# MINOR DONATIONS: USING CHILDREN AS A MEANS TO AN END

**By: Misbahul Fatima**[1]

## I. Introduction

Pre-implantation genetic diagnosis ("PGD") is a process that uses in vitro fertilization ("IVF") to deselect embryos carrying genetic defects.[2] One of the most controversial uses of PGD technology is for human leukocyte antigen ("HLA")-matching, an embryo screening process that allows parents to choose the child with the best-matched genes.[3] This child, known as the "savior sibling," is then used to aid a preexisting ailing sibling in need of a stem cell transplant.[4] Because PGD is a recent development in the medical field, its "savior siblings" legal framework in the United States remains undeveloped.[5] In the absence of guidelines regarding PGD in the United States, providers and patients find support in two ethics committees while making their decision: the American Society of Reproductive Medicine and the American Medical Association.[6] The former does not discuss using PGD for human HLA-matching, which is how PGD is used to create savior siblings, while the latter states that PGD can be used to "prevent, cure, or treat genetic diseases."[7] These ethics committees provide the backdrop for the use of PGD to create savior siblings, but they do not explicitly address the issue of donations from these minor children. The purpose of this article is to inform readers about the current legal framework regarding minor sibling donations and to demonstrate how the methodology applied by courts today is sufficient given the individualized nature of children presented in the limited amount of case law on the topic of "savior siblings."

## II. National Organ Transplant Act (NOTA)

Before exploring the cases discussing transplantation between minor donors, it is necessary to explore the origins of PGD and the creation of savior siblings. In 1984, Congress

passed the National Organ Transplant Act (NOTA) to outlaw the sale of organs for compensation.[8] The lack of monetary incentives to organ donors for their donations led to a less effective organ procurement system in America.[9] In the United States, over 95,000 Americans waited for organs in the year 2006.[10] Fewer than 14,000 of those received donations.[11] Recognizing the average wait time to be somewhere between nine to ten years for procuring an organ, parents became inclined to create their own supply system.[12] The process of creating one's own organ procurement system is less expensive and more accessible than the national organ procurement system, and legal scholars predict that the procedure will continue to become less expensive and more accessible and the moral debate surrounding assistive reproductive techniques will abate.[13] They argue that currently, minor sibling donations cases represent only a small population of cases in the United States court system, but if the predicted trend comes to fruition, these cases will become extremely common and create a predicament for the courts.

The concerns expressed by legal scholars arise from an ethical, and even psychological debate, but fail to address shortcomings in the way that cases of minor organ donations are handled legally. In American legal history, conflicts regarding savior sibling donations have not reached trial or appellate court level due to the unregulated use of PGD-technology in creating these donors. If a disagreement were to arise between either the parents of the savior sibling or the providers and patients of the procedure, the case would become a state issue, similar to how other minor medical donations are addressed.[14] The decisions made under certain states are fact-specific, considering the best interest of both the parents and the children, along with the legal competence of the donor child.

## III. Current Legal Applications

Cases of "savior siblings" specifically are of a limited nature thus far in the American courts, and the legal discussion on the matter is generally analogized to past minor donation cases. In the cases regarding minor donations, American courts have applied preexisting legal standards: the *substituted judgment doctrine* and the *best interest standard*.[15] In the case of substituted judgment doctrine, parents are given permission to make a decision in lieu of their children as though these minors were formally competent decision-makers.[16] The best interest standard requires the courts to use various tests in order to measure whether or not the psychological benefits of the transplantation outweighs the physical risks associated with it for the donor sibling.[17] The two standards are used hand-in-hand by the court system, making them hard to distinguish from one another.

In reality, the courts are using the best interest standard and the substituted judgment standard interchangeably, indicating that although there are formal doctrinal distinctions between the two, there is no practical distinction. For example, in *Hart v. Brown*, the Connecticut Superior Court decided in favor of the transplant between two identical twins, as recommended by their parents and guardians *ad litem*.[18] Although the court attempted to use parental consent as their reasoning for the ruling, their final decision was based on the fact that the donor sibling would be "better off in a happy family than a distressed one." [19] Similarly, in *Little v. Little*, the court reasoned that a fourteen-year-old would benefit psychologically from donating a kidney.[20]

