rather than the future risks of transplantation.

b. Psychosocial Harms

“Critics of tissue typing-PGD have also expressed concerns that the future child will experience emotional and psychological harms as a result of being born, even in part, for someone else’s benefit.”¹¹³ These concerns “include fears that the future child may feel that she is nothing more than a source of spare parts for her sibling, may experience feelings of inadequacy if the stem cell transfusion is unsuccessful, or may lose some sense of unconditional love from her parents,”¹¹⁴ “who are less likely to value and nurture” the child, given that they wanted it primarily to save the life of the sibling.¹¹⁵

Others contend:

[T]he donor child is at lifelong risk of exploitation, of being told that he or she exists as an insurance policy and tissue source for the sibling, of being repeatedly subjected to testing and harvesting procedures, and of being pressured, manipulated, or even forced over protest, perhaps for its entire life.¹¹⁶

Savulescu and Briggs reject these arguments as “unlikely,” claiming that “these remain at best speculative fears because no one knows quite what the psychological effects of having been conceived through tissue typing PGD might be.”¹¹⁷ That the fears may be speculative should be no reason to discount them, at least from a legal perspective.¹¹⁸

112. Ram, *supra* note 1, at 278–282.

113. *Id.* See also Sheldon & Wilkinson, *supra* note 58, at 149. Frame the issue as concern for all children involved—which enables some specious arguments—discussed *infra*. In actuality, the legislation focuses on the needs of the savior sibling, only.

114. Ram, *supra* note 1.

115. Sheldon & Wilkinson, *supra* note 58, at 151.

116. *Id.*

117. Spriggs & Savulescu, *supra* note 28.

118. *But see* Wolf et al., *supra* note 49, at 327 (“[The] HLA-matched child . . . may be . . . asked for tissues and organs throughout his or her life. False We thus recommend safeguards to attend not only to IVF, PGD and the birth process, but all subsequent harvesting of the donor until the donor can decide for him or herself.”). In fact, *because the donor embryo clearly could not give consent, this . . . may loom large in later life when the . . . offspring realizes someone else gave . . . consent on its behalf.* See R.G. Edwards, *Ethics of PGD: thoughts on the consequences of typing HLA in embryos*, 9 REPROD. BIOMED ONLINE 222, 223 (2004), [https://www.rbmojournal.com/article/S1472-6483\(10\)62133-5/pdf](https://www.rbmojournal.com/article/S1472-6483(10)62133-5/pdf) [https://perma.cc/5ASF-KCTC]; see *infra* Part II.B.4. (“In fact, because the donor embryo clearly could

4. Harm to a Wronged Child: The Lacuna of Legal Remedies

Further discounting or diminishing claims the savior sibling might have, proponents of the technology revert to arguments heretofore raised to dismiss actions brought by children injured during IVF via Wrongful Genetic Manipulation, or medical malpractice.¹¹⁹ They argue: what harm could the savior child possibly claim? After all, it is alive! And, as the theory goes, any life is better than none,¹²⁰ which raises the Non-Identity Problem, ascribed to Derrick Parfit.¹²¹ This model asserts that life and any harm the child has (or may suffer) are, in the calculus, incomparable, as any life is better than none.¹²²

The proponents then couch the equation as follows:

For if the relevant benefit is being caused to exist (rather than being cured of a genetic disorder) then clearly both [siblings . . .] stand to gain more or less equally in this respect—since both are caused to exist by the selection process and probably would not have existed without it.¹²³

The proponents of this argument rely on the net benefit test.¹²⁴ The newly devised re-formulation asserts that the procedure is acceptable because we are “offsetting the loss of one possible life against the creation of another life with better prospects.”¹²⁵ This fabrication turns the “offset rule” as explained in the Restatement (Second) on its head, as the original offset rule is only acceptable in weighing comparable losses and benefits of the same type—in the same individual,¹²⁶ and presumably at the same time.¹²⁷

not give consent, this . . . may loom large in later life when the . . . offspring realizes someone else gave . . . consent on its behalf.”)

119. Billauer, *The Sperminator*, *supra* note 25.

120. See *Becker v. Schwartz*, 46 N.Y. 2d 401 (N.Y. 1978).

121. See Cherkassky, *supra* note 40, at 7 (citing *McKay v. Essex Area Health Authority* 43 [1982] Q.B. 1166). This problem was first discussed by Parfit (1984) and developed in the context of the HFEA 1990 by Harris (2000); Gavaghan (2000) and Boyle and Savulescu (2001). See Billauer, *The Sperminator*, *supra* note 25; Heyd, *supra* note 40.

122. Sheldon & Wilkinson, *supra* note 58, at 535 (contending that the risk benefit analysis for the donor, is not “being healthy rather than having a genetic disorder” rather, the benefit is “existing rather than not existing”).

123. *Id.* at 536.

124. *Id.* at 535–536 (Agreeing that “a future child should be exposed to the risks of PGD only if she will probably derive enough benefits to outweigh those risks . . . [but] that it really makes [no] sense to say of an individual that they were benefited [or harmed] by events that caused them to exist.” This is the substance of the Parfit Non-Identity Problem which serves as the underpinning for rejecting wrongful life claims. Sheldon and Wilkinson then note that “relevant here are thoughts about how our attitudes to saviour [sic] siblings cohere with our attitudes to children with disabilities. For in the debate about prenatal screening, selective termination, eugenics and such, the thought that people with severe and painful disabilities are ‘glad to be alive’ is (rightly) taken seriously,” turning the eugenics argument on its head.)

125. *Id.* at 533 (“This is because banning the use of PGD to create saviour [sic] siblings will lead to the death of a number of children who could have been saved by sibling donation False”).

126. See *Emerson v. Magendantz*, 689 A.2d 409, 414 (1997).

127. *Id.*

B. Social Concerns

1. Mixed Paradigm Cost-Benefit Analysis: The Trump Card of Saving a Child's Life

Societal concerns arise in the context of a novel cost-benefit conundrum, with the benefits and burdens disproportionately falling on two different individuals on one hand, balanced against harms to society on another.¹²⁸ Some have said, societally speaking, that “[y]ou have got to have a very powerful reason to resist the means by which a child’s life can be saved,”¹²⁹ although this must be balanced against concerns of eugenics, disrespect for children born with congenital ailments, and moral repugnance. Many experts discount concerns of eugenics on the basis that decisions will be private,¹³⁰ without governmental interference.¹³¹ Others have countered the moral repugnance argument with the claim that “unless our private reproductive decisions cause harm to others, they should remain immune to legislation even if some people morally disapprove of them.”¹³²

But the elephant in the room is continually ignored in these analyses: there well may be significant harm to others, including to both the recipient, as well as the savior sibling.¹³³

128. Ram, *supra* note 1, at 281 (notes that another societal problem is allocation of scarce resources for countries where the procedure is covered by state health insurance).

