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## THE MINOR DONOR-SIBLING DILEMMA: ARE BONE MARROW DONATION DECISIONS UP TO THE PARENT OR THE CHILD?

*Christina Carone\**

*For a society which respects the rights of one individual, to sink its teeth into the jugular vein or neck of one of its members and suck from it sustenance for another member, is revolting to our hard-wrought concepts of jurisprudence. Forcible extraction of living body tissue causes revulsion to the judicial mind. . . .*

—The Honorable Flaherty<sup>1</sup>

### I. INTRODUCTION

The American Cancer Society predicts that in 2018, 174,250 people living in the United States will be diagnosed with a type of blood cancer.<sup>2</sup> This statistic signifies that approximately every three minutes a person living in the United States is diagnosed with a serious

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\* Touro College Jacob D. Fuchsberg Law Center, J.D. Candidate 2018; University of Florida, B.S., in Psychology, 2014; SUNY Farmingdale State College, Certificate, in Health Science for Health Professionals, 2015. I dedicate this Note to my brother, Raffaello, who was diagnosed with acute lymphoblastic leukemia when he was two years old. I write this Note to bring light to this issue because I was a minor donor-sibling bone marrow match and was subjected to match testing when I was just ten years old. I was not prepared for this responsibility prior to being tested, nor did I feel that I had the choice to say no. I would have donated to Raffaello if he needed a transplant in a heartbeat; however, I was not adequately prepared for the responsibility imposed on me, and I believe that minor donor-siblings should be properly screened. I thank Associate Dean Deseriee Kennedy and Dean Myra Berman for appreciated comments, helpful discussions and mentorship throughout the writing process. And I thank Professor Rena Seplowitz for her invaluable insight, support and guidance as this Note would not have been possible without her.

<sup>1</sup> *McFall v. Shimp*, 10 Pa. D. & C.3d 90, 92 (Ct. Com. Pl., Allegheny Cty. 1978) (emphasis added).

<sup>2</sup> *Facts and Statistics*, LEUKEMIA & LYMPHOMA SOC'Y, <http://www.lls.org/facts-and-statistics/facts-and-statistics-overview> (last visited Oct. 30, 2018).

blood disorder.<sup>3</sup> Childhood blood cancers are one of the most common types of cancers affecting children, adolescents and adults younger than twenty years old.<sup>4</sup> For example, leukemia, a cancer that prevents blood-forming tissues from producing normal blood cells in bone marrow,<sup>5</sup> is the second leading cause of death among this age group,<sup>6</sup> and children younger than five years old have the highest risk for developing acute lymphoblastic leukemia.<sup>7</sup>

A child afflicted with a life-threatening illness such as leukemia may need a bone marrow transplant.<sup>8</sup> Bone marrow transplants can be used as a treatment option; thus, parents are often overjoyed when they discover a Human Leukocyte Antigen (hereinafter “HLA”) matched sibling because finding a donor is a critical component of the transplantation process.<sup>9</sup> HLA-matching is the most relevant factor when selecting a donor, and HLA-matched siblings are usually preferred if available because they are the best donors for the child in need of a transplant (“patient-recipient”).<sup>10</sup> Biological siblings are usually tested first because there is an increased likelihood that a biological sibling is genetically compatible with the patient-recipient and may qualify as a suitable donor.<sup>11</sup> If a matched sibling is identified, that child is considered the best donor option.<sup>12</sup> A biological sibling<sup>13</sup> has a 25% chance of being a complete HLA-match, a 25% chance of being an HLA-non-match and a 50% chance of

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<sup>3</sup> *Id.*

<sup>4</sup> *Id.*

<sup>5</sup> *Blood Cancers*, AM. SOC’Y HEMATOLOGY, <http://www.hematology.org/Patients/Cancers/> (last visited Oct. 30, 2018).

<sup>6</sup> *Key Statistics for Acute Lymphocytic Leukemia*, AM. CANCER SOC’Y, <https://www.cancer.org/cancer/acute-lymphocytic-leukemia/about/key-statistics.html> (last updated Jan. 4, 2018).

<sup>7</sup> *Facts and Statistics*, *supra* note 2.

<sup>8</sup> A bone marrow transplant is a type of allogeneic transplant in which bone marrow is the source of the hematopoietic graft. CLINICAL MANUAL OF BLOOD AND BONE MARROW TRANSPLANTATION 3 (Syed A. Abutalib & Parameswaran Hari eds., 2017). Peripheral blood and umbilical cord cells are other options available that use a different source of hematopoietic grafts. *Id.* at 1.

<sup>9</sup> Alternative donor options are pursued in the absence of an HLA-matched sibling. *Id.*

<sup>10</sup> *Id.* at 2.

<sup>11</sup> *HLA Matching*, BE THE MATCH, <https://bethematch.org/patients-and-families/before-transplant/find-a-donor/hla-matching/> (last visited Oct. 30, 2018).

<sup>12</sup> CLINICAL MANUAL, *supra* note 8, at 1. It can be inferred that match testing ends once an HLA-matched sibling is identified since that child is considered the best donor. CLINICAL MANUAL, *supra* note 8, at 2.

<sup>13</sup> A patient-recipient’s full biological sibling shares the same biological parents. CLINICAL MANUAL, *supra* note 8, at 2.

qualifying as an HLA-haploidentical-match.<sup>14</sup> An HLA-matched sibling makes the best donor and is favored because the child is readily available for use, graft extraction, and possible future need.<sup>15</sup> Moreover, using these children as donors avoids complications of graft versus host disease.<sup>16</sup> Desperate parents have resorted to the use of genetic engineering techniques to conceive a child for the sole purpose of finding a bone marrow match for their child in need.<sup>17</sup> Children known as *savior siblings*<sup>18</sup> are *designer babies* designed and born because their genetic makeup will be used to save a sibling's life.<sup>19</sup>

As soon as a minor sibling is marked as a suitable donor for the patient-recipient, that child is immediately labeled as a bone marrow match and *possible* donor regardless of whether the child has consented to participating in the process. Contrary to what one would expect, these siblings do not have an option.<sup>20</sup> This labeling simultaneously changes the identity of a parent's child from a minor sibling—a child unaware of the responsibility that was just imposed on her—into a minor donor-sibling, who will have her bone marrow harvested for the benefit of the patient-recipient. Minor donor-siblings play an integral role in the patient-recipient's treatment plan, and this unsolicited commitment immediately burdens the donor child. The bone marrow transplantation process can require the minor donor-sibling to miss school to attend medical appointments and receive injections in preparation of the bone marrow harvest.<sup>21</sup>

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<sup>14</sup> CLINICAL MANUAL, *supra* note 8, at 2. A haploidentical donor is a half-matched donor. For example, a parent is a half-match to her child. *HLA Matching*, *supra* note 11.

<sup>15</sup> CLINICAL MANUAL, *supra* note 8, at 2.

<sup>16</sup> CLINICAL MANUAL, *supra* note 8, at 2.

<sup>17</sup> CLINICAL MANUAL, *supra* note 8, at 2.

<sup>18</sup> See Kristie L. Trifolios, *Savior Siblings: The Ethical Debate*, SETON HALL L. SCH. STUDENT SCHOLARSHIP, May 1, 2014, [https://scholarship.shu.edu/cgi/viewcontent.cgi?article=1432&context=student\\_scholarship](https://scholarship.shu.edu/cgi/viewcontent.cgi?article=1432&context=student_scholarship).

<sup>19</sup> *Id.* at 2.

<sup>20</sup> CLINICAL MANUAL, *supra* note 8.

<sup>21</sup> SickKids staff, *Filgrastim*, ABOUT KIDS HEALTH, <http://www.aboutkidshealth.ca/En/HealthAZ/Drugs/Pages/Filgrastim.aspx> (last updated Feb. 28, 2018). If a patient-recipient is fortunate enough to discover that a minor donor-sibling is a compatible bone marrow match, the sibling may be required to endure a series of injections containing the medication filgrastim, which can have serious side effects, in preparation for the donation procedure. *Filgrastim Injection*, DRUGS.COM (Sept. 5, 2018), <https://www.drugs.com/cdi/filgrastim-injection.html>; *Filgrastim*, CHEMOCARE, <http://chemocare.com/chemotherapy/drug-info/filgrastim.aspx> (last visited Oct. 30, 2018).

A donor's cells can be collected in several ways; however, bone marrow is the preferred graft source for children patient-recipients and common for pediatric transplants.<sup>22</sup> Bone marrow is harvested in the operating room and requires the minor donor-sibling to be sedated under anesthesia.<sup>23</sup> This surgical procedure is typically one day and has the risks common to general anesthesia, bleeding, pain, and surgical injury.<sup>24</sup> The minor donor-sibling is put into a medically induced coma absent any purpose that provides a direct medical benefit to her.<sup>25</sup> While the child is unconscious, a physician injects a needle into the center of the child's bone and extracts the marrow.<sup>26</sup> Transplant centers differ in the amount of bone marrow they extract from the minor donor-sibling.<sup>27</sup>

The bone marrow transplantation process can have a significant negative impact on a minor donor-sibling and may seriously affect that child for the rest of her life.<sup>28</sup> Minor donor-siblings often do not know they have a choice in participating in the transplantation process and feel pressured by their families to donate, despite the short-term and long-term physical and emotional impact the minor donor-sibling may

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<sup>22</sup> See CLINICAL MANUAL, *supra* note 8, at 10. Bone marrow is preferred in children with hematologic diseases.

<sup>23</sup> *Bone Marrow Transplant*, U.S. NAT'L LIBR. MED., <https://medlineplus.gov/ency/article/003009.htm> (last visited Oct. 30, 2018).

<sup>24</sup> CLINICAL MANUAL, *supra* note 8, at 3.

<sup>25</sup> *Medically Induced Coma vs. Sedation*, AM. SOC'Y ANESTHESIOLOGISTS, <http://www.asahq.org/lifeline/anesthesia%20topics/medically%20induced%20coma%20and%20sedation> (last visited Oct. 30, 2018); *Risks of Anesthesia in Children*, U.S. ANESTHESIA PARTNERS, <https://www.usap.com/patients/pediatrics/risks-of-anesthesia-in-children> (last visited Oct. 30, 2018).

<sup>26</sup> *Bone Marrow Transplantation*, JOHNS HOPKINS MED., [https://www.hopkinsmedicine.org/healthlibrary/conditions/hematology\\_and\\_blood\\_disorders/bone\\_marrow\\_transplantation\\_85,P00086](https://www.hopkinsmedicine.org/healthlibrary/conditions/hematology_and_blood_disorders/bone_marrow_transplantation_85,P00086) (last visited Oct. 30, 2018). The medical risks known to be associated with extracting bone marrow through aspiration include the risk of being sedated under anesthesia. *Id.*

<sup>27</sup> There is a recommended cell dose for collection, but no indication of a limit on the amount extracted. CLINICAL MANUAL, *supra* note 8, at 7. Transplant centers differ in the approach used for deciding how much marrow to extract. CLINICAL MANUAL, *supra* note 8, at 7.

<sup>28</sup> See Taylor E. White et al., *Family Strategies to Support Siblings of Pediatric Hematopoietic Stem Cell Transplant Patients*, 139 PEDIATRICS 1 (2017), [https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5260146/pdf/PEDS\\_20161057.pdf](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5260146/pdf/PEDS_20161057.pdf); see also *Harvesting Blood Stem Cells for Transplantation*, U.S. NAT'L LIBR. MED., <https://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0072612/> (last updated Dec. 30, 2016).

suffer.<sup>29</sup> The American Academy of Pediatrics has recognized that medical professionals do not fully understand the long-term physical, emotional and psychological effects donating bone marrow has on the minor sibling.<sup>30</sup> However, research has revealed that donor-siblings with an active involvement in the patient-sibling's treatment have experienced feelings of anxiety, helplessness and guilt, which can have long-term effects on sibling development.<sup>31</sup> Donor-siblings may feel isolated from their families after donating bone marrow and experience intense stress as a result of possible post-transplant complications and the possibility of the patient-recipient's death.<sup>32</sup> Further investigations of these long-term effects and the influence of the transplantation process on the minor donor-siblings' development are necessary.<sup>33</sup>

This Note will analyze the underlying constitutional principles respecting a parent's and a child's fundamental rights which relate to consenting to match testing and donations. Part II of this Note will provide background about the requisite medical information in relation to bone marrow, the donation procedure, and the transplantation process. Part III will address the legal arguments concerning a minor donor-sibling's right to consent to, or refuse to submit to, medical testing and the transplantation process with respect to age and the appointment of a donor advocate. This author will argue that a minor donor-sibling has a constitutionally protected due process right under the Fourteenth Amendment to refuse to submit to medical testing that subjects the child to an invasive procedure or to have an independent advocate represent her interests if she is not legally competent because (1) a child has a property interest in her body and its products such as bone marrow; (2) a child has a privacy right to be protected from bodily intrusions; (3) a child has the procedural due process right to be heard

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<sup>29</sup> See Jane Elfer, To Investigate The Emotional Impact Of Sibling Bone Marrow Donation 133 (October 2017) (unpublished Ph.D. thesis, University of East London), <http://roar.uel.ac.uk/7137/1/Jane%20Elfer%20-%20Final%20Thesis%205th%20Nov%202017.pdf>.

<sup>30</sup> See *Policy Statement—Children as Hematopoietic Stem Cell Donors*, 125 PEDIATRICS 392 (2010), <http://pediatrics.aappublications.org/content/pediatrics/125/2/392.full.pdf>. The AAP Ethics Committee addressed the need to conduct research monitoring donors and recipients to advance the effectiveness of transplants. See *id.*

<sup>31</sup> *Id.* at 395.

