The Ethics and Policy Issues in Creating a Stem Cell Donor: A Case Study in Reproductive Genetics

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During the nearly ten years of its existence, preimplantation genetic diagnosis (PGD) has been used predominantly to avoid giving birth to a child with identified genetic disease. Recently, PGD was used by a couple not only to test embryos created by in vitro fertilization (IVF) for genetic disease, but also to test for a nondisease trait related to immune compatibility with a child in the family in need of a hematopoetic stem cell transplant. This chapter describes the case, analyzes some of the ethical issues it raises, highlights gaps in U.S. policy, and, finally, makes some ethics and policy recommendations for addressing advancing genetic and reproductive technologies.

THE NASH FAMILY CASE

The story of the Nash family and their successful use of preimplantation genetic diagnosis to cure their daughter received national attention for a variety of reasons. First, it is a compelling human interest story, and one with a happy ending. Second, for many in the national media it raised the specter of genetic testing run amok. Third, and most importantly for this discussion, it is a case that raises numerous ethical issues and exposes the lack of institutional or policy controls over the burgeoning uses of genetic and stem cell technologies. In this chapter, we examine the issues raised by the case, and make some recommendations regarding the growing need for oversight mechanisms.

The Nash family relied on the relatively new technology of PGD, which allows for genetic testing of very early-stage human embryos prior to their implantation. PGD relies on traditional IVF techniques, followed by a “biopsy”
of the embryo at the eight-cell stage at two to three days postfertilization. The biopsy is performed by nicking the embryo’s outer membrane, and then removing one of the eight dividing cells. The DNA is removed from the single removed cell, and genetic testing techniques are applied to the DNA. PGD has been used to help prospective parents avoid bearing children with genetic diseases, primarily in cases where parents have known genetic risks.

In the Nash case, both parents were carriers for the genetic disease Fanconi anemia (FA) but were unaware of their carrier status. Since FA is a recessive genetic disease, when two carriers mate there is a one in four chance that the disease will affect their offspring. In the Nashes’ case, their first child, Molly, was born with FA after being conceived the “normal” way, that is, without medical intervention. Children born with FA face a number of obstacles. There are physical problems typical to children with FA, including fused joints in the hips and wrists, missing thumbs, and incomplete guts and, most important for this story, the children become leukemic at six- to eight-years old (Wagner et al. 1999). To treat the leukemia associated with FA, the children require a hematopoietic stem cell (HSC) transplant for their survival. HSC can be donated either by collection of bone marrow or peripheral blood stem cells or collected from the umbilical cord blood after a baby’s birth. The most likely HSC donors are siblings, since they are the closest genetic relatives to the patient. In the Nash case, Molly was their first and only child, so no sibling donors were available. The next best donor source would have been other relatives, but nobody in the family was a sufficiently close immune match to qualify as a donor. When no related donors are available, the National Marrow Donor Program can be used to match unrelated individuals willing to be donors with patients in need of an HSC transplant.

Research has shown that in children with FA, those with sibling transplants have a substantially higher success rate than those with transplants from unrelated donors (Wagner et al. 1999), so the Nashes hoped that a future child would be closely enough matched to act as a donor of umbilical cord blood stem cells. Other couples who found themselves in similar situations had gone through a process of deliberate conception followed by prenatal diagnosis to determine whether the fetus was (1) FA negative and (2) immunematched to their sick child. The results of the prenatal testing led to a potential abortion decision if the developing fetus was found to be carrying the FA mutation. In at least two documented cases, couples aborted otherwise healthy fetuses that were FA negative but immune incompatible with their sick children (Auerbach 1994). Because of the limited time in which to find a donor for Molly and to avoid the need for an abortion decision, the Nashes sought to use PGD to test embryos made in vitro rather than going through the process of prenatal testing and subsequent decisions about abortion. The PGD is a two-stage process: testing first for the FA mutation, and then testing for human leukocyte antigen (HLA) compatibility with Molly among those embryos that tested FA-negative. Five separate times over a period of many months, the Nashes went through the process of collecting ova and IVF in Denver followed by PGD performed by a lab in Chicago before achieving a successful pregnancy with an FA-negative, HLA-matched embryo. That pregnancy resulted in the birth of Adam—so named for the biblical story that it was one of Adam’s ribs that was used to create Eve—in August 2000 in Denver. The umbilical cord blood was collected and flown to Minneapolis where it was frozen until the hematopoietic stem cells it contained were infused into Molly in September 2000 at the University of Minnesota. One hundred days later a news conference was held at the university, where it was announced that Molly’s bone marrow was identical to that of her brother Adam, evidence that the transplant had been successful. The Nashes returned to their home in Denver in January 2001, where Molly for the first time enjoyed life as a healthy child.