129. Sheldon & Wilkinson, *supra* note 58 (quoting J. Glover, *Doctor plans “designer baby” clinic*, BBC (Dec. 11, 2001), <http://news.bbc.co.uk/1/hi/health/1702854.stm> [<https://perma.cc/PCN9-T4XQ>]).

130. See Boyle & Savulescu, *supra* note 45, at 1242 (“The famous legal scholar H L A Hart . . . argued effectively . . . on sexual behaviour [sic] that there is a sphere of private conduct that should be immune to legislation regardless of popular opinion, and that popular opinion or even morals are not always sufficient grounds for legislation.”).

131. JENNIFER DOUNDNA & SAMUEL STERNBERG, *THE CRACK IN CREATION* 234 (2017); see also JONATHAN GLOVER, *CHOOSING CHILDREN: GENES, DISABILITY AND DESIGN* 6–27 (2007).

132. Boyle & Savulescu, *supra* note 45, at 1242.

133. Ann Pietrangelo, *What Are the Risks of Bone Marrow Donation?*, HEALTHLINE (Apr. 10, 2018), <https://www.healthline.com/health/bone-marrow-donation-risks#risks> [<https://perma.cc/Z7ZB-XXRU>] (Risks to the donor are reported at 2.4%); “A bone marrow donation requires the hipbone to be punctured one hundred times to remove approximately two cups of marrow. The physical risks include pre-harvest screening, anaesthesia (allergy, deprivation of oxygen, brain damage, heart attack and stroke), bone fracture . . . infection, rupture of an artery, skin scarring, hypertension, anaemia, broken needles, blood transfusion, and pain. The psychological risks may also include fear of operations, fear of losing a body part, a feeling of worthlessness, spite, resentment, refusal (if harvested repeatedly) . . . manipulation, exploitation, guilt, rejection, and being treated as an insurance policy. [citations omitted] The legal question at this juncture is: how do the courts justify a non-therapeutic harvesting procedure on a baby designed specifically for that purpose?” See Cherkassky, *supra* note 40, at 8; see also Halter, *supra* note 89, at 99–100 (noting a mortality rate of 1/10,000, and morbidities including twenty blood cancers in the cohort studies, with a latency period of a few months to more than 10 years after the donation); Michael A. Pulsipher et al., *Peripheral Blood Stem Cell (PBSC) Donors Experience Higher Levels of Pain and Toxicities Early On, While Bone Marrow (BM) Donors Experience Slower Recovery and More Late Pain: A Prospective Study of the National Marrow Donor Program (NMDP)*, 116 BLOOD 1107 (2010).

2. Loss of Genetic Diversity

The most serious concern, I suggest, from a societal standpoint, is the potential loss of genetic diversity, which also heralds a lack of respect for cultural and societal diversity. The more homologous a population is from a biological or genotypic standpoint, the more it is subject to ecological devastation.¹³⁴ The less diverse a population in terms of phenotype expression standpoint, the more society is prone to “isms” of all sorts. The consequences of loss of diversity are brushed away by proponents Boyle and Savulescu, who harp on their now oft-repeated grounds that it is speculative, with the even more speculative counterargument that the procedure won’t be used much because it is expensive.¹³⁵

Unfortunately for Boyle and Savulescu, the genetic diversity impact of over-matching HLA is neither speculative nor insignificant. Research has determined an evolutionary preference for diverse HLA-encoding genes.¹³⁶

Basically what these [HLA] genes are about is fighting infection, fighting diseases and helping our immune system do really well [. . .]. The more diverse those genes are, the more diverse are the kinds of infections you can fight. And if your partner has a slightly different combination of these genes than you do, then you’re going to produce offspring that can fight an even broader array of pathogens and diseases.¹³⁷

Further, “humans, are programmed to give our offspring the best chance for survival, our bodies have developed all sorts of methods to reward the strongest, most diverse and compatible mate possible,”¹³⁸ and this means that it is to the offspring’s benefit to have a more diverse retinue of genes in its

134. *What is Genetic Diversity?* THE TEACHER FRIENDLY GUIDE TO THE EVOLUTION OF MAIZE, <http://maize.teacherfriendlyguide.org/index.php/genetic-diversity-and-evolution#> [<https://perma.cc/KH48-XKYN>] (“Genetic diversity is important because it helps maintain the health of a population, by including alleles that may be valuable in resisting diseases, pests and other stresses. Maintaining diversity gives the population a buffer against change, providing the flexibility to adapt. If the environment changes, a population that has a higher variability of alleles will be better able to evolve to adapt to the new environment. In extreme situations (e.g., drought, disease epidemics) diversity could even mean the survival of the population.”).

135. Boyle & Savulescu, *supra* note 45, at 1242 (“Some people might argue that by selecting embryos we risk reducing the genetic diversity of our species and exposing the human race to unforeseen risks. Such arguments are speculative. Moreover, the number of requests for PGD is likely to remain limited given the emotional and financial costs of the procedure.”).

136. J. Winternitz et al., *Patterns of MHC-Dependent Mate Selection in Humans and Nonhuman Primates: A Meta-Analysis*, 26 *MOLECULAR ECOLOGY*, 668, 668 (2017) (“results indicate that preference for more MHC-diverse mates is significant for humans and likely conserved across primates”).

137. Sandee LaMotte, *A woman’s eggs choose lucky sperm during last moments of conception, study finds*, CNN HEALTH (June 9, 2020, 10:53 PM), <https://www.cnn.com/2020/06/09/health/sperm-choice-female-eggs-wellness/index.html> [<https://perma.cc/TK3V-TKFB>].

138. *Id.*

HLA repertoire.¹³⁹ This beneficial diversity inures to the benefit of the species as a whole. Nevertheless, even if HLA-genetic diversity is beneficial on a population level, perhaps under limited circumstances immune-capacity redundancy might benefit a specific family, say the last of a lineage which risks “extinction,” even as it has a negative effect on the societal biome. In this regard, perhaps reducing immunological genetic diversity within families—might, on a net scale, be a good thing? Such a result would also guarantee the availability of scarce transplant materials should *anyone* in the family get sick. This approach would condone creating protective progeny even if no one is yet sick—as the reciprocal availability of transplantation is equally transferable to the newly born child from HLA-matches within the family. Additionally, the transplantation might be deferrable until the child is old enough to voluntarily consent. These critical questions have not been fully addressed heretofore and will be visited below.

3. Reproductive Liberty

Proponents of the technique tout the need for reproductive liberty.¹⁴⁰ Others rhetorically ask:

Who is harmed by allowing PGD to be performed solely for the benefit of a *relative*? Not the couple who wish to produce an embryo. Nor the child who would not otherwise have existed. Nor the person who receives the stem cell transplant that might save his or her life. We must avoid the trap of interfering with individual liberty by preventing such procedures for no good reason, simply out of the “genophobia” that grips much of society today.¹⁴¹

“[Commingle] the concept that] if these procedures are acceptable, as they are in many countries, it is reasonable to use them to both bring a new person into the world and to help save *an existing* life.”¹⁴²

Currently, in the United States, there are no clear professional guidelines regarding using PGT to create donors for the benefit of an existing

139. *Id.* See also Idan Alter et al., *HLA class I haplotype diversity is consistent with selection for frequent existing haplotypes*, 13 PLOS COMPUTATIONAL BIOL. (2017) (“New HLA alleles may have an advantage over existing frequent alleles since immune escape mutations in pathogens within a population are maintained primarily in epitopes presented on frequent HLA alleles.”).