<sup>32</sup> See Melissa A. Alderfer et al., *The Social Functioning of Siblings of Children With Cancer: A Multi-Informant Investigation*, 40 J. PEDIATRIC PSYCHOL. 309 (2015); see also *Policy Statement—Children as Hematopoietic Stem Cell Donors*, *supra* note 30.

<sup>33</sup> See G. Gail Gardner et al., *Psychological Issues In Bone Marrow Transplantation*, 60 PEDIATRICS 625 (1977), <http://pediatrics.aappublications.org/content/60/4/625.pdf>.

by a neutral court, or be represented by an independent advocate prior to genetic compatibility testing; and (4) a child or the appropriate representative must give complete informed consent prior to medical testing. Part IV of this Note will address how other countries and jurisdictions manage the care of a minor donor-sibling throughout the bone marrow transplantation process. Part V will discuss this author's proposal for a program, and finally, Part VI will conclude by addressing the critical need to protect a minor donor-sibling's best interests throughout the transplantation process.

## II. THE BONE MARROW TRANSPLANTATION PROCESS

The bone marrow transplantation process is a complicated medical process that can have an emotional, psychological, and physical impact on a minor donor-sibling.<sup>34</sup> Parents have the recognized right to make healthcare decisions for their minor children;<sup>35</sup> however, a clear conflict of interest exists in cases involving minor donor-siblings that will affect their judgment. Parents can prioritize and make decisions concerning the best interests of their sick child and minimize or neglect the effect of such decisions on the minor donor-sibling throughout the transplantation process.

Bone marrow—a spongy tissue located inside bones—contains hematopoietic stem cells (hereinafter “HSCs”).<sup>36</sup> HSCs are unique cells that have the extraordinary capability to differentiate into various types of cells that are responsible for producing the body's blood components such as red blood cells, white blood cells, and platelets.<sup>37</sup> In a bone marrow transplant, a donor's marrow is extracted and then

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<sup>34</sup> See W.L. Packman et al., *Psychosocial Consequences of Bone Marrow Transplantation in Donor and Non-Donor Siblings*, 18 J. DEV. BEHAV. PEDIATRICS 244 (1997), <https://www.ncbi.nlm.nih.gov/pubmed/9276831>; see also K.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), <https://www.ncbi.nlm.nih.gov/pubmed/12730279>.

<sup>35</sup> See *Newmark v. Williams*, 588 A.2d 1108 (Del. 1991).

<sup>36</sup> *NCI Dictionary of Cancer*, NAT'L CANCER INST., <https://www.cancer.gov/publications/dictionaries/cancer-terms?cdrid=693540> (last visited Oct. 30, 2017). Hematopoietic cells, also known as stem cells, are immature cells that are capable of developing into any type of blood cell. *Id.* These cells are located in bone marrow. *Id.*

<sup>37</sup> *Blood & Marrow Transplantation for Children*, MEMORIAL SLOAN KETTERING CANCER CTR., <https://www.mskcc.org/pediatrics/cancer-care/treatments/cancer-treatments/transplantation> (last visited Oct. 30, 2018).

transplanted into a patient to treat a disease.<sup>38</sup> However, a bone marrow transplant requires identifying a compatible donor whose genes at least partially match the patient's genes; hence, siblings often serve as the best match candidates.<sup>39</sup>

Ideally, the donor's bone marrow should match the genetic make-up of the patient-recipient's marrow as perfectly as possible.<sup>40</sup> HLA typing is used to match bone marrow donors and patients and thus determines whether a sibling is a suitable<sup>41</sup> bone marrow donor for the patient-recipient.<sup>42</sup> A minor donor-sibling can donate if she is considered a suitable match. A bone marrow transplant procedure, also known as the *bone marrow harvest*, may be comprised of an aspiration component, which requires that the minor donor-sibling be sedated under anesthesia.<sup>43</sup> During aspiration, a physician inserts a long needle into the minor donor-sibling's bone—typically a large bone like the pelvic bone—to extract bone marrow which produces blood cells.<sup>44</sup> The donor can remain in the hospital from early morning through late afternoon, or overnight for observation depending on the child's age, response to receiving anesthesia, and the physician's discretion.<sup>45</sup> Among the common side effects of bone marrow donation reported two days after the procedure are back or hip pain, fatigue, throat pain, muscle pain, insomnia, headaches, dizziness, loss of appetite, and nausea.<sup>46</sup> After the bone marrow donation takes place, a physician harvests the extracted HSCs from the donor's marrow.<sup>47</sup> One or two days later, the doctor transplants the bone marrow into the patient-recipient's body.<sup>48</sup> However, a patient-recipient's condition

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<sup>38</sup> *Allogeneic Stem Cell Transplant*, CANCER TREATMENT CTRS. AM., <https://www.cancercenter.com/treatments/allogeneic-stem-cell-transplant/> (last visited Oct. 30, 2018).

<sup>39</sup> CLINICAL MANUAL, *supra* note 8, at 1.

<sup>40</sup> CLINICAL MANUAL, *supra* note 8, at 1. The likelihood that the transplant will be a successful increases with a closer match.

<sup>41</sup> *Allogeneic Stem Cell Transplant*, *supra* note 38. A suitable donor is genetically similar enough to qualify as a bone marrow donor.

<sup>42</sup> *HLA Matching*, *supra* note 11.

<sup>43</sup> *Bone Marrow Transplantation*, *supra* note 26.

<sup>44</sup> *Steps of PBSC or Bone Marrow Donation*, BE THE MATCH, <https://bethematch.org/transplant-basics/how-marrow-donation-works/steps-of-bone-marrow-or-pbpc-donation/> (last visited Oct. 30, 2018). Although no stitches are involved, the donor will suffer from bone punctures and skin punctures.

<sup>45</sup> *Id.*

<sup>46</sup> *Id.*

<sup>47</sup> *Id.*

<sup>48</sup> *Id.*



may not improve even after a minor donor-sibling donates her marrow, and the transplantation process is far from insignificant for her because of the medical complications and subsequent mental health concerns associated with the procedure.<sup>49</sup>

### III. LEGAL ISSUES CONCERNING MINOR DONOR-SIBLINGS

Parents have the constitutional right to make healthcare decisions for their children; however, the state can challenge a parent's authority when the intervention is necessary to protect the safety or health of a child.<sup>50</sup> The state has the burden to prove by clear and convincing evidence that intervening in the parent-child relationship is necessary to ensure the health and safety of a child.<sup>51</sup> Furthermore, the expectation of such intervention and proposed treatment must greatly outweigh the potential medical risks inherent for the procedure.<sup>52</sup> Minor donation cases have been consistently decided on a fact-specific basis and take into account the best interests of the parties involved and the legal competence of the minor.<sup>53</sup> Litigation may arise if a minor donor-sibling has the recognized right to challenge a decision made by a parent or a medical provider concerning her best interest. Disagreements about this matter would create a state issue.<sup>54</sup>

#### A. Preexisting Legal Standards That Have Been Applied to Minor Donation Cases

Courts have employed various tests when deciding minor donation cases. Courts have used the best interest test, which weighs the gravity of illness, the physician's evaluation, the child's preference,

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<sup>49</sup> *Bone Marrow Transplantation*, *supra* note 26. Such complications may arise resulting from the following factors: the type of disease the recipient is being treated for; whether the recipient had prior treatments of chemotherapy and/or radiation and the dosages of such treatments; the recipient's age, prognosis, and overall health and the closeness of the genetic match of the donor to the recipient. *Bone Marrow Transplantation*, *supra* note 26. Possible complications the patient-recipient may experience include anemia, internal bleeding, blood clotting, organ damage, delayed growth in children, graft failure, graft-versus-host disease, infections, and pain. *Bone Marrow Transplantation*, *supra* note 26.

<sup>50</sup> *Newmark v. Williams*, 588 A.2d 1108 (Del. 1991).

<sup>51</sup> *Id.* at 1116.

<sup>52</sup> *Id.* at 1113.

<sup>53</sup> *In re Quinlan*, 355 A.2d 647 (N.J. 1976).

<sup>54</sup> Although the states have the responsibility to protect children, issues concerning minor donor-siblings should be addressed by Congress and will be discussed later in this Note.

and the risks involved.<sup>55</sup> Other courts have used the competing interests test, which weighs competing rights and the substituted judgment doctrine in which a court substitutes its judgment for the minor's to determine the child's best interests.<sup>56</sup> Generally, courts will make two inquiries when using any of these tests. First, the court will consider the effectiveness of the proposed treatment by assessing the patient-recipient's chance of survival with and without receiving the care at issue.<sup>57</sup> Second, the court will examine the nature of the treatment and its risks by weighing the expected medical benefit to the patient-recipient against the invasiveness and effect of the treatment on the minor donor.<sup>58</sup> Other courts have considered the mature minor doctrine, which gives a minor who can show maturity the legal authority to provide medical consent to a procedure.<sup>59</sup> Courts utilize these legal standards to rationalize subjecting a minor donor, not legally capable of deciding for herself, to an invasive procedure that confers no direct medical benefit on that child.<sup>60</sup> Courts have further supported minor donor decisions by anticipating the psychological benefits that may stem from the sibling relationship to justify proceeding with the transplant procedure.<sup>61</sup>

### *1. The Substituted Judgment Doctrine*

The substituted judgment doctrine allows a surrogate decision-maker, such as a parent or legal guardian, to establish what decision an incompetent person would make if that person were competent.<sup>62</sup> Courts that apply the substituted judgment doctrine to minor donor cases weigh the psychological benefits a minor donor will receive from proceeding with a transplant or donation against the medical risks associated with undergoing the procedure.<sup>63</sup> Courts that use this doctrine grant parents the authority to make decisions for their

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<sup>55</sup> *Newmark*, 588 A.2d at 1114.

<sup>56</sup> *In re E.G.*, 549 N.E.2d 322 (Ill. 1989).

<sup>57</sup> *Curran v. Bosze*, 566 N.E.2d 1319 (Ill. 1990).

<sup>58</sup> *Id.* at 1330.

<sup>59</sup> *See Bellotti v. Baird*, 428 U.S. 132 (1976).

<sup>60</sup> *Curran*, 566 N.E.2d at 1330.

<sup>61</sup> *See Little v. Little*, 576 S.W.2d 493 (Tex. Civ. App. 1979) (reasoning that a fourteen-year-old would benefit psychologically from donating a kidney to a sibling).

<sup>62</sup> *Hart v. Brown*, 289 A.2d 386 (Conn. Super. Ct. 1972).

<sup>63</sup> *Curran*, 566 N.E.2d at 1332.

children.<sup>64</sup> Arguably, the court should not apply this doctrine in minor donation cases because an obvious conflict of interest exists. In these cases, parents have a personal interest in saving their sick child and will prioritize that child's needs over the minor donor-sibling's needs and interests. Therefore, the court should not utilize the substituted judgment doctrine because parents can be biased and their judgment may not be based on what the minor donor would do, but their judgment may be based on what they need for the patient-recipient.

## 2. *The Best Interest of the Child Standard*

Family courts employ the best interest of the child standard when making decisions that affect the care, custody, and well-being of children.<sup>65</sup> This standard is a subjective and discretionary test which takes into account all circumstances that affect the child.<sup>66</sup> Courts have used this standard when addressing cases that involve sibling donors and assess whether the psychological benefits of donating bone marrow outweigh the risks associated with the procedure.<sup>67</sup> The medical definition of the best interest standard states that the standard is an "ethical requirement that people who care for others will do so in good faith, placing their assessment of that person's best interests above their own."<sup>68</sup> This standard is relevant to the care of incompetent or dependent persons.<sup>69</sup>

In *Hart v. Brown*, a seven year-old girl needed a kidney transplant.<sup>70</sup> Her twin sister was a perfect candidate and identical match for the procedure.<sup>71</sup> The Superior Court of Connecticut held that the parents had the right to provide medical consent for the minor donor-sibling to undergo the procedure.<sup>72</sup> The court found that parents could consent to a kidney transplant on behalf of the donor child when the transplant was necessary for survival, procedure risks to each child

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<sup>64</sup> See generally *Hart*, 289 A.2d at 386.

<sup>65</sup> *Curran*, 566 N.E.2d at 1331.

<sup>66</sup> *Id.*

<sup>67</sup> *Id.*

<sup>68</sup> *Best Interest Standard*, FREE DICTIONARY, <https://medical-dictionary.thefreedictionary.com/best+interest+standard> (last visited Oct. 30, 2017).

<sup>69</sup> *Curran*, 566 N.E.2d at 1322-23.

<sup>70</sup> *Hart*, 289 A.2d at 386. Bone marrow donations involve a less invasive procedure compared to kidney donations; however, both require anesthesia.

<sup>71</sup> *Id.* at 387.

<sup>72</sup> *Id.*

were negligible, the donor did not need to take immunosuppressive drugs post-procedure, and each child's prognosis for good health was excellent.<sup>73</sup> Furthermore, the court and each child's guardian and physician reviewed the parents' motivations for moving forward with the procedure.<sup>74</sup> In this case, the minor donor-sibling wanted to donate her kidney, and the court focused on the child's intent.<sup>75</sup> Moreover, the court used the best interest standard and assessed the risks and benefits of the kidney transplant before ruling and concluded that the minor donor would be better off in a happy family than a distressed one.<sup>76</sup>

In *Curran v. Bosze*,<sup>77</sup> the Supreme Court of Illinois used the best interest of the child standard to decide that three-and-a-half-year-old twins should not donate bone marrow to their half-brother because the twins were not legally competent and did not yet possess personal value systems.<sup>78</sup> The court determined that parental consent was insufficient to justify subjecting the minors to medical testing that would determine match eligibility for the donation.<sup>79</sup> The court initially found that the substituted judgment doctrine failed to provide conclusive evidence of the twins' subjective intent regarding donation because the twins' morals, religious beliefs, and life goals could not be determined.<sup>80</sup> Consequently, the court used the best interests of the child standard<sup>81</sup> and addressed its three requirements.<sup>82</sup> First, the parent providing medical consent for the minor has knowledge of the risks and benefits of the medical procedure.<sup>83</sup> Second, the minor receives emotional support from the parent providing medical consent on her behalf.<sup>84</sup> Third, the donor and the recipient currently share a

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<sup>73</sup> *Id.*

<sup>74</sup> *Id.*

<sup>75</sup> *Hart*, 289 A.2d at 387-88.