Why Does This Case Matter?

This case raises a range of ethical and policy issues, and serves as a very effective example for both the types of social issues that we face as biotechnology advances, and challenges us to consider whether there are limits of ethical acceptability and, if so, what they ought to be. It is a useful case in that it is far from hypothetical, with real people whose names and story make them seem like us—forcing us to consider what we would do faced with similar choices. The fact that the Nashes were able to use a combination of existing technologies in the way they did can also serve as an object lesson for why we need to think about institutional and policy controls. Their case offers a glimpse into some of the real ways that stem cell technologies will be used. Finally, the Nash case serves as a concrete example around which to craft principles, rules, or frameworks. If such approaches prove sufficiently robust, they can help inform approaches for addressing other controversial policy areas such as other reproductive technologies, stem cell research issues, and even cloning.

SOME ETHICAL ISSUES

The Nash case is interesting as both a human interest story and for the ethical and policy issues it raises. In the publicity surrounding the case, many pundits questioned both what characteristics the Nashes chose through the use of PGD and their motivations for choosing them (Belkin 2001). Examining these general claims is one way of exploring the ethical and policy issues the case raises.
Do Characteristics Chosen Matter?

Some of the concern raised by the Nashes' behavior centered on the mistaken claim that they had manipulated human embryos to create a stem cell donor for their daughter. This is a misunderstanding of the function of PGD, of course, which can only be used to test, not alter, the genetic makeup of an existing embryo. Any sort of genetic manipulation would be on the order of gene therapy, a technology yet to show successful application aside from a very few patients. What had happened in the Nashes' use of PGD, however, was that a line had been crossed. In the seven or so years since PGD has been developed and introduced, its use has been restricted to avoiding disease in future children for couples at risk of passing on genetic disease. The most common use has been to avoid bearing children with diseases like cystic fibrosis, but the technology can be used to test for any disease (or other trait) for which a genetic test has been developed.

In the Nash case, however, this distinction had been ignored. The first stage of PGD was in fact used to avoid disease—embryos were screened and only those that were Fanconi-negative proceeded to the second stage of testing. The second stage crossed the line between avoiding genetic disease and selecting for some nondisease trait by testing for HLA status. Further complicating the analysis, the selection of HLA status was not to benefit the child that would develop from the tested embryo, but to ensure immune compatibility with the future child's sister Molly. So not only was PGD used to select for a nondisease trait, it was used to select a nondisease trait selected to benefit somebody other than the child who would be born. For some, this is softened by the argument that were it not for the fact that Adam was both FA-negative and HLA-matched to his sister, he would not have been born. On this argument, the choice of a nondisease trait to benefit Molly actually also carried the ultimate benefit to Adam of being brought into the world (Robertson 1994; Robertson et al. 2002; Parfit 1984). The problem with such an argument is that it can justify selecting nearly any characteristic one chooses in the embryo on the grounds that it is better to be brought into the world under such circumstances than not to exist at all. We argue below that such arguments ought to have their limits.