140. Boyle & Savelescu, *supra* note 45, at 1242 (“[W]e should be loath to restrict liberty in the absence of evidence of serious harm to others, especially in private behaviour and especially when the activity in question is potentially life-saving (and life-creating).”); on procreative liberty generally, see JOHN A. ROBERTSON, *CHILDREN OF CHOICE: FREEDOM AND THE NEW REPRODUCTIVE TECHNOLOGIES* 16–18, 22–24 (1994) (Robertson argues not for an absolute commitment to procreative liberty, but rather a strong presumption, and maintains that a demonstration of harm can justify limits).

141. Boyle & Savelescu, *supra* note 45, at 1243 (emphasis added).

142. *Id.* (emphasis added).

person.¹⁴³ Boyle and Savelescu claim that the American Society of Reproductive Medicine and the American Medical Association considered the specific issue and agreed that the procedure was justified,¹⁴⁴ with the clear implication that the procedure should be available for use beyond siblings, even beyond family members.¹⁴⁵ However, I see no indication or substantiation for this claim.

In further minimizing concerns regarding the donor child, the proponents of savior children creation refer to the Warnock Report, the precursor to the Human Fertilisation and Embryology (“HFE”) Act, noting that although “the human embryo is entitled to some added measure of respect beyond that accorded to other animal subjects, that respect cannot be absolute”¹⁴⁶ But the fact is that at some point, this embryo becomes a *bona fide* human whose rights and dignity is pitted against another person needing a body part owned by the newly created child, and these rights appear to have been overlooked.¹⁴⁷

4. Informed Consent

Since recent data indicates that bone marrow transplantation is an all-but-certainty for these children, this eventuality cannot be ignored or glossed over either in ethical debate or legal analysis. The issue of by whom and how informed consent is obtained becomes a critical concern. As the author of one study evaluating sequelae of stem cell transfusions cautioned, “[d]onors must be informed about the potential risks of making a donation.”¹⁴⁸ Generally it is the parents who are tasked with providing informed consent. But in the case of emerging reproductive societies, this produces a dilemma.¹⁴⁹ In this case, parents have an innate, inseparable conflict as advocates of both the sick and savior child.¹⁵⁰

143. Nor is there any means or mechanism to report use of the procedure, its successes and other statistics, data which would be useful in assessing the risk-benefits of the procedure, and a mechanism this author ardently supports.

144. Boyle & Savelescu, *supra* note 45, at 1241.

145. *See id.* I find no backup for this statement. The citations given link to “page not found” both by the WHO and the AMA. The Ethics Committee of the American Society for Reproductive Medicine (ASRM) appears to have issued advisories limiting use of the procedure under certain circumstances, noting that there is little evidence upon which to base such policy. Jungheim, *supra* note 7, at 26.

146. Ram, *supra* note 1, at 278.

147. *Id.* (noting “[t]he Medical Research Council in Britain recently . . . report[ed] . . . [a] lack of standard lab techniques and culture media among IVF clinics further compounds the difficulties of obtaining clear information about the safety of assisted reproduction.”).

148. Halter, *supra* note 89, at 100; Pamela Laufer-Ukeles, *From Consent to Empowerment in Support of Decision-making in Embryonic Genetic Design*, 96 CHI.-KENT L. REV. 214 (2021).

149. Cahn, *supra* note 36.

150. Discussed *infra* Part III.B.4.c.

Yet, in perhaps the crassest assessments I have seen, “bioethicist” Merle Spriggs considers the informed consent issue a distraction in the case of savior sibling creation, noting that “[t]he lack of consent is not morally significant in this case.¹⁵¹ Newborn babies are simply not equipped to give consent.¹⁵² Spriggs further discounts considerations of violating the human dignity of the savior sibling: “First of all, it is not clear how . . . [the savior’s] ‘human dignity’ has been or will be compromised or why his dignity is of such magnitude that it is more important than his brother’s life.”¹⁵³

With these injudicious pronouncements emanating from the bioethical community, I now turn to the legal approach.

III. THE LEGAL ANALYSIS

A. United Kingdom Law

On July 21, 2004, the HFEA revised its policy on PGT for tissue typing,¹⁵⁴ a decision affirmed by the United Kingdom’s highest court, the House of Lords, on April 28, 2005, in the *Quintavalle v. Hum. Fertilis. & Embryo. Auth.* case.¹⁵⁵ Whereas the earlier (2002) directive allowed tissue typing only to avoid a serious genetic disorder,¹⁵⁶ the later policy allows pre-implantation tissue typing even where tissue typing is the only purpose,¹⁵⁷ with a view to

151. Autonomy (which the young savior does not have) is a hallmark of any ethical system and is necessary for consent. See, e.g., Shapiro, *Ethical Conundrums*, *supra* note 7, at 433. And consent is a requisite to avoid charges of battery; see CASEBOOK ON BIOETHICS FOR JUDGES 21 (Amnon Carmi & Barbara Pfeffer. Billauer eds., 2016); see also Steven Ertelt, *Rescue Me: The Moral and Ethical Problems of Creating Savior Siblings*, LIFENEWS (Aug. 8, 2008), <https://www.lifenews.com/2008/08/08/bio-2540/> [<https://perma.cc/7YKP-RJMG>] (discussing ethical issues with savior siblings and consent).

152. Merle Spriggs, *Conceiving a child to benefit another against the interests of the new child?* 31 J. MED. ETHICS 341–42 (2004) (Responding to fertility pioneer Lord Winston who asks: “Can you think of any other medical treatment which you would expect anybody to undergo without informed consent. . .?”; Spriggs notes that “Lord Winston’s concern about lack of consent distracts us from more important issues.”); but see Linda Delany, *Altruism by proxy: volunteering children for bone marrow donation*, 312 BMJ 240, 240 (1996) (referring to *S v S, W v Official Solicitor* [1970] 3 All ER. 107); see also PAN AM. HEALTH ORG., RECOMMENDATIONS FOR EDUCATION AND SELECTION 11 (2009); see also S.E., Mumsford, *Donation Without Consent? Legal Developments in Bone Marrow Transplantation*, 101 BRIT. J. HAEMATOLOGY, 599–602 (1998).

153. Spriggs, *supra* note 152, at 341.

154. Press Release, HFEA, HFEA agrees to extend policy on tissue typing (July 21, 2004), <https://www.legislation.gov.uk/uksi/2004/1511/contents/made> [<https://perma.cc/RLR7-7HLM>].

155. See *Quintavalle v. Hum. Fertilis. & Embryo. Auth.* [2005] UKHL 28, [1], [29] (appeal taken from EWCA).

156. Press Release, HFEA, HFEA confirms that HLA tissue typing may only take place when pre-implantation genetic testing is required to avoid a serious genetic disorder (Aug. 1, 2002).