<sup>76</sup> *Id.* at 389.

<sup>77</sup> 566 N.E.2d 1319 (Ill. 1990).

<sup>78</sup> *Id.* at 1320. Minor donor-sibling cases are distinguishable from *Curran* because most of these cases involve a full biological (shares both parents) sibling donor whereas *Curran* applied to half-siblings. This author asserts that a greater conflict of interest exists when full biological siblings are of concern compared to half-siblings because the latter have an independent parent advocating for their best interests.

<sup>79</sup> *Id.* at 1376-77.

<sup>80</sup> *Id.* at 1324-25.

<sup>81</sup> *Id.* at 1324.

<sup>82</sup> *Curran*, 566 N.E.2d at 1324.

<sup>83</sup> *Id.*

<sup>84</sup> *Id.* at 1343-44.

close relationship.<sup>85</sup> The court concluded that the twins should not donate because they did not share a close relationship with their half-brother with whom they did not interact.<sup>86</sup>

*Curran* remains the standard case for courts when addressing minor donation issues. However, courts should not use the best interests of the child standard to assess minor donor-sibling cases such as *Hart* and *Curran*. Arguably, young children, such as the seven-year-old minor donor-sibling in *Hart*, do not adequately understand the nature or the demands that the bone marrow donation process requires.<sup>87</sup> Moreover, parents likely influence their children at young ages, and in cases involving minor donor-siblings, parents may not act in the donor child's best interests when they prioritize the needs of their dying child.

### 3. *The Age of Legal Medical Consent: The Mature Minor Doctrine and Informed Consent*

In general, courts recognize individuals possessing the requisite legal capacity as competent and therefore able to consent to their medical care.<sup>88</sup> Children are routinely presumed to be incapable<sup>89</sup> of consenting to their medical treatment; thus, parents have the legal authority to decide whether their minor children will receive medical attention.<sup>90</sup> Although a parent has the legal authority to provide informed medical consent on behalf of a child regardless of what that child wants, the law does not explicitly establish that a parent has a protected fundamental right to consent for one child to undergo medical testing that simultaneously subjects that child to an invasive procedure that only *may* provide a physical benefit to another child. Similarly, the law fails to make certain whether a minor donor-sibling has a constitutionally protected right to consent to, or refuse, medical

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<sup>85</sup> *Id.* at 1345.

<sup>86</sup> *Id.*

<sup>87</sup> *Hart*, 289 A.2d at 386.

<sup>88</sup> Alex Buchanan, *Mental Capacity, Legal Competence and Consent to Treatment*, 97 J. ROYAL SOC'Y MED. 415 (2004), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1079581/pdf/0970415.pdf>.

<sup>89</sup> Incapable shares the same meaning as legally incompetent.

<sup>90</sup> See Douglas S. Diekema, *Parental Decision Making*, U. WASH. SCH. MED., <https://depts.washington.edu/bioethx/topics/parent.html> (last modified Mar. 14, 2014).

testing that subjects her to, an invasive procedure that extracts bodily substances to be harvested for another's benefit.

The same complex considerations concerning a child's voluntary participation in bone marrow donations are found in research projects in which minors are research subjects.<sup>91</sup> In both contexts, issues of assent and parental permission arise.<sup>92</sup> An independent physician should determine whether a minor donor-sibling is capable of assenting to the bone marrow transplant process.<sup>93</sup> A minor donor assents when she affirmatively agrees to participate in the transplant process by actively demonstrating her willingness.<sup>94</sup> A minor donor fails to assent even when she does not object or resist or when she simply complies with directions.<sup>95</sup> An independent physician should consider the minor donor's age, maturity, psychological state of mind, experience, and level of understanding before conducting bone marrow match testing.<sup>96</sup>

Some jurisdictions apply the mature minor doctrine when addressing issues concerning minors and medical consent. The mature minor doctrine allows a minor to have the legal authority to provide medical consent to a procedure if she can show that she is mature enough to make a decision herself.<sup>97</sup> This doctrine considers the minor's age and the circumstances surrounding the procedure as well

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<sup>91</sup> See Michelle Roth-Cline & Robert M. Nelson, *Parental Permission and Child Assent in Research on Children*, 86 *YALE J. BIOLOGY & MED.* 291 (2013), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3767214/>.

<sup>92</sup> *Id.* See *Guidance and Procedures: Child Assent and Permission by Parents or Guardians*, UCLA OFF. HUMAN RES. PROTECTION PROGRAM, [http://ora.research.ucla.edu/OHRPP/Documents/Policy/9/ChildAssent\\_ParentPerm.pdf](http://ora.research.ucla.edu/OHRPP/Documents/Policy/9/ChildAssent_ParentPerm.pdf) (last updated June 9, 2016). See also A. D'Souza et al., *Is 'Informed Consent' An 'Understood Consent' In Hematopoietic Cell Transplantation?*, 50 *BONE MARROW TRANSPLANT* 10 (2015), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4320584/>.

<sup>93</sup> *Consent and Assent*, INSTITUTIONAL REV. BOARD, <http://www.uaf.edu/irb/faqs/consent-and-assent/> (last updated Aug. 27, 2015). Consent is defined as a voluntary agreement to an act or proposal of another. See *id.* In the United States, the legal age of consent is 18 years old. *Id.* Assent is the intentional endorsement of comprehended facts or an individual not capable of providing legal consent showing agreement to participate in an activity. See *id.* In minor donation cases, a child may be required to assent to the medical procedure. See *id.* The consent of a parent or legal guardian and the assent of the subject may be required when a child or an adult is not capable of providing consent. See *Consent and Assent, supra*.

<sup>94</sup> See Roth-Cline & Nelson, *supra* note 91.

<sup>95</sup> See Roth-Cline & Nelson, *supra* note 91.

<sup>96</sup> See Roth-Cline & Nelson, *supra* note 91.

<sup>97</sup> *The Mature Minor Doctrine*, USLEGAL, <https://healthcare.uslegal.com/treatment-of-minors/the-mature-minor-doctrine/> (last visited Oct. 30, 2018).

as other factors and behavior that can prove maturity.<sup>98</sup> A minority of states has codified or adopted this doctrine.<sup>99</sup> An Arkansas statute is exemplary of the standard representing mature minor doctrine requirements.<sup>100</sup> The Supreme Court has not yet ruled on this doctrine's applicability to medical procedures, exclusive of reproductive rights.<sup>101</sup> Furthermore, the Supreme Court has never decided a case where the mature minor doctrine concerned medical testing.<sup>102</sup>

In *Bellotti v. Baird*, the United States Supreme Court addressed the applicability of the mature minor doctrine to abortion cases.<sup>103</sup> Here, the State of Massachusetts mandated that unmarried, minor women attain parental consent to obtain an abortion.<sup>104</sup> In cases in which the parents do not consent, the minor could petition the state court to determine whether she is mature enough to decide to have an abortion.<sup>105</sup> The Supreme Court recognized that unemancipated minors possessing the maturity to articulate a preference for medical treatment may choose to obtain an abortion without the consent of a parent.<sup>106</sup> The Supreme Court noted that a state court may consider a parent's wishes, but if the court determines that the child is a mature minor, the parent's wishes do not control because a child is not beyond the protection of the Constitution because she is a minor.<sup>107</sup> State courts should consider the mature minor doctrine when addressing minor donor-sibling cases in a similar manner to their treatment of reproductive and organ donation issues involving the requirement of parental consent for a minor to receive a medical procedure. The Supreme Court recognized in *Bellotti* that a mature minor has the right

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<sup>98</sup> *Id.*

<sup>99</sup> *Id.* A few states such as, Arkansas and Nevada, have enacted the mature minor doctrine into statute, whereas Pennsylvania, Tennessee, Illinois, Maine and Massachusetts, high courts have adopted the doctrine as law. *Id.*

<sup>100</sup> ARK. CODE ANN. § 20-9-602 (2018).

<sup>101</sup> *The Mature Minor Doctrine*, supra note 97. The United States Supreme Court created a constitutional zone for children to make their own decisions concerning their health in *Bellotti v. Baird*. 428 U.S. 132 (1976) [hereinafter "*Bellotti I*"]. In that case, the mature minor doctrine was used to justify a child making a medical decision and providing consent on behalf of herself. *Id.* at 132. An analogous justification should apply to minor donor-sibling cases.

<sup>102</sup> *Bellotti v. Baird*, 443 U.S. 622, 622 (1979) [hereinafter "*Bellotti II*"].

<sup>103</sup> *Id.*

<sup>104</sup> *Id.* at 643-44.

<sup>105</sup> *Id.*

<sup>106</sup> *Id.*

<sup>107</sup> *Bellotti II*, 443 U.S. at 633.

to decline or pursue medical treatment regardless of parental consent.<sup>108</sup> In addition, the Supreme Court in *Bellotti* noted the uniqueness of the abortion decision because the procedure is irreversible.<sup>109</sup>

Arguably, the decision to donate bone marrow deserves the same special recognition. Deriving rights that the Supreme Court in *Bellotti* established for a child's decision to obtain an abortion is appropriate because of the difficulty in locating a compatible match, the donor cannot simply postpone donation because the matter is time sensitive, and the invasive nature of the procedure which requires the extraction and harvesting of a child's bodily tissues.<sup>110</sup> Moreover, the decision to donate bone marrow is unique because the procedure is voluntary, elective, and does not provide a medical benefit to the minor donor-sibling.<sup>111</sup>

In the case *In re E.G.*,<sup>112</sup> the Supreme Court of Illinois determined that a mature minor has the right to refuse life-saving medical treatment.<sup>113</sup> The minor was a few months shy of turning eighteen years-old.<sup>114</sup> She was diagnosed with leukemia, and her treatment necessitated the administration of blood transfusions or else she would likely die within a few weeks.<sup>115</sup> Her mother refused to provide consent for this medical procedure because it conflicted with her religious beliefs as a Jehovah's Witness.<sup>116</sup> The minor also did not want to receive any blood transfusions for religious reasons.<sup>117</sup> Consequently, the state intervened and ordered a hearing to address

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<sup>108</sup> *Id.* at 643-46.

<sup>109</sup> *Id.* at 646.

<sup>110</sup> *Id.* at 645. An abortion involves a more invasive medical procedure as compared to a bone marrow donation. *Bellotti II* also addressed a state statute regarding consent; however, minor donor-sibling cases may involve a child too young to be considered a mature minor.

<sup>111</sup> See W. Packman, *Psychological Effects of Hematopoietic SCT on Pediatric Patients, Siblings and Parents: A Review*, 45 BONE MARROW TRANSPLANTATION 1134 (2010), <http://www.nature.com/bmt/journal/v45/n7/full/bmt201074a.html>; K.D. MacLeod et al., *supra* note 34; W.L. Packman, *Psychosocial Impact of Pediatric BMT on Siblings*, 24 BONE MARROW TRANSPLANTATION 701 (1999), <https://www.nature.com/articles/1701997.pdf>.

<sup>112</sup> 549 N.E.2d 322, 327 (Ill. 1989).

<sup>113</sup> *Id.* at 323. This case involved refusing medical treatment due to religious beliefs, and the child's and parent's wishes were in alignment, which is distinguishable from some minor donor-sibling cases.

<sup>114</sup> *Id.*

<sup>115</sup> *Id.*

<sup>116</sup> *Id.*

<sup>117</sup> *Id.*



whether a minor has the right to refuse critical medical treatment.<sup>118</sup> At the conclusion of the hearing, the court appointed a legal guardian who was given the authority to consent to the transfusions on the minor's behalf.<sup>119</sup> The court maintained that this was in the child's best interest.<sup>120</sup>

The trial court addressed this matter further and held that the state's interests outweighed the minor's interest in refusing life-saving medical treatment.<sup>121</sup> First, the court considered the doctor's testimony that he discussed the proposed course of treatment with the minor and concluded that she understood the consequences of accepting or rejecting blood transfusions.<sup>122</sup> In the doctor's opinion, the minor had the maturity level of an eighteen to twenty-one year old and possessed the competency to make an informed decision to refuse the transfusions.<sup>123</sup> Next, the court considered the minor's testimony, which she gave after regaining her strength due to receiving several blood transfusions.<sup>124</sup> She testified that she decided on her own to refuse the medical treatment because of her religious convictions and that she completely understood the nature of her cancer and the consequences of refusing the transfusions.<sup>125</sup> Lastly, she testified that she requested sedation prior to the administration of the transfusions because the guardian's decision upset her.<sup>126</sup> The court noted that the minor was fully aware of the fatal repercussions absent treatment and that she made her decision on an independent basis.<sup>127</sup> Moreover, the court recognized that in making its decision, it accounted for the minor's maturity and her and her parents' religious beliefs and desires.<sup>128</sup> Nonetheless, the trial court maintained that the State had a greater interest in protecting the child and the State's interests outweighed the interests of the child and her parents.<sup>129</sup>

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<sup>118</sup> *In re E.G.*, 549 N.E.2d at 323.