As established in the few cases in the American jurisprudence in which providers and patients disagree about the transplant, the individual states tend to rule mostly in favor of the donation.[21] They justify the transplant by looking to the psychological benefits that it provides to the donor. Although the courts have been met with little resistance in their application of the best interest standard, more recent cases such as *Curran v. Bosze* demonstrate that family

relationships have become harder to define, and thus, the psychological benefits for a sibling have become more difficult to justify.[22] Accordingly, the Supreme Court of Illinois attempted to find support in the substituted judgment standard when deciding whether two twins could donate to their half-brother. The Illinois Supreme Court concluded that parental consent was not enough to justify the donation.[23] Instead, the court sought to redefine the "best interest" of the twins in order to fit the case at hand.[24] Although, it might seem as though the American legal system risks fitting the issue of minor sibling donations in the realm of preexisting standards, in reality, many courts are implementing preexisting standards to fit contrasting cases of minor donation.[25]

### *A. Substituted Judgment Doctrine*

In *Hart v. Brown*, the Connecticut Superior Court used the substituted judgment doctrine to justify permitting the parents of twins, Kathleen and Margaret Hart, to undergo an isograft, a one-egg twin graft, kidney transplant between the two minors.[26] To support their ruling, the court employed the conclusion reached in *Strunk*, in which the parents were allowed to make a decision for their twenty-seven year-old mentally incompetent son to donate a kidney to his brother suffering from a fatal kidney disease.[27] However, critics of the substituted judgment doctrine posit that the doctrine specifically allows substitution of judgment in determining how the minor would decide if he or she were fully competent.[28] In the case of the mentally incompetent, assessing the decisional capacity of the incompetent seems acceptable, for they had or should have once had legal competency; this is contrary to determining the intent of children, who have never been legally competent.[29]

Alternatively, instead of focusing on intent like the court in *Hart*, the Supreme Court of Illinois attempted to assess the patient's *personal value system* in *Curran* to determine if three and a half year old twins would decide to transplant their kidney.[30] The court failed to find

conclusive evidence on the twins' "[m]orals, philosophy, religion, life goals, etc.," and thus, they concluded that the substituted judgment doctrine failed to provide evidence of the minors' subjective intent regarding the donation.[31] Although *Curran* became the exemplary case typifying how courts consider the substituted judgment doctrine in their analysis, most courts ultimately look at some type of best interest standard as well. Trying to determine the personal value system of a child is problematic, for individual cognitive and moral traits have yet to be developed at this age, an area of further discussion later in this article. The best interest standard, similar to the one started in *Curran*, is the proper analysis for courts to employ.

### *B. Best Interest Standard*

When applying the best interest standard, the courts weigh the psychological benefits a child will receive from a donation against physical risks associated with the procedure in order to make a decision on behalf of the child.[32] One scholar argues that even when courts claim they are using substituted judgment, they are applying the best interest standard in deciding minor donation cases.[33] While the parents are deemed decision-makers under the substituted judgment doctrine, courts make a decision for the child under the best interest standard. This is because there is a conflict of interest present when parents make decisions for their children. Arguably, they tend to place the needs of the sick child and their personal interest before that of the donor sibling.[34] Therefore, the courts interfere, explicitly recognizing that parental consent for minor donations should never be enough in deciding transplantation and donation cases.[35]

The application of the best interest standard is exemplified in *Curran*.[36] In *Curran*, the Supreme Court of Illinois affirmed the Circuit Court's decision to disallow the non-custodial parent of twin siblings to test the two for bone marrow transplantation for their half-brother.[37] To reach this conclusion, the court established three ways to determine the best interest of the child:

(1) the consenting parent must have knowledge of the risks and benefits of the procedure; (2) the child must receive emotional support from the primary caregiver; and (3) there must be an existent, close relationship between the donor and the recipient.[38] The twins' half-brother had interacted with them merely twice since their birth, without the twins' knowledge of their relationship. Therefore the court found no existing relationship between the three.[39] As a result, the court ruled in favor of the custodial parent by disallowing the donation to occur.[40] The court clarified that the ruling was based on the best interest of the child because the three and a half years old twins were not legally competent and did not yet possess personal value systems.[41]

Although the best interest standard appears to favor the donor sibling, one scholar criticizes it for vagueness, arguing that in reality, there is no set standard for which factors should be considered in determining the best interest of a child in minor donation cases.[42] In addition, the standard speculates too far into the future without considering the minor's personal wishes before the procedure. Children are unequipped to make medical decisions as the varying age and personal development stages of each child are not individually considered. They are legally marginalized, charging either their parents or the court system with reaching a decision on their behalf. In the best interest analysis, the decision-making power is merely transferred from the parents to the courts, and the issue of the child's incompetence is never addressed.[43]