157. Sheldon & Wilkinson, *supra* note 58, at 137–139 (“The broad [HFEA] ‘strict controls’, [of 2001] included that. (a) the condition of the affected child should be severe or life threatening, of a sufficient seriousness to justify the use of PGD; (b) the embryos conceived in the course of this treatment should themselves be at risk from the condition by which the existing child is affected; (c) all other

creating savior children and harvesting bone marrow.¹⁵⁸ The new policy was considered a victory for British bioethicists.¹⁵⁹

Legal scholar Lisa Cherkassky describes the seminal *Quintavalle* case¹⁶⁰ as providing assurances that a savior child will receive the full protection of the law.¹⁶¹ Nevertheless, she posits that the case also seems to hold that children can be created, even if a sibling is not ill, and that the mother may be allowed to choose a child with characteristics of her choice.¹⁶² Cherkassky raises the troubling incorporation of the phraseology allowing selection for “purely social purposes.” The sole limitation, it seems, is that the tissue must be used for a sibling.¹⁶³

This may be fine and good in the United Kingdom with its strict regulations. But what about in unregulated countries such as the United States—where “off-label uses” might include, for example, a wealthy sperm or egg donor who, in exchange for donating gametes, expects future use of the child’s tissue?¹⁶⁴ Even if we agree that this is ethically wrong—how can it be stopped? The procedure is not reportable, so how do we know if this has already been attempted? Further, even under British law, where both parents agree to an invasive bone marrow transplant, there appears to be no way to monitor its use after birth. Finally, limiting the procedure to siblings might seem appropriate, but under current guidelines, is this legally or even ethically defensible?

B. An Updated Legal Analysis

One approach to evaluating the matter, suggested by Professors Wolf, Kahn, and Wagner, is to amalgamate the legal analysis of all technologies as a unit because their impact (at the time of their work, there were only three) is synergistic. This approach leads them to advocate more stringent

possibilities of treatment and sources of tissue for the affected child should have been explored; (d) the techniques should not be available where the intended recipient is a parent; (e) the intention should be to take only cord blood for purposes of the treatment, and not other tissues or organs; (f) appropriate implications counselling should be a requirement for couples undergoing this type of treatment; and (h) embryos should not be genetically modified to provide a tissue match.”) (discussed in the context of the Hashimi case).

158. Cherkassky, *supra* note 40, at 3.

159. Ram *supra* note 1, at 278.

160. Cherkassky, *supra* note 40, at 2.

161. *Id.* at 4.

162. *Id.* at 3.

163. *Id.* at 5.

164. A frightening future world premised on this possibility is created in KAZUO ISHIGURO, NEVER LET ME GO 210–211 (2006).

protections than currently exist.¹⁶⁵ While I agree with their conclusions, in light of recent data, I suggest that evaluating each step individually might provide a simpler and more transparent paradigm. This approach also exposes underlying flaws in our expectations, deficiencies in our current means of analysis, and the doctrines on which we rely. This methodology also reveals that real work is necessary to formulate guidelines for dealing with novel reproductive adjuvants and genetic advances, and that regulation of the process of savior sibling creation may lead to unintended consequences, such as seriously limiting its availability and use, as in Great Britain, or unwittingly broadening its use.

As of today, four basic technologies may be involved in creating and maintaining protective progeny: (1) Hormonal stimulation, which is accompanied by its own panoply of issues along with IVF, discussed above; (2) HLA-tissue matching PGT with or without diagnostic PGT for genetic conditions,¹⁶⁶ involving blastocyst biopsy which may also damage the developing embryo;¹⁶⁷ (3) stem-cell transplantation, mostly involving bone marrow; and possibly (4) creative use of CRISPR gene-editing to accomplish a more perfect match of the HLA complex.

1. IVF: The Decision to Have a Child

One objection to savior child creation is that parental motives may be suspect.¹⁶⁸ Legally, it shouldn't matter, and proponents of the procedure rightly attack this objection.¹⁶⁹ From a legal perspective, the parental objective of creating a child is irrelevant, whether to provide a playmate for an existing sibling or to save a marriage. Under current American law, as articulated in *Skinner v. Oklahoma*,¹⁷⁰ reproductive liberty is all but absolute and objections addressed to parental motivation for IVF assistance is legally questionable.

165. Wolf, *supra* note 49, at 327.

166. *Id.* See also Ram, *supra* note 1.

167. Danilo Cimadomo et al., *The Impact of Biopsy on Human Embryo Developmental Potential During Preimplantation Genetic Diagnosis*, BIOMED. RSCH. INT'L (2016) (noting "A critical aspect of this technology is the potential detrimental effect that the biopsy itself can have upon the embryo.").

168. Sheldon & Wilkinson, *supra* note 58, at 534.

169. *Id.* at 533 ("The real question then is: Which reasons are the wrong reasons?").

170. 316 U.S. 535, 541 (1942).

2. Preimplantation Genetic Testing for Tissue-Matching

a. One Test, Two Uses. Does It Matter?

Nevertheless, the right to have a child via IVF does not imply a right to demand that embryos selected for implantation be based on their immunological properties. Indeed, many physicians and ethicists agree that trait selection is not acceptable.¹⁷¹ The question becomes: Does HLA testing fall within the category of treatment under a new exemption transferring the therapeutic function or enhancement (i.e., trait selection) to someone else?¹⁷² There are no answers for this.

The proponents have argued that the tissue-matching test technology is the same as used for the societally beneficial use of preventing the birth of children with genetic diseases, which accrue to some 5.3% of the population,¹⁷³ and thus using PGT to treat anyone's disease reduces healthcare spending, maximizing resources for all.

But the slippery slope reveals its slimy scree when using PGT to not only select against actual (monogenic) genetic disease.¹⁷⁴ We are now using PGT not only to select against disease, but against genetic susceptibility for disease, to the hue and cry of the disability rights community.¹⁷⁵ Some laboratories even used it for trait selection (for family "balancing") and

171. John A. Robertson, *Extending preimplantation genetic diagnosis: the ethical debate: Ethical issues in new uses of preimplantation genetic diagnosis*, 18 HUMAN REPROD. 465–471 (2003); see also Hilde Van de Velde et al., *The experience of two European preimplantation genetic diagnosis centres on human leukocyte antigen typing*, 24 HUMAN REPROD. 732, 738 (2008) ("Any selection on the basis of non-pathological characteristics, whether or not combined with testing for genetic diseases, is condemned.").

172. Van de Velde, *supra* note 171.

173. See I.C. Verma & R.D. Puri, *Global Burden of Genetic Disease and the Role of Genetic Screening*, 20 SEMIN FETAL NEONATAL MED. 354–63 (2015).

174. Verlinsky, *supra* note 7, at 293 (noting that 754 babies have been born as a result of 4,748 PGD attempts as of 2004 in the three largest preimplantation centers over twelve years, since its introduction in 1990).