<sup>119</sup> *Id.* at 324.

<sup>120</sup> *Id.*

<sup>121</sup> *Id.* at 327-28.

<sup>122</sup> *Id.*

<sup>123</sup> *In re E.G.*, 549 N.E.2d at 322-24.

<sup>124</sup> *Id.* at 324.

<sup>125</sup> *Id.* at 324-55.

<sup>126</sup> *Id.* at 324.

<sup>127</sup> *Id.*

<sup>128</sup> *In re E.G.*, 549 N.E.2d at 324.

<sup>129</sup> *Id.*

On appeal, the court extended the holding of the case *In re Estate of Brooks v. Brooks*<sup>130</sup> to mature minors. The court justified its decision by referring to cases in which the United States Supreme Court permitted mature minors to consent to abortions, absent parental agreement or support through the exercise of the privacy rights.<sup>131</sup> The court found this extension to be inevitable, even though the United States Supreme Court has not expanded this constitutional right of minors beyond abortion cases.<sup>132</sup> The court reversed the lower court's decision and held that mature minors can exercise the constitutional right to refuse medical treatment.<sup>133</sup> The court rationalized its holding using the State of Illinois's Emancipation of Mature Minors Act.<sup>134</sup>

Courts will continue to have difficulty applying the mature minor doctrine to these cases because many situations requiring judicial intervention involve children under the age of ten years old who are not fully developed and likely not mature enough to decide to donate alone or understand the nature of the procedure. In addition, precedent has established that a mature minor has the right to refuse life-saving medical treatment; thus, in cases involving minor donor-siblings, a minor's maturity should be assessed to determine whether the child has the recognized right to refuse treatment which conveys no direct medical benefit on her. A parent should be allowed to consent on behalf of a mature minor donor-sibling if a court determines that the parent's interests align with the interests of the mature minor donor-sibling as in situations involving Jehovah's Witnesses who refused to consent to medical procedures for their children because of their religious beliefs.<sup>135</sup>

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<sup>130</sup> 205 N.E.2d 435 (Ill. 1965); *see also* *City of Akron v. Akron Ctr. for Reprod. Health, Inc.*, 462 U.S. 416 (1983).

<sup>131</sup> *In re E.G.*, 549 N.E.2d at 324.

<sup>132</sup> *Id.*

<sup>133</sup> *Id.*

<sup>134</sup> *Id.*

<sup>135</sup> *See id.* at 325. Other state courts have allowed teenagers approaching the legal age of majority to consent who also shared their parents' religious beliefs and agreed with their parents' decision to refuse medical care to provide consent to a medical procedure. *In re E.G.*, 549 N.E.2d at 325.

## B. A Child Has a Property Interest In Her Bone Marrow

The body and its parts are sometimes treated as property and are sometimes the subject of privacy rights.<sup>136</sup> All definitions of property encompass some type of ownership or legal right with respect to an object or thing.<sup>137</sup> A minor donor-sibling should have a recognized property interest in her body and its products, such as bone marrow.

Courts have struggled to determine whether human tissue is personal property. In 2014, the Canadian Superior Court addressed this issue in *Estate of Piljak v. Abraham*.<sup>138</sup> Here, the court concluded that excised liver tissue, which was collected for diagnostic purposes, was no longer personal property of the plaintiff-patient once the tissue was excised.<sup>139</sup> The court maintained that a patient owns the biological tissue prior to its exiting her body; however, a patient loses possession and ownership rights over the tissue once it is excised.<sup>140</sup> The court first defined personal property as a “class of property dealing with rights in a chattel or any movable or intangible thing that is subject to ownership and not classified as real property.”<sup>141</sup> Arguably, bone marrow fits within such definition. The court in *Piljak Estate* concluded that patients own the tissues in their bodies.<sup>142</sup> The court referred to an article published by the Canadian Medical Association Journal, which discussed the rights associated with excised human tissue and how to determine tissue ownership.<sup>143</sup> The article recognized that human tissue is excised either for the purposes of diagnosis, medical treatment or research and explained that it “is unquestionably true that patients own their tissue before it is excised.”<sup>144</sup> Accordingly, the court in *Estate of Piljak* held that the

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<sup>136</sup> Radhika Rao, *Genes and Spleens: Property, Contract, or Privacy Rights in the Human Body?*, 35 J.L. MED. & ETHICS 371 (2007).

<sup>137</sup> *Estate of Piljak v. Abraham*, 2014 CanLII 2893 (Can. Super. Ct. Ont.).

<sup>138</sup> *Id.* at 2897.

<sup>139</sup> *Id.*

<sup>140</sup> *Id.*

<sup>141</sup> *Id.* at 2898. Carol C. Cheung et al., *Defining Diagnostic Tissue in the Era of Personalized Medicine*, 185 CANADIAN MED. ASS'N J. 135 (2013), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3563886/pdf/1850135.pdf>. This Note addresses who has rights to access excised human tissue.

<sup>142</sup> *Estate of Piljak*, 2014 CanLII at 2899.

<sup>143</sup> *Id.* at 2898-99.

<sup>144</sup> Cheung et al, *supra* note 141, at 137.

tissue is subject to ownership rights and can be defined as “personal property” because it is movable.<sup>145</sup>

In *Moore v. Regents of the University of California*,<sup>146</sup> the court similarly addressed the question of whether excised human tissue is personal property.<sup>147</sup> The court held that cells are no longer the property of a patient once they leave the human body.<sup>148</sup> However, Justice Broussard’s dissenting opinion stated:

[T]he majority opinion rests its holding, that a conversion action cannot be maintained, largely on the proposition that a patient generally possesses no right in a body part that has already been removed from his body. Here, however, plaintiff has alleged that defendants interfered with his legal rights before his body part was removed. Although a patient may not retain any legal interest in a body part after its removal when he has properly consented to its removal and use for scientific purposes, it is clear under California law that before a body part is removed it is the patient, rather than his doctor or hospital, who possesses the right to determine the use to which the body part will be put after removal.<sup>149</sup>

Justice Broussard’s dissent properly recognized that an individual has a property interest in her body and its products.<sup>150</sup> As such, a child arguably has ownership rights in her bone marrow.

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<sup>145</sup> *Estate of Piljak*, 2014 CanLII at 2897.

<sup>146</sup> 793 P.2d 479 (Cal. 1990). This case involved an individual’s rights over her excised tissues which is distinguishable from marrow cases in which rights concern tissue inside the body. *See generally id.* *See also* *Hecht v. Superior Court of L.A. Cty.*, 20 Cal. Rptr. 2d 275 (Ct. App. 1993); *In re Estate of Kievernagel v. Kievernagel*, 83 Cal. Rptr. 3d 311 (Ct. App. 2008) (recognizing that gametic material is a unique type of property not governed by the general laws relating to gifts or personal property or their transfer).

<sup>147</sup> *Moore*, 793 P.2d at 498.

<sup>148</sup> *Id.* at 498-99.

<sup>149</sup> *Id.* at 151 (Broussard, J., dissenting).

<sup>150</sup> *Id.*

**C. A Child Has a Privacy Right That Extends to the Right to Bodily Integrity and Personal Autonomy of her Body**

The protection of the human body is safeguarded by various legal doctrines including the constitutional right of privacy,<sup>151</sup> the liberty interest protected by the Fourteenth Amendment's Due Process Clause,<sup>152</sup> and the common law right to refuse medical treatment.<sup>153</sup> In modern medical ethics, personal autonomy is considered to be of great moral importance.<sup>154</sup> Medical ethics requirements oblige healthcare providers to respect a patient's right to personal autonomy,<sup>155</sup> and providers consider this principle to be a significant factor in making decisions about an individual's health.<sup>156</sup>

Arguably, a minor donor should have a privacy right with respect to her bone marrow. The court in *Curran* acknowledged that a healthy child is rendered a victim when subjected to bodily intrusions that convey no direct medical benefit to that child.<sup>157</sup> More specifically, it can be deduced from judicial decisions that taking the bone marrow from a child constitutes a personal bodily invasion and is a violation of a child's constitutional rights.<sup>158</sup> Courts have routinely refused to force one person to undergo a medical procedure for the purpose of benefiting another, even in circumstances where a blood relationship is shared, the risk to one individual is perceived to be minimal and the benefit to the other individual possibly will be great.<sup>159</sup> Moreover, it could be argued that minor donor-siblings are victims whose constitutional rights are being infringed by parents making decisions in *their* best interest. These children are healthy; if they were not, doctors would not sedate them and extract their bone marrow for

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<sup>151</sup> Rao, *supra* note 136.

<sup>152</sup> *Washington v. Glucksberg*, 521 U.S. 702 (1997).

<sup>153</sup> *See id.* at 777-79.

<sup>154</sup> *See* Alireza Parsapoor et al., *Autonomy of Children and Adolescents in Consent to Treatment: Ethical, Jurisprudential and Legal Considerations*, 24 IRANIAN J. PEDIATRICS 241 (2014), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4276576/pdf/IJPD-24-241.pdf>.

<sup>155</sup> *See id.*

<sup>156</sup> *See id.*

<sup>157</sup> Isabel Wilkerson, *In Marrow Donor Lawsuit, Altruism Collides With Right to Protect Child*, N.Y. TIMES (July 30, 1990), <https://www.nytimes.com/1990/07/30/us/in-marrow-donor-lawsuit-altruism-collides-with-right-to-protect-child.html>.

<sup>158</sup> *See* *McFall v. Shimp*, 10 Pa. D. & C.3d 90 (Ct. Com. Pl., Allegheny Cty. 1978).

<sup>158</sup> *Id.* at 90.

<sup>159</sup> *Id.*

harvesting. Further, the extraction of bone marrow from the inside of a child's bone constitutes a bodily intrusion because it requires the use of a large needle that is thick enough to puncture the strong surface of the bone. This bodily intrusion of a healthy child without the child's consent violates the child's constitutional rights.

In *McFall v. Shimp*, the plaintiff asked a court compel his first cousin, the only compatible bone marrow match, to submit to a transplant procedure and donate his bone marrow.<sup>160</sup> Judge Flaherty of the Pennsylvania court addressed whether society can infringe upon an individual's absolute right to her *bodily security* to save another's life when the infringement is the only means available.<sup>161</sup> First, Judge Flaherty discussed a moral argument embedded in common law that has maintained that individuals do not have a legal obligation to give aid or take action to save or rescue another.<sup>162</sup> Next, Judge Flaherty asserted that the government exists to protect individuals from being invaded and hurt by another.<sup>163</sup> Judge Flaherty then stated:

[T]o submit to an intrusion of his body would change the very concept and principle upon which our society was founded. To do so would defeat the sanctity of the individual, and would impose a rule which would know no limits, and one could not imagine where the line would be drawn. . . . For a society which respects the rights of *one* individual, to sink its teeth into the jugular vein or neck of one of its members and suck from it sustenance for *another* member, is revolting to our hard-wrought concepts of jurisprudence. Forcible extraction of living body tissue causes revulsion to the judicial mind.<sup>164</sup>

Judge Flaherty correctly reasoned that an individual cannot be compelled to submit to a medical procedure that benefits another. However, minor donor-siblings do not have the legal authority to consent to, or refuse to submit to, medical testing or procedure, and parents with an interest to save another child hold the authority to

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<sup>160</sup> *Id.* at 91.

<sup>161</sup> *Id.* at 91-92.

<sup>162</sup> *McFall*, 10 Pa. D. & C.3d at 92.

<sup>163</sup> *Id.*

<sup>164</sup> *Id.* (emphasis in original).

decide for these children. These children need to be protected from being invaded by another as Judge Flaherty stated.<sup>165</sup>

### I. *Congress's Spending Power*

Congress can exercise its spending power to enact a statute for a program that is funded through a federal grant and protects minor donor-siblings through conditional spending.<sup>166</sup> Although states have the responsibility to protect children, Congress should address issues concerning minor donor-siblings to achieve adequate protection for these children. Article I, section 8, of the United States Constitution provides Congress with the authority to govern according to its enumerated powers.<sup>167</sup> However, the United States Constitution does not explicitly authorize Congress to regulate minor donations.<sup>168</sup> Consequently, Congress cannot compel the states to enact or implement laws that protect minor donor-siblings.<sup>169</sup> Nonetheless, Congress can exercise its spending power to influence state law by incentivizing states to comply with the enactment of a federal program, funded through a grant, to protect minor donor-siblings.<sup>170</sup> The federal program must explicitly state its conditions and have *some* relationship to the purpose of the spending program.<sup>171</sup> States may opt to participate and comply with the program's requirements.<sup>172</sup>

Such legislation is critical to protect the minor who lacks the legal capacity to consent to, or refuse to submit to, medical testing over a parent's decision in situations involving minor donor-siblings. Consequently, desperate parents frenzied over one dying child continue to hold the absolute legal authority to consent to medical testing for another child while expecting to act in the minor donor-sibling's *best interest*. Although legal, ethical, and psychological concerns have been expressed about minor sibling donations, few

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<sup>165</sup> *Id.*

<sup>166</sup> U.S. CONST. art 1, § 8, cl. 1 (granting the power to issue and collect taxes "to pay the Debts and provide for the common Defense and General Welfare of the United States").

<sup>167</sup> *See id.*

<sup>168</sup> *See id.*

<sup>169</sup> *See id.*

<sup>170</sup> *See id.*

<sup>171</sup> *See* U.S. CONST. art 1, § 8, cl. 1.

<sup>172</sup> *See* Albert J. Rosenthal, *Conditional Federal Spending and the Constitution*, 39 STAN. L. REV. 1103 (1987).

cases have reached the courts because the legal management of minor sibling donations remains undeveloped.