While scholars' discomfort with the fluid standards of what constitutes a child's best interest is understandable, it is nevertheless unachievable to give children full decision-making powers when it comes to donations. In cases of donations made by minors, a significant amount of weight is placed on the child, regardless of whether or not he or she is the decision-maker. Children conceived for the purpose of donations often begin to feel an obligation to donate to their siblings whenever necessary. For this reason, researchers assess the psychological

development of children to decide whether they are capable of being responsible decision-makers. Such research leads them to conclude that while children should be allowed to exercise self-determination, they should not be burdened with the responsibility if they do not understand the implications of their decision.[44]

### *C. Piagetian Theory*

Jean Piaget, a psychologist best known for his theory on cognitive development, divided children's intellectual development into three stages: (1) the preoperational stage; (2) the concrete operational stage; and (3) the formal operational stage.[45] Table 1.1 describes the age and type of cognitive skills children develop during each stage.

*Table 1.1: Classic Piagetian Theory*[46]

| **Stage** | **Age** | **Cognitive Skills** |
|---|---|---|
| Preoperational | Under 7 | Magical thinking (cannot determine the finality of death) |
| Concrete-operational | 7-14 | Concrete facts and logical cognitive operations (can mostly determine the finality of death) |
| Formal operational | Above 14 | Abstract thinking (can determine the finality of death) |

### *D. Kohlberg's Theory of Moral Development*

Similar to Piaget's theory of cognitive development, psychologist Lawrence Kohlberg developed a theory of moral reasoning that led him to divide children's moral development into three stages: (1) preconventional; (2) conventional; and (3) postconventional.[47] Table 1.2 describes the age and type of moral reasoning children develop during each stage.

*Table 1.2: Kohlberg's Moral Development*[48]

| **Stage** | **Age** | **Cognitive Skills** |
|---|---|---|
| Preconventional | Under 7 | Good and bad/ right and wrong determined through punishment and reward |
| Conventional | 8-14 | Dedication to familial and |

| | | |
|---|---|---|
| | | societal expectations |
| Postconventional | Above 14 | Define moral values and principles |

### *E. Summary and Application*

As demonstrated above, the cognitive and moral development of children engenders confusion for legal decision makers. Arguably, children under the age of seven who engage in magical thinking cannot fully understand the risks and benefits that transplantation entails. Similarly, children at the postconventional stage might only think in terms of positive and negative consequences of the transplants. This makes it likely that a negative transplant procedure can lead children to create a cause and effect relationship in which they blame themselves for their sibling's illness.[49] Additionally, children at the initial stage of moral development are vulnerable and easily influenced by their parents' decisions. Considering their decisions to be completely independent would be fallacious.[50] This leads critics of minor transplantation to conclude that children, especially in the initial stages of cognitive and moral development, should be completely banned from participating in living donation procedures.[51]

Others, however, disagree with this argument, stressing the importance of the last stages in both the Piagetian theory and Kohlberg's model. From approximately the age of fourteen, children begin to exhibit adult-like thinking. They become capable of thinking more abstractly about "truth, morality, justice, and the nature of existence."[52] Lois Weithorn, famous for her experiments with the Piagetian theory, concluded that when placed in complex scenarios, adolescent children did not make decisions dramatically different than those of adults.[53] Thus, advocates of informed consent by minors promote legislative standards that deter coercion in children by demanding consent and/or assent by the children themselves.[54]

These psychological models should, nonetheless, be used for observational and experimental purposes. Both sides of the issue on minor donations should recognize that the models do not provide a clear-cut age limit as to when children have reached their full cognitive and moral development. In reality, "other people, environment, and culture" largely influence a child's development and thus, the stages cannot be used to create rigid boundaries.[55] The trouble American courts are faced with is whether children are cognitively and morally developed enough to make self-determinations or whether these models place a heavy burden upon children who cannot understand the consequences of the transplantation procedure.[56]

## IV. Conclusion

A child's moral and cognitive development is not set in stone. Therefore, the legal framework regarding donations by minors, especially "savior sibling," is not flawed. Rather, the implementation of a case-by-case analysis by the American judicial system is the most reasonable approach in determining what is in the best interest of the donor, the recipient, and the parents. While it seems ideal for the legislature to enact broad-sweeping regulation on the subject, it is untenable to do so given the individualized nature of cases that come before the courts. Best interest has always been contextual in family law, and savior sibling cases are no different.