175. *Embryo Checks 'Should be Widened'*, BBC NEWS (May 8, 2006), <http://news.bbc.co.uk/2/hi/health/4750341.stm> [<https://perma.cc/GYK6-3YVL>] ("The UK Human Fertilisation and Embryology Authority currently allows embryos to be screened for inherited diseases such as cystic fibrosis . . . and two inherited cancer conditions . . . familial adenomatous polyposis (FAP), a type of bowel cancer, and cancer of the retina" using pre-implantation genetic diagnosis (PGD). Following a government report recommending screening for susceptibility genes linked to cancer, stakeholders objected: "[the] director of the group Comment on Reproductive Ethics, said: 'PGD is currently nothing more than a weapon of destruction, aimed at the ruthless elimination of any embryo which does not conform to eugenic concepts of perfection.' . . . Rachel Hurst, of Disability Awareness in Action, said: 'If you say that it's OK to say that you can eliminate embryos which would lead to disabled people, you're saying that disabled people are not people. And you're saying that their quality of life is not worth living, which is discriminatory and extremely prejudicial.'" See also Sagit Mor, *The Dialectics of Wrongful Life and Wrongful Birth Claims in Israel: A Disability Critique*, in 63 STUDIES IN L, POL. AND SOC'Y 113–146 (Austin Sarat ed., 2014).

although eventually the practice was stopped,¹⁷⁶ it appears it has since reappeared.¹⁷⁷

The “cost” of reducing genetic diversity inherent in the procedure and the “benefit” of producing available transplantable tissue or organs that would be reciprocally available to the child and family members has been described above. Evaluating the cost-benefits of this calculus requires robust societal colloquy which, to date, has been missing. Without it, adequate policy cannot be drafted, and recrafting common law to deal with negligent-injury production that might arise in various steps of the process will continue to elude us.

b. The Kit and Caboodle Test: Individual vs. Joint Best Interest

The United Kingdom HFEA’s position makes it hard to avoid a determination that selecting *for* an HLA-match test might be considered an enhancement rather than a treatment. They cover their tracks by arguing that since its purpose is to save a life, the entire procedure is acceptable, using a “kit and caboodle” approach (i.e., bundling the evaluation for the entire process). Some proponents use this approach to argue that the children’s interests should be considered jointly, evaluating their “collective interests” as a whole. If one might be subject to a risk to save another, the collective benefit lies in favor of subjecting that child to a small risk. These “ethicists” use the case of conjoined twins as a model.¹⁷⁸

One analogy evaluated the rights of conjoined twins who have no existence apart from the other, and compared this to a situation where two

176. *Germline gene-editing research needs rules*, NATURE (Mar. 12, 2019), <https://www.nature.com/articles/d41586-019-00788-5> [<https://perma.cc/8ESZ-MSXC>] (“In the wake of CRISPR babies, there is an urgent need to better regulate and debate whether, when and how related research should be done.”); Paul Knoepfler, *Why NY AG suit against Manhattan stem cell clinic is such a big deal*, THE NICHE (Apr. 7, 2019), <https://ipsell.com/2019/04/why-ny-ag-suit-against-manhattan-stem-cell-clinic-is-such-a-big-deal/> [<https://perma.cc/GB8G-9LBN>].

177. Albeit in the form of risk prediction by polygenic genetic score selection based on evaluation of multiple genes. In the current iteration, this process is not use for trait selectin but for the purposes of selecting out polygenic diseases. See GENOMIC PREDICTION CLINICAL LAB [<https://perma.cc/VKG6-K5EB>]. Nevertheless, the same and existing technology could be used to select for enhanced health, athletic prowess, and even higher intelligence. The implications for expanded use of this technology are vast, perplexing, and outside the scope of this article. See also, Melody Peterson, *A start-up says it helps parents pick healthier embryos. Experts say it’s not that simple*, JERUSALEM POST (June 6, 2021), <http://jpost.pressreader.com/jerusalem-post> [<https://perma.cc/7KFY-M2D6>] (“Laurent Tellier, the chief executive and co-founder of Genomic Prediction, told the Times: the company test of embryos for cognitive disability became so contention that it no longer offers them.”).

178. Sheldon & Wilkinson, *supra* note 58, at 159 (Discussing the case of Re A (citing V. Munro, *Square Pegs in Round Holes: The Dilemma of Conjoined Twins and Individual Rights*, 10 S.L.S. 459 (2001), and comments of the HFEA Ethics Committee, *op.cit.*, n. 9 at para. 2.14–2.15). The case of R v. Cambridge Health Authority “highlights the lack of legal concern for children who become bone marrow donors.” See R v. Cambridge Health Authority, *ex parte* Beckwith [1995] EWCA Civ 49.

separate and independent lives are at stake—one of which is entirely healthy—contradicts the very justifications proffered by its proponents. To consider the savior child and the recipient-elect child a package deal is nothing more than normalizing the objection that the savior child would suffer psychological harm if he or she realizes its very existence was for the purposes of another. Indeed, this model removes from the savior child any legitimacy of an independent existence. Even his or her own rights are not being evaluated independently.

3. Gene-editing

The HLA molecule is extraordinarily complex, involving at least 200 genes to encode for it.¹⁷⁹ Tissue-matching is the best guarantee to avoid rejection, although this is far from perfect, and reactions occur even with HLA matched siblings, as noted.¹⁸⁰ To minimize untoward results, gene-editing might provide better matches between host and donor tissue, leading to fewer adverse reactions.¹⁸¹

One interesting consideration arises when a donor embryo has malformed HLA genes, and these are repaired by gene-editing as part of the tissue matching procedure. In this case, we could claim the gene-editing and HLA testing was therapeutic, and bypass objections raised if PGT was merely for selection. In sum, given that somatic cell gene-editing is now considered an acceptable procedure, if the gene-editing was done to repair malformed HLA molecules, there should be no objection. To the extent, however, that the procedure is used to transform one healthy, but mismatched HLA molecule, into a matched one, the procedure would garner the same objections as PGT-HLA selection.¹⁸²

179. *Histocompatibility*, *supra* note 102.