#### D. The Liberty Interest of the Fourteenth Amendment

The Fourteenth Amendment provides that no state shall “deprive any person of life, liberty, or property, without due process of law.”<sup>173</sup> Upon birth, a child acquires all of the protections afforded by the Fourteenth Amendment including the right of bodily autonomy because a child is a *person*. The Due Process Clause of the Fourteenth Amendment protects against government interference with specific fundamental rights and liberty interests.<sup>174</sup> Additionally, precedent has established that the substantive due process right to bodily integrity is encompassed in the Fourteenth Amendment of the United States Constitution.<sup>175</sup> The Supreme Court has held that the right to bodily integrity allows a woman to obtain an abortion, entitles an individual to refuse medical treatment,<sup>176</sup> and allows families to make decisions concerning contraceptive use.<sup>177</sup> Therefore, the substantive due process right to bodily integrity should be extended to include managing the care of minor donor-siblings, as these children should have the recognized right to refuse unsolicited or non-beneficial medical treatment.<sup>178</sup>

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<sup>173</sup> U.S. CONST. amend. XIV.

<sup>174</sup> *Washington v. Glucksberg*, 521 U.S. 702 (1997); *see also Reno v. Flores*, 507 U.S. 292 (1993).

<sup>175</sup> *See Washington*, 521 U.S. at 702.

<sup>176</sup> *See Planned Parenthood of Se. Pa. v. Casey*, 505 U.S. 833 (1992); *see also Cruzan v. Dir., Mo. Dep’t of Health*, 497 U.S. 261 (1990); *Griswold v. Connecticut*, 381 U.S. 479 (1965).

<sup>177</sup> *See Prince v. Massachusetts*, 321 U.S. 158 (1944) (involving a nine-year-old voluntarily distributing leaflets); *Wisconsin v. Yoder*, 406 U.S. 205 (1972) (involving an Amish child explicitly agreeing to home schooling); *see also Washington*, 521 U.S. at 702; *Cruzan*, 497 U.S. at 261.

<sup>178</sup> *See In re A.C.*, 573 A.2d 1235 (D.C. 1990) (stating that circumstances could never be compelling enough to justify a massive intrusion into an individual’s body, like a Cesarean section, contrary to the wishes of that person); *see also In re Baby Boy Doe*, 632 N.E.2d 326 (Ill. App. Ct. 1994) (recognizing that courts have “consistently refused to force one person to undergo medical procedures for the purpose of benefiting another person—even where the two persons share a blood relationship, and even where the risk to the first person is perceived to be minimal and the benefit to the second person may be great”).



### I. A Parent's Fundamental Right

The Supreme Court has demonstrated in several contexts an unwillingness to intervene in parental decisions.<sup>179</sup> This is demonstrated by a long history of precedent, which has unambiguously established that a parent has a fundamental liberty interest in raising a child as she sees fit.<sup>180</sup> In the context involving minor donor-siblings, the relevant liberty interest at issue pertains to a parent's interest in the care, custody, and control of her child.<sup>181</sup>

Parents have the fundamental right to make decisions affecting the care, custody, control and management of their children.<sup>182</sup> This fundamental right is reflected in *Wisconsin v. Yoder*,<sup>183</sup> where the United States Supreme Court stated that the "primary role of . . . parents in the upbringing of their children is now established beyond debate as an enduring American tradition."<sup>184</sup> Further, in *Parham v. J.R.*,<sup>185</sup> the Court stated that its "jurisprudence historically . . . reflected Western civilization concepts of the family as a unit with broad parental authority over minor children."<sup>186</sup> The Court also held in *Troxel v. Granville* that a fit parent will act in the best interest of her children.<sup>187</sup> In that case, the Court explained that a parent is fit so long as the parent *adequately* cares for her *children*.<sup>188</sup> The State will not intervene in the parent-child relationship or "into the private realm of the family to further question the ability of that parent to make the best decisions concerning the rearing of that parent's children" if the parent is fit.<sup>189</sup> In light of this extensive precedent, it is clear that the Due Process Clause of the Fourteenth Amendment validates a parent's fundamental right to make decisions concerning the care, custody, control and management of her children.<sup>190</sup> Thus, it is accepted that

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<sup>179</sup> *Troxel v. Granville*, 530 U.S. 57 (2000).

<sup>180</sup> *Id.* at 58.

<sup>181</sup> *Id.* at 59.

<sup>182</sup> *Wisconsin v. Yoder*, 406 U.S. 205 (1972); *see also Santosky v. Kramer*, 455 U.S. 745 (1982) (noting that parents have the fundamental liberty interest in the care, custody, and management of their children).

<sup>183</sup> *Wisconsin*, 406 U.S. at 205.

<sup>184</sup> *Id.* at 232.

<sup>185</sup> 442 U.S. 584 (1979).

<sup>186</sup> *Id.* at 602.

<sup>187</sup> *Troxel v. Granville*, 530 U.S. 57, 68-69 (2000).

<sup>188</sup> *Id.* at 68.

<sup>189</sup> *Id.*

<sup>190</sup> *Id.*

courts give considerable deference to parents and challenge their decisions under limited circumstances.

However, the Supreme Court did not intend for the constitutionally protected parent-child relationship to rationalize a parent's decision to prepare her child to undergo an elective surgical procedure like donating bone marrow to a sibling. There are limits to a parent's authority to make decisions concerning the health and safety of her child. The Court addressed this limitation to parental authority in *Prince v. Massachusetts*.<sup>191</sup> Here, a parent was convicted for violating a Massachusetts child labor law because she allowed her nine-year-old child to voluntarily distribute religious pamphlets on the streets in the evening.<sup>192</sup> The Court held that the state's interest to regulate or prohibit child labor outweighed a parent's constitutional right to bring up her children as she desires.<sup>193</sup> The Supreme Court recognized that the rights of parents are subject to limitations because the state as *parens patriae* may intervene to protect a child's well-being.<sup>194</sup> The Court noted that "[p]arents may be free to become martyrs themselves. But it does not follow they are free, in identical circumstances, to make martyrs of their children before they have reached the age of full and legal discretion."<sup>195</sup> Accordingly, parents should not make martyrs out of minor donor-siblings by analogous reasoning.

At present, parents can continue to make martyrs of their children because siblings are likely the best bone marrow matches. Parents should not be able to use the Fourteenth Amendment to justify exposing a child to a match test that simultaneously subjects that child to an invasive medical procedure and conveys no direct medical advantage to the minor donor-sibling. The state should intervene in the parent-child relationship and should be able to further question the ability of a parent to make decisions involving minor donor-siblings, even if the parent is fit, because a clear conflict of interest exists that likely affects the parent's judgment. In cases involving minor donor-siblings, courts should not give considerable deference to parents.

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<sup>191</sup> 321 U.S. 158 (1944). While *Prince* concerns a parent violating a state labor law which causes the state to intervene in the parent-child relationship, minor donor-sibling cases do not involve this issue.

<sup>192</sup> *Id.* at 159.

<sup>193</sup> *Id.* at 160.

<sup>194</sup> *Id.* at 163.

<sup>195</sup> *Id.* at 170.

## 2. *The Legal Authority To Provide Informed Medical Consent*

A child or an appointed legal guardian, not a parent, should have the legal authority to provide informed medical consent when a transplant involving a sibling is considered. A child should be appointed by an independent advocate to represent her interests in the matter. Arguably, an explicit conflict of interest exists when a parent decides whether to subject a minor donor-sibling to the bone marrow transplantation process. Consequently, under these circumstances, it should not be presumed that parents will act according to the best interests of their children. Courts should not give considerable deference to parents in these limited circumstances and should analyze their decisions.

In *Bellotti v. Baird*,<sup>196</sup> the Supreme Court balanced the interests of minor women in making the decision to obtain an abortion with their parents' interests in having the constitutional right to raise their children.<sup>197</sup> Here, the Court recognized that a parent should not have the absolute authority to decide nor the power to trump the decision of a doctor and his patient.<sup>198</sup> It could be argued that minor donor-siblings should similarly be provided an alternative, such as having their interests represented by an independent advocate or guardian, when addressing whether the minor donor-siblings want to donate bone marrow after being completely informed about the process. As pregnant minors can prove to the court that they are mature enough to decide to have an abortion, minor donor-siblings should have the same chance to prove to the courts that they are mature enough to decide whether to consent to donate bone marrow. If not capable, the court may appoint a legal guardian or decide based on the minor donor-sibling's best interests, even over a parent's objection.

The court in *In re Grady*<sup>199</sup> recognized that it should be the court's judgment, in place of a parent's good faith decision, that substitutes for an incompetent child's judgment.<sup>200</sup> Here, the parents of a mentally incompetent child asked the court to appoint a special

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<sup>196</sup> 428 U.S. 132 (1976).

<sup>197</sup> See generally *id.*

<sup>198</sup> See generally *id.*

<sup>199</sup> 426 A.2d 467 (N.J. 1981).

<sup>200</sup> This case is distinguishable because it involves reproductive capabilities and the incompetence at issue is due to a mental impairment and a medical condition.

guardian to authorize and consent to a medical procedure to sterilize their child.<sup>201</sup> The court in *Grady* held that an appropriate court has the power as *parens patriae* and must exercise such power to make the final determination whether consent to sterilization should be given on behalf of incompetent individual;<sup>202</sup> a similar position should be taken on behalf of minor donor-siblings. The court also concluded that an independent guardian *ad litem* should be appointed when applying for authorization to sterilize an incompetent person. The court maintained that it cannot authorize the sterilization of such person unless persuaded by clear and convincing evidence that sterilization is in an incompetent person's best interests.<sup>203</sup> The court noted that if a person is legally incompetent in some matters, it does not follow that the individual is incapable of deciding in other matters.<sup>204</sup> For example, a child who is fifteen-years-old may be legally incompetent because she has not reached the age of majority; however, this does not mean she is mentally incapable of deciding to donate bone marrow.

Arguably, minor donor-sibling cases would not involve taking away a person's reproductive ability or mental impairment condition as in *Grady*. Furthermore, minor donor-sibling cases may not require as invasive of a procedure like in *Grady*; however, such cases similarly involve providing consent for an incompetent person to undergo a medical procedure.<sup>205</sup> The court in *Grady* held that the authorization to sterilize an incompetent person cannot be given by a court unless persuaded by clear and convincing proof that sterilization is in the incompetent person's best interests.<sup>206</sup> For minor donor-sibling cases, a court should similarly not authorize a minor sibling to participate in the transplantation process unless persuaded by clear and convincing evidence that donating is in that minor donor-sibling's best interests.

The court also recognized the importance of appointing an attorney for the child when an application is made for the authorization of an invasive medical procedure such as to sterilize an allegedly incompetent person.<sup>207</sup> This case signifies that appointed guardians must have full opportunity to meet with incompetent persons to

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<sup>201</sup> *In re Grady*, 426 A.2d at 478-80.

<sup>202</sup> *Id.*

<sup>203</sup> *Id.* at 482.

<sup>204</sup> *Id.* at 483.

<sup>205</sup> *Id.* at 475.

<sup>206</sup> *Grady*, 426 A.2d at 482-83.

<sup>207</sup> *Id.* at 478-80.

properly represent their interests.<sup>208</sup> As a legal guardian was appointed in *Grady*,<sup>209</sup> an independent donor advocate should be provided to minor donor-siblings when a parent provides informed consent on behalf of a child not yet sufficiently mature to decide alone. Congress should enact legislation that sets up a program to provide guidance in assessing whether a child is capable of deciding to donate, or whether a neutral court should hold a hearing to establish what is in the donor child's best interests, which ensures that the child's due process liberty interest is protected. A standard should require the court to appoint a legal guardian or neutral advocate for the minor donor-sibling in which the advocate can provide informed consent. Informed consent includes disclosing the risks inherent in the procedure, the potential side effects and the possible long-term effects to the minor donor-sibling prior to submitting to any medical test.<sup>210</sup> Moreover, such a standard would safeguard the child's interests prior to submitting to bone marrow testing. Therefore, a minor donor-sibling should have a recognized constitutionally protected due process right under the Fourteenth Amendment to have a neutral court hold a hearing or have a legal guardian represent her to determine what is in that child's best interests when parental conflict<sup>211</sup> arises or ethical questions arise.

### 3. *Judicial Intervention and Parental Conflict*

The state has a compelling interest as *parens patriae* to protect the well-being of children who are unable to protect themselves.<sup>212</sup> Judicial intervention is necessary when a parent's decision to use one child to benefit another conflicts, does not align with the minor sibling's or donor advocate's wishes, or is contrary to a professional's recommendation about moving forward with the procedure. In such circumstances, a neutral court should determine the best interests of a minor donor-sibling, and the parent should bear the burden to prove why subjecting the child to an invasive procedure is reasonable or in that child's best interest.<sup>213</sup> Minor donor-sibling cases involve ethical

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<sup>208</sup> *Id.* at 482-83.

<sup>209</sup> *Id.*

<sup>210</sup> *Id.*

<sup>211</sup> Parental conflict may arise when a parent's decision does not align with the recommendations of an ethics committee, a physician, a donor advocate or the desires of the minor donor-sibling.

<sup>212</sup> See *In re E.G.*, 549 N.E.2d 322 (Ill. 1989).

<sup>213</sup> *Id.*

considerations that produce legitimate conflicts of interest for a parent because such conflicts of interest are likely to affect the parent's judgment when making a decision that affects *two* children and has irreversible consequences. The fit parent presumption should not apply in minor donor-sibling cases because parents will not make an unbiased decision concerning the best interests of their children.