[1] Misbahul ("Misbah") Fatima is a first year law student pursuing the health law concentration. Misbah earned her B.A. in Jurisprudence and English with a minor in Philosophy from Montclair State University in 2014. While an undergraduate, Misbah did research on the use of pre-implantation genetic diagnosis ("PGD") for the purpose of creating children to be donors. This yearlong research project sparked her interest in health law and compliance. Before pursuing law school, Misbah worked at Deutsch Atkins, P.C., a New Jersey employment firm, where she familiarized herself with compliance in the work environment. In addition, Misbah served as a legal assistant for Robert Biagiotti, who is a Defense Attorney in Hackensack, New Jersey. Misbah is now focused on entering the health law field, along with being a member of the Health Law Forum, the Women's Law Forum, and the Riccio Moot Court Board. She will be completing an externship with Horizon Blue Cross Blue Shield this summer.

[2] Michele Goodwin, *The Politics of Health Law: My Sister's Keeper?: Law, Children, and Compelled Donations*, 29 W. NEW ENGLAND LAW REV. 357, 368 (2007).
[3] Nicole Herbert, Note, *Creating a Life to Save a Life: An Issue Inadequately Addressed by the Current Legal Framework Under Which Minors are Permitted to Donate Tissues and Organs*, 17 S. CAL. INTERDISC. L.J. 337, 342-43 (2008).
[4] *Id.*
[5] *Id.*
[6] *Id.* at 344.
[7] *Id.*
[8] Louis M. Solomon et al., *Compelled Organ Donations*, 6 Gender Med. 519 (2009).
[9] *Id.*
[10] Goodwin, *supra* note 2, at 361.
[11] *Id.* at 362.
[12] *Id.*
[13] Herbert, *supra* note 3, at 340.
[14] Goodwin, *supra* note 2, at 382
[15] Herbert, *supra* note 3, at 356.
[16] *Id.* at 361.
[17] *Id.* at 356.
[18] Hart v. Brown, 29 Conn. Supp. 368, 378 (Conn. Super. Ct. 1972). Cordelia Thomas, *Pre-Implantation Testing and the Protection of "Savior Sibling,"* 9 DEAKIN LAW REV. 134 (2004).
[19] *Hart*, 29 Conn. Supp. at 374-75.
[20] Little v. Little, 576 S.W.2d. 493, 496 (Tex. Civ. App. 1979).
[21] *Hart*, 29 Conn. Supp. 368 (Conn. Super. Ct. 1972). *Little*, 576 S.W.2d. 493 (Tex. Civ. App. 1979). *Strunk v. Struck*, 445 S.W.2d 145 (Ky. 1969).
[22] *Curran*, 566 N.E.2d at 1338.
[23] *Id.* at 1341.
[24] *Id.*
[25] Herbert, *supra* note 3, at 356.
[26] *Hart*, 29 Conn. Supp. at 378.
[27] *Id.* at 376-77; *Strunk*, 445 *S.W.2d* 145.
[28] Amy T.Y. Lai, *To Be or Not to Be My Sister's Keeper? A Revised Legal Framework Safeguarding Savior Siblings' Welfare*. 32 THE JOURNAL OF LEGAL MED. 284 (2011).
[29] *Id.*
[30] *Curran*, 566 N.E.2d at 1326.
[31] *Id.* at 1323.
[32] Lai, *supra* note 28, at 284.
[33] Herbert, *supra* note 3, at 356.
[34] *Id.*
[35] *Id.*
[36] *Curran*, 566 N.E.2d at 1326.
[37] *Id.* at 1345.
[38] *Id.* at 1343-45.
[39] *Id.*
[40] *Id.* at 1345.
[41] *Id.*
[42] Herbert, *supra* note 3, at 360.
[43] *Id.* at 361.
[44] Victoria Weisz, *Psychological Issues in Sibling Bone Marrow Donation*, 2 ETHICS AND BEHAVIOR 185, 198 (1992).
[45] Lai, *supra* note 28, at 289.
[46] Weisz, *supra* note 44, at 193.
[47] *Id.* at 196.
[48] *Id.*
[49] *Id.* at 197.

[50] *Id.*
[51] Goodwin, *supra* note 2, at 404.
[52] Herbert, *supra* note 3, at 368.
[53] *Id.* at 369.
[54] *Id.* at 367.
[55] *Id.* at 369.
[56] Weisz, *supra* note 44, at 197.