180. Ben-Senior, *supra* note 1.

181. See Brezina *supra* note 44.

182. Van de Velde, *supra* note 171, at 736.

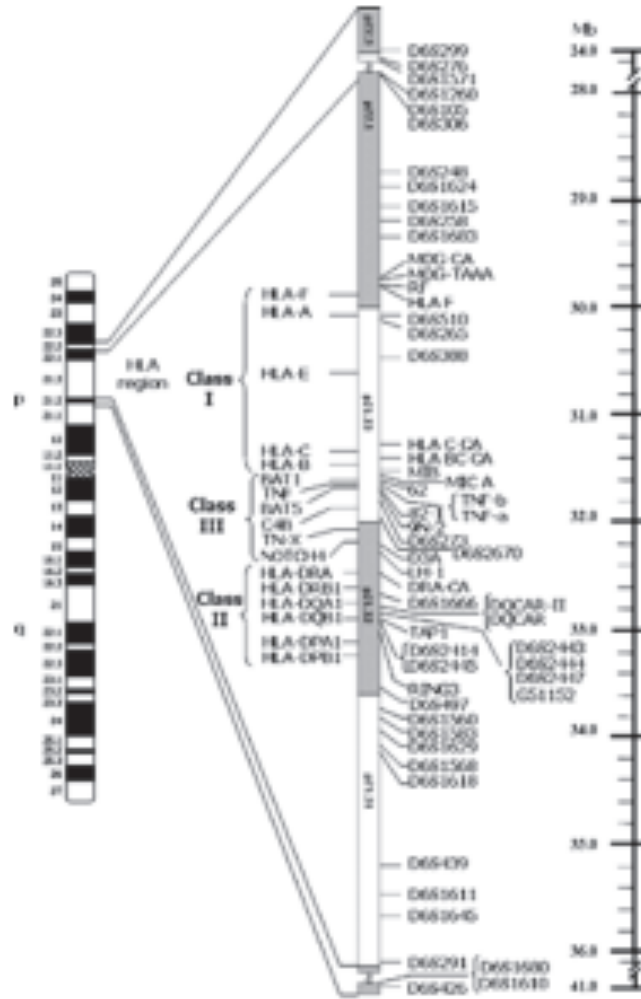


Diagram 1: A map of the 200 genes encoding for HLA and its three sub-groups¹⁸³

183. *Id.* (The following copyright applies to the content of this slide: Published by Oxford University Press on behalf of the European Society of Human Reproduction and Embryology 2008.); *see also Histocompatibility, supra* note 102.

4. Transplantation and the Best Interest Test

The most critical issue in assessing legitimacy of protective progeny revolves around bone marrow transplantation. As noted, the HFEA requires that all decisions involving the donor child must be decided according to “the best interest test,” a problem neatly side-stepped by the procedure’s proponents, by simply claiming, *ipse dixit*, that the procedure is indeed in the child’s best interest.¹⁸⁴ The legal matrix is not nearly as forgiving. While tissue donation by savior children has not faced the courts, the issue has been litigated in the course of regular tissue donations. This is relevant, as it has been suggested that “[o]ne way to check whether the interests of the future child are respected is by applying the postnatal test: if it is acceptable to use an existing child for a certain reason, it is also acceptable to create a new child for the same reason.”¹⁸⁵

We now confront the layered use of the “best interest” test. First, as used by the HFEA, all decisions concerning both children must be made in their best interests. This applies even at the first step of creation—IVF—and the PGT-tissue-matching phase. Second, the best interest of the donor child—who would be required to undergo bone marrow transplant surgery—requires informed consent.¹⁸⁶ Notwithstanding the disdain to which some Commonwealth bioethicists attach to that right, in the United States “[n]o right is held more sacred, or is more carefully guarded by the common law, than the right of every individual to the possession and control of [the individual’s] own person”¹⁸⁷

Determining informed consent by a minor, proceeds along two alternative pathways since the child, himself or herself, is incapable of consenting if the transplant is performed at a tender age. (It appears the convention is to perform the bone marrow transplant at one or two years of age to spare the

184. Sheldon & Wilkinson, *supra* note 58, at 140, 160 (stating without support that “it should be noted that such donations are routinely permitted on the basis that it is in the donor child’s best interests to preserve the life of a sibling, see n. 58 *infra* footnote 11 at 140,” and further noting that section 13(5) of the HFEA 1990 directs us that . . . [the child’s welfare] is merely [one] . . . factor of which ‘account must be taken’, consideration (of all children) being of equal concern, and “[n]either consideration is paramount over the others.” This is in direct contravention of section 1(1)(a) of the Children Act 1989 establishing the child’s welfare as the paramount factor in any decision involving any aspect of a child’s upbringing.”).

185. F. Shenfield et al., *Taskforce 9: the application of preimplantation genetic diagnosis for human leukocyte antigen typing of embryos*, 20 HUMAN REPROD. 845, 846 (2005).

186. Cherkassky, *supra* note 40, at 7–8 (noting that bone marrow removal is omitted from the HFEA statute and governed by the common law of informed consent, which has its roots in the doctrine of *parens patriae* and allows the state to act for the benefit of those “who are incapable to take care of themselves.”).

187. *Union Pac. Ry. Co. v. Botsford*, 141 U.S. 250, 251 (1891).

sick child more time in pain).¹⁸⁸ The decision itself usually vests in a guardian, which is not always the parent.¹⁸⁹

One mechanism for the guardian or parent's determination is the substituted judgment test—where the parent subjectively determines what the child would have wanted. The other mutually exclusive route is employing a second “best interest” test: Would *the donation* be in the best interests of the child? This second-best interest test, as used in the British Commonwealth, was routinely used to protect children from non-therapeutic procedures.¹⁹⁰ The dichotomy becomes clearer in end-of-life decisions.¹⁹¹

a. The Best Interest Test for Donation Determination

The hallmark American case on tissue donation by incompetents is *Curran v. Bosze*.¹⁹² Therein, after rejecting the substituted judgment methodology, the Illinois Supreme Court provided a three-part test for child bone marrow donation under a best interest determination: (i) the consenting parent must understand the risks and benefits of the procedure, (ii) there must be emotional support from the person with parental responsibility, and (iii) there must be an existing close relationship between the donor and the sick child.¹⁹³

For the procedure to be in the child's best interest, the *Curran* court held that the donor child must derive some benefit. It would be high unlikely for a savior child to experience any kind of physical benefit from a bone marrow donation,¹⁹⁴ even to a sibling.¹⁹⁵ However, the court noted that if there is an *existing* relationship between the donor and the sibling, we can say the

188. See generally WHITEHOUSE, *supra* note 3 (describing the trials and tribulations of the Trebing family as they proceed from PGT to transplant).

189. See Shapiro, *Ethical Conundrums*, *supra* note 7, at 448.

190. Cherkassky, *supra* note 40, at 9 (noting that La Forest J “held that a correct application of the *parens patriae* jurisdiction would never validate a nontherapeutic procedure” (citing *In Re Eve*, [1986] S.C.R. 38 (Can.))) (noting that an alternative characterization of the best interest test is to describe the purpose of wardship in objective terms of what a reasonable parent would do (citing *In Re J* citing *In Re D (A Minor)* citing *in re Eve*, . . . where La Forest J held that a correct application of the *parens patriae* jurisdiction would never validate a nontherapeutic procedure)).

191. See *infra* Part III.B.4.b.

192. 566 N.E.2d 1319 (Ill. 1990).

193. *Id.*

194. Although it could be argued that the creation of a tissue match sibling could benefit the savior child as well, should that child later need an organ transplant her or his sibling might be able to supply it.