Tremendous conflict may arise in cases involving minor donor-siblings because of the many ethical and legal concerns surrounding the interests of all relevant parties. Consequently, these concerns must be assessed by balancing the interests of all four parties: the parents, the patient-recipient's medical team, the patient-recipient, and the minor donor-sibling. The parents are in a difficult situation when deciding whether to subject one child to a painful medical procedure in the hope of saving another. This difficulty should not be minimized as parents likely do not want to imagine that they may lose their child to a life-threatening illness. The parents have an interest in saving their dying child. This includes an interest in subjecting a minor sibling to medical testing and in consenting to that minor's bone marrow donation to benefit their other child. Moreover, parents have the responsibility to decide the best interest of each child and should employ a cost-benefit analysis that minimizes the detriment to the minor donor-sibling. However, parents' judgment may be impaired when making these decisions because a clear conflict of interest exists.

Overall, the patient's medical team has an interest in effectively treating the patient in their care. The physician has an interest in saving his patient battling a disease and has a responsibility only to his patient. The hospital has an ethical and legal responsibility to respect parents' decisions concerning their minor children and has an interest in saving the patient. Thus, the medical team has a primary interest in recommending treatments that it believes would fully and successfully treat their patient.

The patient-recipient has an interest in surviving and undergoing a bone marrow transplant if a compatible match is identified. The patient may put pressure on a sibling who is a compatible match to donate bone marrow. On the other hand, the minor donor-sibling has a self-interest in refusing to submit to a painful medical procedure that requires anesthesia. The minor donor-sibling may also have an interest in wanting to help her sibling to please her parents. Arguably, the donor-sibling might feel pressured by her parents, her sibling, and the patient's medical team when deciding

whether to donate bone marrow. Therefore, only a neutral and independent third party, such as a guardian *ad litem*, can decide what is in the best interest of the minor donor-sibling.<sup>214</sup>

In the case *In re A.M.P.*,<sup>215</sup> the court agreed with the procedure employed by the lower court before granting the parents' petition for authorization of electroconvulsive therapy for their sixteen-year-old child.<sup>216</sup> Here, the court held a hearing and determined by clear and convincing evidence that the child was not a mature minor competent to make a rational decision on his behalf.<sup>217</sup> The court considered the opinions from the treating psychiatrist and court-appointed medical expert and provided the child with an opportunity to be heard with the assistance of counsel and a guardian *ad litem*.<sup>218</sup> The court looked to a statute governing involuntary treatment of adults for guidance in protecting the child's best interests and her due process liberty interests.<sup>219</sup>

In *Parham v. J.R.*,<sup>220</sup> the Supreme Court held that a child's liberty and due process rights were violated when she was committed to a mental institution, as desired by a parent, without independent medical review.<sup>221</sup> Here, the court noted that parents have broad rights in raising their children, which includes medical decision-making, regardless of what the child wants.<sup>222</sup> However, the state has the right to question a parent's discretion when decisions put a child's mental or physical well-being at risk.<sup>223</sup> Furthermore, the Court maintained that parents should retain the roles of making substantial decisions that affect their children; however, involuntary commitment constitutes a

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<sup>214</sup> A guardian *ad litem* should immediately be appointed to represent the donor-sibling in minor donor-sibling cases requiring judicial intervention. The guardian's recommendation to the court should be based on what would actually be in the best interest of the donor-sibling in light of all circumstances, even if the recommendation is contrary to what the child desires. See the Child Abuse Prevention and Treatment Act, Pub. L. No. 93-247, § 105 (1988), codified as amended 42 U.S.C. § 5103, which requires states to appoint guardians *ad litem* for children in abuse or neglect proceedings.

<sup>215</sup> 708 N.E.2d 1235 (Ill. App. Ct. 1999).

<sup>216</sup> *Id.* at 1236. This case concerns a minor patient's due process rights whereas minor donor-sibling cases involve a sibling's rights.

<sup>217</sup> *Id.* at 1239-40.

<sup>218</sup> *Id.*

<sup>219</sup> *Id.*

<sup>220</sup> 442 U.S. 584 (1979).

<sup>221</sup> *Id.* at 631.

<sup>222</sup> *Id.*

<sup>223</sup> *Id.* at 585.

deprivation of liberty and invokes due process rights.<sup>224</sup> In addition, the Court in *Parham* stated that review by an independent medical examiner must occur prior to commitment.<sup>225</sup> The Court recognized that review by the institution's superintendent failed to qualify as independent, whereas review by the institution's staff physician satisfied the due process requirement.<sup>226</sup>

The enactment of a statute for a program that establishes a standard should similarly be used to review minor donor-sibling cases. A court should hold a hearing if conflict arises about a donor's best interests, especially when the donor child is not considered to be competent or a mature minor. Courts addressing this issue should determine by clear and convincing evidence whether the minor sibling is a mature minor competent to make a rational decision on his behalf as in *A.M.P.*<sup>227</sup> In making this determination, courts should consider the opinions from a medical expert, a donor advocate, and a neutral physician. Additionally, courts should provide the donor-sibling with an opportunity to be heard and appoint an independent guardian to represent the child's interests.

Although review by an employee of the medical facility was determined to be neutral in *Parham*, in minor donor cases, review by an employee or individual associated with the transplant center should not be considered an independent review because such persons may receive paychecks from that institution, which exacerbates the conflict of interest issue. Furthermore, medical facilities have a financial interest in performing the donation or transplant procedure. As the Court in *Parham* reasoned that involuntary commitment invokes due process, a parent's ability to subject the child to medical testing that could lead to an invasive medical procedure should also invoke due process. In addition, the Court in *Parham* recognized that due process does not require a full hearing by a fact-finder.<sup>228</sup>

States can create ethical committees that only review minor donor-sibling cases which would satisfy due process. For example, such committees would evaluate and independently assess a minor

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<sup>224</sup> *Id.* at 586.

<sup>225</sup> *Parham*, 442 U.S. at 631.

<sup>226</sup> *Id.* In minor donor-sibling cases, a transplant center physician should not qualify as independent. *Parham* involved involuntary confinement and did not concern anesthesia as in minor donor-sibling cases.

<sup>227</sup> *Id.*

<sup>228</sup> *Id.*



donor-sibling's physical, mental, and emotional health and consider the recommendations of medical professionals, such as independent physicians, social workers, and psychologists specializing in child development. Such medical professionals would evaluate the overall health of the child and give an opinion about the minor donor-sibling's mental, cognitive, emotional, and physical maturity. The committee would review the professional reports and consider the minor's age, the parties' interests, the prognosis and condition of the patient-recipient and the age and maturity of the minor donor-sibling when deciding whether judicial intervention is appropriate. The committee members could be chosen through an application process and, if selected, be required to attend a training session that addresses legal, ethical, and medical issues surrounding minor donor cases. Enacting a system like this would protect minor donor-siblings' interests. Lastly, this process would consider the interests of the parents, the minor donor-sibling, the recipient, and the medical institution.

#### **IV. COMPLEX ISSUES CONCERNING THE MANAGEMENT OF MINOR DONOR-SIBLINGS THROUGHOUT THE TRANSPLANTATION PROCESS**

Managing the care of a minor donor-sibling is complex. It is reasonable to conclude that a minor donor-sibling is at a disadvantage during the care management process because of divided loyalties, pressures, and guilt within the family context.<sup>229</sup> Thus, it is also reasonable to presume that conflicts of interests arise that may adversely affect the best interests of the minor donor-sibling.<sup>230</sup>

It is evident that pediatric patients suffering from life-threatening illnesses and in need of bone marrow transplants experience various psychological reactions throughout this process.<sup>231</sup> Most minor donor-siblings are not given a real choice or are pressured, if not forced, to undergo these donation procedures at such young ages without giving meaningful consent. Congress and state governments have not put mechanisms in place to protect these children. However,

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<sup>229</sup> Janelle Mills, *Understanding the Position of the Savior Sibling: How Can We Save Lives and Protect Savior Siblings?* (Dec. 2013) (unpublished M.A. thesis, Wake Forest University), [https://wakespace.lib.wfu.edu/bitstream/handle/10339/39113/Mills\\_wfu\\_0248M\\_10493.pdf](https://wakespace.lib.wfu.edu/bitstream/handle/10339/39113/Mills_wfu_0248M_10493.pdf)

<sup>230</sup> *Id.*

<sup>231</sup> D. Hutt et al., *Hematopoietic Stem Cell Donation: Psychological Perspectives of Pediatric Sibling Donors and Their Parents*, 50 *BONE MARROW TRANSPLANTATION* 1337 (2015), <https://www.nature.com/articles/bmt2015152>.

the transplantation process unduly burdens and challenges every member of the patient-recipient's family. Parents are likely in distress when their child is dying, trying everything possible, including conceiving a *savior sibling*, for the sole purpose of saving the other child.<sup>232</sup> In this difficult situation, parents are often relieved when discovering that a sibling has been identified as a donor. However, the transplantation procedure involves *two* children (the patient-child and the donor-child), and each child's best interest must be considered. During this difficult time, parents can experience high levels of emotional reactions that may interfere with their judgment because of worry, apprehension of the loss of a child, and fear of relapse if the transplant is not successful.

Minor donor-siblings also experience reactions to the transplantation process. These include emotional issues, such as post-traumatic stress disorders, anxiety, and low self-esteem after donating bone marrow to a sibling.<sup>233</sup> In a study that explored the psychosocial effects of bone marrow transplants, it was concluded that donor-siblings are more likely to develop new behavior problems compared to non-donor-siblings.<sup>234</sup> An additional study examined the psychosocial effects that sibling donors experienced after an unsuccessful transplant. In that study, sibling donors reported having negative feelings including guilt.<sup>235</sup> Moreover, a different study assessed sibling perceptions concerning the bone marrow transplant process, and siblings reported that they felt lonely, were not getting attention from their parents, did not have a choice, and were not needed for support.<sup>236</sup> Lastly, in a study that analyzed siblings' willingness to donate, siblings recognized concerns about the process in which they decide whether to donate, and a majority reported having no choice but to agree to donate.<sup>237</sup> This study revealed that approximately one-third of sibling donors felt forced to donate.<sup>238</sup> It cannot be presumed that a parent will only subject a child to an invasive and painful procedure when the health benefits exceed the risks of the donation. Minor siblings must be protected throughout the transplantation process.

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<sup>232</sup> Mills, *supra* note 229.

<sup>233</sup> *Policy Statement—Children as Hematopoietic Stem Cell Donors*, *supra* note 30.

<sup>234</sup> See K.D. MacLeod et al., *supra* note 34.

<sup>235</sup> See K.D. MacLeod et al., *supra* note 34. The duration of experiencing these feelings is not specified.

<sup>236</sup> See K.D. MacLeod et al., *supra* note 34.

<sup>237</sup> See K.D. MacLeod et al., *supra* note 34.

<sup>238</sup> See K.D. MacLeod et al., *supra* note 34.

### A. Recommended Guidelines in the United States

At present, Congress has not codified a standard addressing how to manage the care of a minor donor-sibling throughout the transplantation process. The enactment of a federal law would provide guidance to transplant centers and protect minor donor-siblings from the many legal implications elicited from using a minor donor-sibling for a transplant procedure. In the United States, transplant centers follow different recommended guidelines published by ethics committees and various organizations.

The American Academy of Pediatrics Bioethics Committee (hereinafter “AAP Ethics Committee”)<sup>239</sup> issued a policy statement that addresses the ethical considerations related to minor donors, not siblings, serving as stem cell donors.<sup>240</sup> In analyzing these considerations, the committee used the benefit-burden test from the perspectives of the minor donor and the patient-recipient.<sup>241</sup> The statement addresses the following ethical concerns: (1) an assessment of circumstances for when it is appropriate for a minor to serve as a donor and participate in the transplant; (2) methods to minimize the risks imposed on a minor donor; (3) the criteria involved in the informed-consent process; and (4) the donor advocate’s role.<sup>242</sup> The AAP Ethics Committee ultimately concluded that minors can ethically serve as stem cell donors when certain conditions of the recommended criteria are satisfied.<sup>243</sup>

The AAP Ethics Committee examined the risks and benefits to the minor donor, the recipient, and the family to determine whether it is ethically permissible for a minor to donate.<sup>244</sup> Congress should provide guidance to transplant centers by delineating what a substantial benefit could be in minor donor cases. For example, if the donor shares a close relationship with the recipient-sibling and the transplant would likely achieve an outcome of remission for the recipient, this would confer a donor benefit of continuing to share a close relationship because the patient may live after a donation. Congress should also prescribe a mechanism for using the benefit-

<sup>239</sup> *Policy Statement—Children as Hematopoietic Stem Cell Donors*, *supra* note 30, at 392.

<sup>240</sup> *Policy Statement—Children as Hematopoietic Stem Cell Donors*, *supra* note 30, at 393.

<sup>241</sup> *Policy Statement—Children as Hematopoietic Stem Cell Donors*, *supra* note 30, at 396.

<sup>242</sup> *Policy Statement—Children as Hematopoietic Stem Cell Donors*, *supra* note 30, at 397.

<sup>243</sup> *Policy Statement—Children as Hematopoietic Stem Cell Donors*, *supra* note 30, at 398.