195. See Robert W. Griner, *Live Organ Donations Between Siblings and the Best Interest Standard: Time for Stricter Judicial Intervention*, 10 GA. ST. U. L. REV. 589, 590 (1994) (Live organ donations between siblings and the best interest standard: time for stricter judicial intervention); see also J Hunter, *Consent for the legally incompetent organ donor. Application of a best-interests test*, 12 J. LEGAL MED 535, 556 (1991); James F. Childress, *The gift of life: ethical problems and policies in obtaining and distributing organs for transplantation*, 13 PRIM. CAR. 379–94 (1986); see Caplan, *supra* note 69, at 1199.

donor-child derives psychological benefits, and this would be sufficient to infer the procedure inured to the child's best-interests.¹⁹⁶

With rare exceptions, perhaps in the case of twins, one would be hard-pressed to believe that a very young child ever could forge a close enough relationship with a sibling to offset the negative physical and psychological consequences involved in invasive tissue or organ donation. Being compelled by its parents to suffer in any way could also harm the entire family fabric if the donor child later comes to believe that the sick child is preferred. Even if, in reality, that is not the case, the time devoted to caring for a child, sick or otherwise, is often internalized by a sibling as preferential treatment. We need look no further than the biblical verse cited at the outset to intuit what would happen under those circumstances.¹⁹⁷

Moreover, siblings do suffer *negative* psychological affects if the transfusion doesn't work.¹⁹⁸ For savior siblings, any positive psychological impact must be additionally balanced against the previously identified negative emotional toll of being created for the benefit of someone else, a consideration which does not arise in a normal transplantation case. In short, for the savior sibling, any positive psychological benefit would be offset by the negative aspects of the procedure. In other words, if the decision was foisted on a very young savior sibling, let's say a year old, before psychological bonds with the ill sibling had formed, the risks of the procedure would outweigh any benefits.

b. Substituted Judgement and Solidarity

In reaching their conclusion, the *Curran* court rejected the doctrine of substituted judgment,¹⁹⁹ which might actually be of more relevance in the case of savior siblings. The doctrine of substituted judgment requires a surrogate decisionmaker to "attempt[] to establish, with as much accuracy as possible, what decision the patient would make if [the patient] were competent to do so."²⁰⁰ This approach is often used at the end-of-life stage where

196. Cherkassky, *supra* note 40, at 12.

197. *See supra* p. 175.

198. These include "anger, guilt and blame." Other negative psychological impacts derive from situations where the child was "uninformed about potential medical complications or did not receive adequate support afterwards." *See* Shapiro, *Ethical Conundrums*, *supra* note 7 at 438; *see also* 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).

199. The doctrine was recognized by the court in *In re Estate of Longeway*, 549 N.E.2d 292 (Ill. 1989), and *In re Estate of Greenspan*, 558 N.E.2d 1194 (Ill. 1990).

200. *Curran*, 566 N.E.2d at 1322.

the patient is incompetent, and the decision-maker relies on statements or messages left by the patient during his or her lifetime regarding what they would intend under the circumstances. “If there is no clear evidence of such intent, then the patient’s personal value system must guide the surrogate.”²⁰¹ Thus, while a substituted judgment test might allow a patient to be taken off a respirator, a best-interest test would result in the opposite result—since it results in the patient’s death.

In deciding normative behavior in this context there might well be cases where the family believes it would be in the child’s best interests to donate bone marrow, or even an organ. This outcome, however, clearly trespasses on the legal reasoning employed in *Curran*. Nevertheless, in some cultures there can be instances where life-giving transfusions may well psychologically benefit even a young child.²⁰² Such cultures place such a high value on saving a life such that a child conceived to fulfill this precept would feel that his entire being is tantamount to saving the world. In communities or groups with value systems venerating saving a life,²⁰³ children born with the knowledge that they were created to fulfill a sacred precept might feel honored and empowered. This psychological well-being might even be more profound in a child who learns his very existence was enabled to give life to another (similar to the rhetoric used with the adopted child who is told he or she is loved more than a natural child, since he or she was selected).

A family who so believes would feel that by creating such a life-giving entity, they are fulfilling sublime and divine commandments. To deprive this family (and the ensuing child) of this positive experience, while saddling it with the travesty of losing a child, might be traumatic not only to the family, but to the community to which they subscribe. This result would apply regardless of whether the child is donating tissue to a sibling, a parent, or even to a complete stranger, as counter-normative as that might be to some of us.

Allowing savior donation in these cases could well proceed, legally speaking, under a substituted judgement test. We can reach the same conclusion using a bio-ethical analysis, under the rubric of solidarity, either as it is

201. *Id.* at 1333 (explaining “[i]f no prior specific statements were made, in the context of the individual’s entire prior mental life, including his or her philosophical, religious and moral views, life goals, values about the purpose of life and the way it should be lived, and attitudes toward sickness, medical procedures, suffering and death, that individual’s likely treatment/nontreatment preferences can be discovered. the family’s knowledge exists nevertheless, intuitively felt by them and available as an important decision-making tool.” (citations omitted)).

202. *Strunk v. Strunk*, 445 S.W.2d 145, 146 (Ky. 1969).

203. E.g., the Jewish view (echoed in the Quran) that saving one life is tantamount to saving the world. See generally Philologos, *The Origins of the Precepts “Whoever Saves a Life Saves the World*, MOSAIC MAG. (Oct. 1, 2016), <https://mosaicmagazine.com/observation/history-ideas/2016/10/the-origins-of-the-precept-whoever-saves-a-life-saves-the-world/> [<https://perma.cc/8C37-CU95>].

articulated under Article 13 of the UNESCO Declaration on Bioethics and Human Rights,²⁰⁴ or under the general principle of philosophical solidarity—as so eloquently expressed by Professors Efrat Ram-Tiktin and Roy Gilbar in their work on posthumous use of sperm.²⁰⁵

c. Unintended Consequences

While the HFEA excludes PGT for tissue-matching if used for parents, counter-normatively, creation of such children for parental use might be legally justifiable in the United States. Under the discussion outlined in *Curran*, if the parent is suffering a severe disease,²⁰⁶ it might well be in the child's best interest to donate tissue or even an organ to the parent. Certainly, even an infant forges psychological bonds with her or his mother. As the child grows, these bonds become stronger. In the hypothetical envisioned at the outset, where one parent is seriously ill and might die, it becomes even more imperative for the child to enable the other parent to live—not just for psychological reasons but to sustain his or her physical life. Further, the child might benefit by reciprocal parental donation later, creating a mutual benefit. If all children in the family are created to either match father or mother, the family can serve as its own tissue/organ reserve, which opens a “Pandora's Box” of its own.

Finally, since one approved test to determine what is appropriate for savior siblings is to consider what would be acceptable in children not so conceived, it is noted that intra-family donations are allowable within families, especially if a close bond exists, and even more so if the parents agree.²⁰⁷ This can either be a net positive or give rise to abuses.²⁰⁸ Given the grave possibility for abuse, under this approach I advocate that *all* tissue or organ donations between family members involving minors should be subject to court oversight, a court designated *Guardian ad Litem*, supervision by an ethics tribunal or some impartial specially-trained consortium—even if the parents agree. While this outcome might be offensive to some, it highlights

204. CASEBOOK ON BIOETHICS FOR JUDGES, *supra* note 151, at 104–107.

205. See, e.g., Efrat Ram-tiktin & Roy Gilbar, *Solidarity as a Theoretical Framework for Posthumous Assisted Reproduction and the Case of Bereaved Parents*, 22 ETHICAL THEORY AND MORAL PRAC. (2019).

206. E.g., parents must meet the following criteria to be eligible for PGT-HLA procedures: Diseases eligible for PGT diagnosis must be lethal or severe. See Liat Ben-Senior, *Creating a Savior Child*, PARENTS GUIDE CORDBLOOD (Aug. 2019), <https://parentsguidecordblood.org/en/news/creating-savior-child> [<https://perma.cc/MX6Y-6UA4>].

207. Shenfield, *supra* note 185, at 846.

208. See ISHIGURO, *supra* note 164, at 210–11 (relating a dystopian vision of children created in this fashion).

the fact that parents can rarely be objective in some situations,²⁰⁹ such as in assessing their children's pain.²¹⁰ When the welfare of two siblings are involved, parental objectivity is seriously wanting.²¹¹ Since courts do get involved if there is parental discord,²¹² one is hard-pressed to understand how the child's interests differ where there is no discord between parents—the boundaries between child and parent do exist, although often in these situations they are blurred.

IV. CONCLUSION

Some hold that:

The creation of a child for the purpose of harvesting non-regenerative organs is extremely difficult to justify in view of the risks involved for the donor child. Since solid organ donation by children or incompetent adults is not considered morally acceptable because of the more than minimal risk for the donor, creating a child in order to obtain an organ for a sibling is not acceptable either.²¹³

On the other end of the spectrum, others contend that it is a moral imperative to create such children since they have the potential to save a life. Some say the entire issue should be addressed by regulation, akin to the HFEA,²¹⁴ perhaps without recognizing that this approach would almost entirely foreclose the practice. Others contend it is for the mother to decide, as per the HFEA.²¹⁵

Others suggest that only donations found to be in the child donor's best interests, as determined by reference to a statutory checklist of factors (which

209. Cherkassky, *supra* note 40, at 10, 11 (In a case of conjoined twins, the Court noted that “it may seem unduly harsh on these desperate parents to point out that it is the child's best interests which are paramount, not the parents,” which is suggestive of the difficulty that parents have in recognizing these boundaries. (quoting *Re A*, [2001] Fam. 147, per Ward L.J. at 195).

210. Gerry Kent, *Volunteering Children for Bone Marrow Donation: Studies Show Large Discrepancies Between Views of Surrogate Decision Makers and Patients*, 313 *BMJ* 49 (1996), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2351450/> [<https://perma.cc/8JLV-DK5A>].

211. See Cherkassky, *supra* note 40, at 10 (citing *Re A (Children) (Conjoined Twins: Surgical Separation)*).

212. The United Kingdom's Human Tissue Authority has published a Code of Practice on bone marrow donations from children. The court is only required to validate the harvest if there is disagreement as to the best interests of the child. See U.K. HUMAN TISSUE AUTHORITY, CODE OF PRACTICE FOR DONATION OF ALLOGENEIC BONE MARROW AND PERIPHERAL BLOOD STEM CELLS FOR TRANSPLANTATION, ¶ 48 (2017).

213. Shenfield, *supra* note 185, at 846.

214. See Shapiro, *Ethical Conundrums*, *supra* note 7 at 451–2.

215. Cherkassky, *supra* note 40, at 7 (noting that the HFEA recognizes that deciding the purposes for which the child is selected must be suitable “for the woman”).

would include ascertainable wishes of the child) should be permitted. A forum, independent of the parents and medical advisers, should vet each proposed graft. An informal tribunal or independent medical social worker, rather than a court, might be used for this purpose.²¹⁶

Some say a best interest test should be employed to determine transplants.²¹⁷ In that case, given the risks to the donor child, no court could agree—as any psychological benefit derived from transplantation would be offset by psychological harm incident to its creation (as well as additional potential negatives should the transplant fail). Others say that decision should be based on what would be done if the child was not conceived as a savior child. In that case, protective progeny could be created to save a parent or any close relative. A substituted judgment test would support that result.

In short, many have sounded in without any consistent legal or ethical or biological matrix upon which to base decisions, resulting in haphazard, contradictory, confusing, and/or unintended consequences. We are left with the following conclusions:

1. The risks of transplantation, for *both* children, is not insignificant, which leads to the conclusion that PGT for HLA-matching (which carries risks of its own), cannot be considered in the best interests of the donor child.
2. HLA-matching is no guarantee of success, although gene-editing might provide for both safer procedures and better therapeutic intervention and outcomes if performed on unhealthy embryos. The availability of gene-editing might therefore remove some ethical and biological constraints.
3. The issue of biological and social diversity must be carefully considered. If this is not considered an obstacle, then creation of protective progeny—even leading to parental-child transplant—would allow all children so created to have reciprocal benefits with those tissues they are designed to match, although the potential for abuse is so large that this should be undertaken with great care.
4. Objective consent by parents is impossible. The parents, even if the children were not created for their benefit, are so emotionally vested in saving the life of their existing child by the time they embark on the procedure, that their emotional interests are inextricably intertwined with that child's.

216. Wolf, *supra* note 49, at 334.

217. *Id.*

5. At present, court review only ensues if the parents disagree. In none of the hundreds of cases of savior children created in this fashion, are there any reports that the parents disagreed, and in the scores of such savior children who underwent bone marrow transplantation, we see no court intervention. The interests of the children do not change according to the state of parental marital harmony, and yet children born of parents united in interest are at a disadvantage.
6. Should it be deemed societally beneficial to allow the procedure (to conserve resources, for example), only the use of the substituted judgment paradigm could allow for its justification, and all transplants should be undertaken with impartial oversight.

I suggest that before deciding how to regulate or address the savior child issue—the medico-legal issues must be clearly identified, including the biological ones. I further advise that societal needs must be evaluated along with personal ones. This includes balancing the need for biological diversity against resource-conservation and organ availability. Further, and of critical import, I suggest integration of the *Guardian ad Litem* or similar formal external review process must become an institutionalized legal requirement in all transplant procedures involving children, but especially those where the rights of one child are pitted against the needs of others.

Finally, those focusing on psychological benefits should be mindful that family dysfunctionality often arises from the perception that a parent favors one child over another. One needs only to check the Bible.²¹⁸

218. *Genesis* 37: 3 (“And Israel loved Joseph more than all his sons, because he was a son of his old age; and he made him a fine woolen coat.”). The great commentator Rashi, citing *Genesis Raba* 84:8, noted that Jacob favored Joseph because he looked like him. See THE COMPLETE JEWISH BIBLE WITH RASHI COMMENTARY, https://www.chabad.org/library/bible_cdo/aid/8232/showrashi/true/jewish/Chapter-37.htm [<https://perma.cc/X7BB-D2KP>].