<sup>244</sup> *Policy Statement—Children as Hematopoietic Stem Cell Donors*, *supra* note 30, at 392.

burden test in which the benefits of using the minor donor and proceeding with the transplantation process are weighed against the potential harm or risks associated with the procedure for each child.<sup>245</sup>

Additionally, the AAP Ethics Committee addressed the psychosocial risks and benefits experienced by the minor donor.<sup>246</sup> Minor donors do not receive any direct medical benefit from donating to a sibling.<sup>247</sup> The benefit of helping a sibling in need is referred to as a *psychosocial* benefit. Most importantly, children reported experiencing distress in relation to their role as a donor.<sup>248</sup> Many pediatric donors believe that they did not have the option to say no to serve as a marrow donor, report being poorly prepared for the procedures, and describe feeling responsible for the recipient's course after the transplant.<sup>249</sup> Data has signified that donors experienced feelings of being inadequately prepared for what to expect post-donation.<sup>250</sup> Lastly, donor-siblings, as well as non-donor-siblings, have reported feeling neglected by their parents throughout this process.<sup>251</sup>

The AAP Ethics Committee then recommended five requirements in which a minor may serve as a donor.<sup>252</sup> First, there are no genetically compatible adult matches willing and available to donate.<sup>253</sup> Second, at the present, the minor donor-sibling and the recipient-child share a close and strong personal relationship.<sup>254</sup> Third, the bone marrow donation will confer a reasonable benefit to the recipient in need of a transplant.<sup>255</sup> Fourth, the clinical, emotional, and psychosocial risks to the donor are minimized and are reasonable in relation to the benefits expected to accrue to the donor and to the

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<sup>245</sup> See *Policy Statement—Children as Hematopoietic Stem Cell Donors*, *supra* note 30, at 392-93.

<sup>246</sup> *Policy Statement—Children as Hematopoietic Stem Cell Donors*, *supra* note 30, at 398.

<sup>247</sup> *Policy Statement—Children as Hematopoietic Stem Cell Donors*, *supra* note 30, at 399.

<sup>248</sup> *Policy Statement—Children as Hematopoietic Stem Cell Donors*, *supra* note 30, at 395.

<sup>249</sup> *Policy Statement—Children as Hematopoietic Stem Cell Donors*, *supra* note 30, at 395.

<sup>250</sup> See WI Sharma, *The Experience and Preparation of Pediatric Sibling Bone Marrow Donors*, 27 SOC. WORK HEALTH CARE 89 (1998), <https://www.ncbi.nlm.nih.gov/pubmed/9579018> (last visited January 4, 2018).

<sup>251</sup> See *id.*

<sup>252</sup> *Policy Statement—Children as Hematopoietic Stem Cell Donors*, *supra* note 30, at 396-98.

<sup>253</sup> *Policy Statement—Children as Hematopoietic Stem Cell Donors*, *supra* note 30, at 396.

<sup>254</sup> *Policy Statement—Children as Hematopoietic Stem Cell Donors*, *supra* note 30, at 396.

<sup>255</sup> *Policy Statement—Children as Hematopoietic Stem Cell Donors*, *supra* note 30, at 397.

recipient.<sup>256</sup> The fifth condition recommends that parental permission and, when appropriate, child assent be obtained.<sup>257</sup>

The first condition supports screening both adult and child family members in the initial donor search.<sup>258</sup> However, national and international registries exist that are comprised of thousands of adults willing to donate and should be searched before subjecting a minor to the complicated transplantation process. The rationale for the second condition identifies that sharing a close relationship with the patient-recipient could increase the likelihood that the donor will experience *some* psychological benefit. However, there is no guarantee that the donor will receive any benefit. The third condition fails to define what qualifies as *some likelihood* that the patient-recipient will benefit from transplantation, and it does not provide examples of circumstances that could meet this threshold for guidance. However, the statement acknowledged the difficulty of determining the threshold for the patient-recipient to justify proceeding with the donation procedure. Delineating this threshold is challenging because the patient-recipient's prognosis post-donation is uncertain. The fourth condition states that the patient's transplant team should help the parent consider the risks and benefits of using a sibling to donate from the neutral viewpoints of the recipient and of the donor.<sup>259</sup> However, arguably, the patient-recipient's transplant team is biased because it may be willing to proceed with the donation irrespective of the likelihood of its success. Likewise, the parents might be unable to make a neutral decision that does not favor the interests of the child needing a donation. As for the fifth condition, this author disagrees with the AAP Ethics Committee's delineation of the donor advocate's role. The donor advocate's primary obligation should only be considered to the minor donor when the advocate represents the child's best interests throughout the transplantation process; donor advocates should not have any obligation to the parents.

In the United Kingdom, legal scholars and physicians proposed that our policy be modified to protect minor donor-siblings to satisfy the legal requirements for application in the United Kingdom and other

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<sup>256</sup> *Policy Statement—Children as Hematopoietic Stem Cell Donors*, *supra* note 30, at 397.

<sup>257</sup> *Policy Statement—Children as Hematopoietic Stem Cell Donors*, *supra* note 30, at 398.

<sup>258</sup> *Policy Statement—Children as Hematopoietic Stem Cell Donors*, *supra* note 30, at 396.

<sup>259</sup> *Policy Statement—Children as Hematopoietic Stem Cell Donors*, *supra* note 30, at 396.

jurisdictions with comparable laws protecting minors.<sup>260</sup> The United Kingdom's statement explains that there is no moral or legal basis to violate a minor donor-sibling's right to bodily integrity unless the recipient sibling will die without the transplantation and no other medically equivalent donors are available.<sup>261</sup>

Although tissue harvest serves the best interests of recipient siblings, parents are also obliged to act in the best interests of the donor[-]sibling in the UK. Tissue harvest should proceed if and only if it serves the best interests of both the donor and recipient. Parents should be forbidden, and they are by UK law, to consent to tissue harvest unless there are substantial benefits for an incompetent minor that can outweigh the potential harm. There is no basis to subject a minor to the medical risks of tissue harvest if the recipient sibling can wait without significant risks of complications until the donor becomes Gillick competent. We also argue that the Policy fails to take into account recent advances in haematopoietic transplantation from haploidentical donors or related tissue-matched donors.<sup>262</sup>

The United Kingdom's statement properly recognized that a parent is obligated to act in the best interests of the minor donor-sibling as well as the patient-recipient child.<sup>263</sup> Parents and doctors should ensure, if the medical conditions of the sick sibling permit a search, that no other sources of equally or similarly effective transplant are available before subjecting a minor to the physical risks and short-term psychological harm of donating.

The AAP Ethics Committee's recommended policy fails to protect a minor donor-sibling's interest throughout the transplantation process. In cases involving minor donor-siblings, the United Kingdom correctly proposed that the first condition should be replaced with a requirement in which the patient-recipient's medical condition allows

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<sup>260</sup> See Tak Kwong Chan & George Lim Tipoe, *The Policy Statement of The American Academy of Pediatrics—Children As Hematopoietic Stem Cell Donors—A Proposal of Modifications for Application in the UK*, 14 BMC MED. ETHICS 1 (2013). Foreigners have commented on and critiqued the recommended guidelines used in the United States regarding the care management of minor donor-siblings. See *id.*

<sup>261</sup> *Id.* at 1.

<sup>262</sup> *Id.*

<sup>263</sup> See *id.*

a search; no medically equivalent related adult or histocompatible unrelated adult who is willing and able to donate exists prior to subjecting minor siblings to medical testing.<sup>264</sup> This author further supports the United Kingdom's proposal to replace the AAP's third condition with a requirement allowing an incompetent minor sibling to be subjected to the donation process only if the patient-recipient would likely die without transplantation prior to becoming Gillick competent.<sup>265</sup> However, the United Kingdom's proposed modification of the AAP's fifth condition<sup>266</sup> fails to consider the issues surrounding parental decision-making and the clear conflicts of interest. The United Kingdom identified that a parent must act in the best interests of the minor donor when making medical decisions that affect both children, not just the recipient; however, that expectation is not realistic because parents want to help their child in need. The United Kingdom's statement appropriately recognizes that a parent's choice to use and harvest bone marrow tissue from one child to benefit another reflects an emotive desire to help the recipient sibling.<sup>267</sup> Moreover, the statement recognizes that a donor-sibling may not necessarily obtain any benefits in light of the risks of serious injuries arising from bone marrow transplantation. It is this author's position that satisfying the five conditions provided in the AAP's statement, alone, is not sufficient to justify harvesting bone marrow from a minor donor-sibling because the guidelines fail to sufficiently protect the interests of a minor donor-sibling.

### B. The Judiciary's Role in Protecting Minor Donor-Siblings

The AAP Ethics Committee maintains that minor donations should not require court review or approval and that judicial intervention should be pursued as a last resort.<sup>268</sup> The Committee asserts that the primary role of the judicial review process is to ensure an advocate for the incompetent potential donor; however, an independent donor advocate should be appointed to the possible minor

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<sup>264</sup> Chan & Tipoe, *supra* note 260, at 1.

<sup>265</sup> *Id.* at 2. See Richard Griffith, *What is Gillick Competence?*, 12 HUMAN VACCINES & IMMUNOTHERAPIES 244 (2016), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4962726/>.

<sup>266</sup> *Policy Statement—Children as Hematopoietic Stem Cell Donors*, *supra* note 30, 398.

<sup>267</sup> Chan & Tipoe, *supra* note 260, at 5.

<sup>268</sup> *Policy Statement—Children as Hematopoietic Stem Cell Donors*, *supra* note 30, at 400.

donor as soon as match testing is discussed.<sup>269</sup> The Committee contends that an ethics consultation *may* be appropriate in situations where there is a concern about a parent's motives or what is in the minor donor's best interest.<sup>270</sup> Requiring judicial intervention in all minor donor-sibling scenarios would open a floodgate of litigation and unduly burden the courts' caseloads; however, in such situations judicial intervention should be required.

The AAP Ethics Committee states that the role of the courts is to ensure that an advocate is appointed for an incompetent potential donor.<sup>271</sup> Arguably, the law does not recognize a minor donor as competent as parents have the authority to make medical decisions for minor children. Next, with respect to appointing an independent donor advocate, these advocates are not truly *independent*. Medical facilities often appoint social workers who are employees to serve as independent donor advocates. These facilities could be motivated financially to perform a donation procedure. Thus, an employee of a medical facility might be biased to act in favor of her employer because the employer compensates her. Additionally, in situations where there is a concern about a parent's motives or what is in the minor donor's best interest, judicial intervention is essential; however, the Committee states that a healthcare committee *may* be appropriate to review a case with such a concern.<sup>272</sup>

## V. OTHER CARE MANAGEMENT SYSTEMS AND RECOMMENDATIONS

Other countries and jurisdictions have codified uniform standards for managing the care of minor donor-siblings throughout the bone marrow transplantation process. In Canada, the Oncology Division of Pediatric Medicine Department published guidelines for the performance of bone marrow aspirations in children.<sup>273</sup> Prior to the donation procedure, hospitals in Canada require that the minor donor-sibling be assessed according to written policies and procedures.<sup>274</sup>

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<sup>269</sup> *Policy Statement—Children as Hematopoietic Stem Cell Donors*, *supra* note 30, at 398-99.

<sup>270</sup> *Policy Statement—Children as Hematopoietic Stem Cell Donors*, *supra* note 30, at 400.

<sup>271</sup> *Policy Statement—Children as Hematopoietic Stem Cell Donors*, *supra* note 30, at 398.

<sup>272</sup> *Policy Statement—Children as Hematopoietic Stem Cell Donors*, *supra* note 30, at 400.

<sup>273</sup> M. Campbell et al., *How Young Is Too Young to Be a Living Donor?*, 13 AM. J. TRANSPLANTATION 1643 (2013).

<sup>274</sup> *Id.* at 1645.



The World Marrow Donor Association (hereinafter “WMDA”) also published recommended guidelines for managing related donors, not sibling donors, that some transplant centers implement.<sup>275</sup> First, WMDA recommends that counseling be available for each family member prior to HLA testing.<sup>276</sup> Counseling includes written information inclusive of all aspects of the family donation procedure and care management processes.<sup>277</sup> Counseling should also include the option for the donor to decide not to donate.<sup>278</sup> However, if the donor is not capable of making a meaningful decision or is not legally competent to provide consent, an independent donor advocate should determine if moving forward with the transplantation process is in the child’s best interest. Next, transplant centers should establish procedures to ensure that donors are appropriately counseled regarding their right to refuse typing or donation because related donors may be emotionally or physically unable or hesitant to donate while simultaneously experiencing pressure from other family members.<sup>279</sup> The donor should be appointed a donor advocate and be examined by a physician not associated with the transplant center or involved in the recipient’s care.<sup>280</sup> The donor must maintain the right to disclose or not disclose the communications with the advocate to interested parties such as the recipient or relatives.<sup>281</sup> Lastly, the WMDA recommends establishing procedures which evaluate the clinical risk to the donor and address the recording of adverse events and long-term follow ups for related donors.<sup>282</sup>

The WMDA properly recognized that it is important for an independent physician who understands donors’ rights to examine the potential minor donor-sibling prior to match testing. Some transplant centers substitute a donor advocate or independent physician for a transplant team member; however, the donor advocate should be a person who is not a member of the transplant team, is not involved with the recipient’s care, is educated about the risks and side effects of the transplant procedure, can perceive any coercion during the

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<sup>275</sup> S.M. van Walraven et al., *Family Donor Care Management: Principles and Recommendations*, 45 BONE MARROW TRANSPLANTATION 1269 (2010).

<sup>276</sup> *Id.* at 1270.

<sup>277</sup> *Id.*

<sup>278</sup> *Id.*

<sup>279</sup> *Id.*

<sup>280</sup> Walraven et al., *supra* note 275, at 1270.

<sup>281</sup> Walraven et al., *supra* note 275, at 1270.

<sup>282</sup> Walraven et al., *supra* note 275, at 1273.

independent donor assessment, and can represent the donor in an unbiased manner.<sup>283</sup> This author endorses the WMDA's recommendation that potential donors be counseled prior to match testing.<sup>284</sup> If a counselor identifies any obvious reluctance to donate, or any medical problems that would preclude donation, a deferral of complete match testing is allowed.<sup>285</sup> A counselor's qualifications and role are not delineated in the guidelines.

Additionally, the WMDA properly recommends that the family member is provided the opportunity to decide whether to become a donor.<sup>286</sup> Minor donor-siblings do not have the anonymous choice when deciding whether to become a donor, whereas volunteers have the luxury to decide for themselves without feelings of coercion or the knowledge that a sibling needs a match to survive. Generally, a minor sibling is directly approached by a parent accompanied by a hospital representative with the request for an HLA compatibility typing or bone marrow match test for her sick sibling.<sup>287</sup> At the time of this request, the recipient is often identified as a candidate for a bone marrow transplant.<sup>288</sup> This author also maintains that a positive balance should exist prior to proceeding with the process.<sup>289</sup> This balance is found by comparing the risks to the donor with the benefit to the recipient, in addition to the benefit to the donor with the risks to the patient, including the physical and emotional effects.<sup>290</sup>

## VI. PROPOSAL FOR A FEDERAL ACT TO PROTECT MINOR DONOR-SIBLINGS

Under Article I, section 8, of the United States Constitution, Congress can use its spending power to incentivize states to comply with its laws.<sup>291</sup> States could adopt the program created by the statute and accept its conditions,<sup>292</sup> provided that such conditions, which could provide an adequate minimum standard of protection, are explicitly

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<sup>283</sup> Walraven et al., *supra* note 275, at 1271.

<sup>284</sup> Walraven et al., *supra* note 275, at 1273.

<sup>285</sup> Walraven et al., *supra* note 275, at 1273.

<sup>286</sup> Walraven et al., *supra* note 275, at 1270-71.

<sup>287</sup> Walraven et al., *supra* note 275, at 1271.

<sup>288</sup> Walraven et al., *supra* note 275, at 1270-71.

<sup>289</sup> Walraven et al., *supra* note 275, at 1273.

<sup>290</sup> Walraven et al., *supra* note 275, at 1271-72.

<sup>291</sup> See U.S. CONST. art. I, § 8.

<sup>292</sup> Conditions are statutory requirements that must be met in order to receive funds.

stated and have some relationship to the purpose of the act. Here, the purpose of the act would be to protect minor donor-siblings, and states would use the funds to achieve such purpose. The act should require all transplant centers in the state to establish a specific ethics committee to address minor donor-sibling cases to protect these children's interests and screen for possible issues requiring judicial intervention.<sup>293</sup>

Legislation addressing how to handle this issue would benefit the states, courts, healthcare facilities, and minor donor-siblings. For example, the section of the legislation regarding ethics may state that the purpose of the program is to enable states to develop and establish ethical committees in all transplant centers managing minor donor-siblings to accomplish specific objectives. The section may include the following objectives: (1) to protect minor donor-siblings and their interests throughout the transplantation process; (2) to ensure minor donor-siblings' safety and prevent subjecting them to unnecessary medical procedures and risks; (3) to address any and all conflicts of interest; and (4) to provide support services such as counseling prior to match testing and post-donation. Such an act would provide a minimum degree of protection for all minor donor-siblings in the United States, would provide guidance to transplant facilities overseeing minor sibling donations, and would decrease future litigation surrounding this issue. Congress should take into account the nature of the proposed donation,<sup>294</sup> the ages, maturity, and psychological state of the children involved, and the substantial benefit to the donor.

The act may prescribe requirements for pre-transplantation data gathering in which the patient and possible donor-sibling are evaluated. The evaluation can include taking detailed histories, reviewing physical examinations, and performing imaging and laboratory studies on the patient and minor sibling.<sup>295</sup> The detailed history should include the history of the underlying disease prior- and post-treatment, history of infectious complications associated with the procedure, family medical history, drug allergies, past medical conditions, and social and psychological status.<sup>296</sup> Laboratory studies

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<sup>293</sup> See Rosenthal, *supra* note 172.

<sup>294</sup> Congress should consider the invasiveness of the donation procedure in conjunction with all possible side effects, both long-term and short-term. See CLINICAL MANUAL, *supra* note 8.

<sup>295</sup> CLINICAL MANUAL, *supra* note 8, at 36.

<sup>296</sup> CLINICAL MANUAL, *supra* note 8, at 36.

may include HLA-typing, blood typing, blood counts, and liver function tests.<sup>297</sup> A subsequent condition may require appointing an independent donor advocate to siblings ten-years-old or younger prior to match testing. Lastly, a condition may require checking national and international bone marrow registries for an adult donor prior to subjecting the minor sibling to HLA-testing.

Minor siblings acting as donors require special consideration before beginning the care management process; therefore, this author recommends the following proposals. An independent physician must first examine the child to establish whether the minor donor-sibling is capable of assenting or providing informed consent to donating. A donor advocate with legal training or a court could make the determination that a child is a mature minor. If the child is not capable of assenting or providing informed consent, an independent donor advocate, such as an attorney, for the child should be appointed to protect the child's interests. This is essential because the parent providing consent on behalf of the minor donor-sibling likely has conflicting feelings concerning the welfare of both the patient and the donor. Next, it must be determined whether the possible donor-sibling could and would endure the donation procedure, both physically and mentally, prior to subjecting that sibling to match testing. In addition, a *per se* rule could apply for children who are fifteen-years-old or older in which they are presumed to be competent to consent to a medical procedure alone.

States could use the grant funding to establish, train, and staff ethical committees at transplant centers that only review minor donor-sibling cases which would screen for ethical issues and concerns about using a child as a donor for her sibling. For example, such a committee would evaluate and independently assess a minor donor-sibling's physical, mental, and emotional health after medical professionals examine the child. The committee would consider the recommendations of medical professionals, such as independent physicians, social workers, and psychologists specializing in child development. Such medical professionals would evaluate the overall health of the child and give an opinion about a minor donor's mental, cognitive, emotional, and physical maturity. The committee would review the professional reports and consider the minor's age, the parties' interests, the prognosis and condition of the patient-recipient

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<sup>297</sup> CLINICAL MANUAL, *supra* note 8, at 36.

and the maturity of the minor donor-sibling when deciding whether judicial intervention is appropriate. The committee members could be chosen through an application process and, if selected, be required to attend a training session that addresses legal, ethical, and medical issues surrounding minor donor cases. Lastly, this process would consider the interests of the parents, the minor donor-sibling, the recipient, and the medical institution.

This author recognizes that using children as donors involves the same complex considerations relating to voluntary participation and using children in research.<sup>298</sup> In both contexts, issues of assent, consent, and parental permission arise.<sup>299</sup> For minor donor-siblings involving children whose capacity to understand resembles that of adults, the initial inquiry to determine whether the child is capable of assenting or advocating for herself should be assessed. Congress may refer to Piaget's theory of cognitive development and Kohlberg's theory of moral development when addressing the maturity of a minor respecting age.<sup>300</sup> This mechanism would assist courts in determining the maturity of a child when making decisions concerning a minor donor-sibling's interests and what the child wants to do.

In addition, Congress could categorize minors according to an established age range based on known scientific information about the cognitive and moral development of children.<sup>301</sup> For example, Congress may recommend that children who are fifteen years old or older can decide to donate for themselves *per se* as long as the child is not mentally incompetent due to a physical condition or disability. This system will assist courts in determining the maturity of a child when making decisions concerning a minor donor-sibling. Additionally, Congress should establish factors the courts may consider to determine what is in the best interest of the minor donor-sibling and the patient-recipient. Concerning the minor donor-sibling,

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<sup>298</sup> See *Research with Children FAQs*, U.S. DEP'T HEALTH & HUMAN SERVS, <https://www.hhs.gov/ohrp/regulations-and-policy/guidance/faq/children-research/index.html> (last visited Oct. 30, 2018). The Institutional Review Board considers the child's age, maturity, and psychological state when determining whether a child is capable of assent. See *id.*

<sup>299</sup> Roth-Cline & Nelson, *supra* note 91.

<sup>300</sup> Hing Keung Ma, *The Moral Development of the Child: An Integrated Model*, 1 FRONTIERS IN PUB. HEALTH 57 (2013), <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3860007/>.

<sup>301</sup> See *Kohlberg's Theory and Piaget's Theory*, PSYCHOL. NOTES HQ (Jan. 20, 2016), <https://www.psychologynoteshq.com/kohlbergstheory/>.

factors may include pre-operation requirements, associated risks or complications of donating, absence from school, requirements to take medication post-donation and pre-donation, and the invasiveness of the operation. Concerning the patient-recipient, factors may include the prognosis post-procedure, the associated medical risks, and the quality of life post-donation.

Congress should further delineate, based on age, a way that state courts or ethics committees can assess what the child wants and whether the child is being pressured into donating. Each child's development will vary; thus, courts must assess each minor donor-sibling case on an individual and fact-specific basis. Congress should enact a statute for a program that would be funded by a grant in which states can adopt and implement the program to protect minor donor-siblings' interests and Fourteenth Amendment Due Process rights. Managing minor donor-siblings should be addressed by Congress and not state legislatures because the adoption of such a program contributes to maintaining a uniform standard that provides minimum protection for these children throughout the transplantation process.

However, if the child is not a mature minor, then whether the minor donor is capable of assenting to the bone marrow donation should be assessed. A minor donor assents when the child affirmatively agrees to participate in the transplant process by actively demonstrating her willingness instead of just following directions to participate.<sup>302</sup> Failure to object, not resisting, or just complying with directions should not be construed as assent. The minor donor's age, maturity, psychological state of mind, experience, and level of understanding should be taken into account. A minor who may be mature enough to fully comprehend the nature of the transplant process should be consulted about being tested and donating. Such a minor should be provided with an accurate picture of what the experience of donating bone marrow is likely to be. For example, such possible minor donors should be provided with the information a doctor would provide his patient when obtaining informed consent.<sup>303</sup> The assent procedure should reflect a reasonable effort to enable the child to understand—to the degree they are capable—what their participation in the donation process would involve. This determination should be made for all minor donor-siblings prior to subjecting them to bone

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<sup>302</sup> *Research with Children FAQs*, *supra* note 298.

<sup>303</sup> See *Informed Consent*, AMA, <https://www.ama-assn.org/delivering-care/informed-consent> (last visited Oct. 30, 2018).

marrow match testing. After a minor sibling donates, the child should participate in a routine psychological evaluation and follow up process involving counseling of the donor.

Although parents have the recognized right to make healthcare decisions for their minor children, a strong argument can be made that a clear conflict of interest exists that will affect their judgment in cases involving minor donor-siblings. Parents might prioritize and make decisions according to what is in the best interest of their sick child, and they might minimize and neglect how such decisions affect the minor donor-sibling throughout the transplantation process. As such, Congress should establish factors to be considered in determining what is in the best interests of the minor donor-sibling and the patient recipient.

Congress should also prescribe a mechanism that compares the benefits of proceeding with the transplantation against the potential harm or risks associated with the procedure for each child. Lastly, Congress should specifically delineate what constitutes a substantial benefit in minor donor cases.<sup>304</sup> To help, a neutral donor advocate should be appointed and have the right to consent, or refuse consent, to bone marrow match testing on behalf of a possible minor donor-sibling regardless of what a parent believes is in the best interests of the donor-sibling because a clear conflict of interest exists which can inherently impair the parent's judgment.

A donor advocate should be appointed for all minors who are being considered as bone marrow donors prior to match testing. The independent donor advocate should determine what the child wants and determine whether the child is being pressured to donate given the totality of circumstances. The donor advocate's primary role is to represent the potential minor donor-sibling's interests and well-being throughout the transplant process. Such an advocate should be appointed prior to genetic compatibility testing to ensure that the child fully understands what the procedure entails prior to deciding whether submitting to testing is in the minor donor-sibling's best interest. Donor advocates who become alerted to or concerned about the interests of the minor donor-sibling should seek judicial intervention to delay or prevent the donation.

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<sup>304</sup> For example, if the donor shares a close relationship with the patient-sibling and there is a strong likelihood that a transplant would place the patient-sibling in remission, then the donor would enjoy the benefit of continuing to share a close relationship with the patient-sibling.

Under circumstances that warrant concern,<sup>305</sup> a judicial bypass procedure such as a conference before a judge should occur within a reasonable time to address the minor's interests, to determine whether an attorney for the child should be appointed and whether parental authority to consent on behalf of the child should be waived. Lastly, it should be noted that each child's development<sup>306</sup> will vary, and cases should be determined on an individual and fact-specific basis.

## VII. CONCLUSION

Hematopoietic cell transplants that use bone marrow as the graft source are not only a potentially life-saving treatment, but they are also a high-risk medical procedure.<sup>307</sup> Minor donor-siblings must be thoroughly evaluated prior to match testing and the extraction procedure, and they must be monitored post-transplant.<sup>308</sup> In addition, parents are torn between forcing their healthy child to provide bone marrow to their other child and doing what is in the best interests of the both children; both options are at odds with one another. However, the current legal scheme is deficient and needs extensive reform. Therefore, Congress should enact a statute that protects minor donor-siblings' interests throughout the transplantation process in the United States. States may enact laws that provide additional protections to these children. These protections will help to eliminate some of the conflicts of interest present in the current system in the United States.

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<sup>305</sup> For example, an ethics committee member may express concern about a minor donor-sibling.

<sup>306</sup> Hing Keung Ma, *supra* note 301.

<sup>307</sup> CLINICAL MANUAL, *supra* note 8.

<sup>308</sup> CLINICAL MANUAL, *supra* note 8.