As genetic research yields increasing information about both disease and nondisease traits, it is only a matter of time until couples choose not only disease-free embryos, but embryos that have particular physical or behavioral characteristics, such as musical aptitude, athletic ability, outgoing personality, blue eyes, average above height, and so on. The only limits in sight seem to be what tests are available, which will only increase as the Human Genome Project yields more and more meaningful results. Which characteristics are chosen, or more correctly, which characteristics are avoided, are so far up to the couple and their health-care provider to decide. But as more tests become available, we should be increasingly uncomfortable leaving decisions that have both individual and societal implications up to individuals alone to decide. At the very least, we ought to give some guidance to parents and physicians about the limits of acceptable uses of genetic testing of embryos.

One basic standard should be that the characteristics chosen be in the best interests of the child who will be born, not merely to benefit someone else, such as parents or siblings. In the Nash case, a particular HLA status was selected to help save Molly's life rather than to directly benefit the child that is Adam. However, having one combination of HLA antigens versus another has no effect one way or the other on Adam's health, so its selection is effectively neutral for him. Given that testing was also used to ensure that the embryos selected (including Adam) were negative for Fanconi anemia, the best interest standard was met in the Nashes' selection of a Fanconi negative and HLA-matched embryo that would produce baby Adam. This conclusion forces a more refined analysis of whether the couple's motivations for having a donor child matter.

Does Motivation Matter?

A consistent claim in discussions about the Nash case was that their motivation for having Adam was suspect in that he was brought into the world at least partly to save the life of his sister. The concern in these claims is that parents could use predictive genetic testing technologies like PGD to serve motivations that served themselves or their existing children but had very little to do with the interests of the future child. But why should the Nashes' motivation be open to this sort of second-guessing and assessment of moral propriety and not those of other parents? Were we to have access to the true reasons that people have children, we'd find everything from the "right" answer of the desire to bring children into the world for the intrinsic value they have, to love and cherish them, and nurture them in caring environments, to less wholesome motivations like carrying on one's family legacy and having siblings for one's other children. In fact, if we understood the true reasons behind many children's births we'd hear that they were accidents, unplanned pregnancies due to failed birth control or just plain carelessness. In many cultures, including some agricultural areas of the United States, families historically have had many children in order to ensure that there are enough hands to do the work required and to care for the other children in the family. In short, we need to think hard about whether there are wrong reasons for having children, and if there are, what we might do about it. Given the fact of the very wide range of reasons and motivations for having children, it is difficult to convincingly argue that having a child to save the life of an existing sick child is such a bad answer to the question.
All this being said, there are still limits we impose on what parents do with the children that they bear, and such limits may be instructive for limits in using PGD. Parents are prevented from aborting or neglecting their children, with the state stepping in and even removing children from their parents when their health and safety are threatened. We can unfortunately envision cases when parents create children to serve their own or their other children's interests in ways that could violate those limits. From a moral perspective, we want to prevent parents from violating the Kantian norm of treating their children as ends unto themselves and never as a mere means to the ends of others. Consider two examples that arguably cross that line. For one, the Nashes could have gone through the process of IVF, followed by PGD to select an embryo that was both FA-negative and HLA compatible with Molly, eventually resulting in a baby whose umbilical cord blood could be collected and used as a transplant for Molly. But instead of taking Adam home, the Nashes could have put him up for adoption. Instead of bringing Adam into the world to love and cherish as their child, the couple would have effectively brought Adam into the world for the cells in his umbilical cord—not for him, but for his parts. This seems to be using Adam as a mere means to his parents' and Molly's ends rather than treating him as an end unto himself.

A second scenario is less clear. It turns out that some couples have figured out that the same cells that will be in the umbilical cord blood at birth are in the fetal liver after approximately sixteen weeks of development. So rather than wait for the baby to be born, the fetus could be aborted after sixteen weeks and the hematopoetic stem cells collected from the fetus's liver. Rather than being a speculative scenario, there are reports of a few couples who have asked to pursue this approach in cases where they have a son with adrenoleukodystrophy (ALD, or Lorenzo's Oil disease), which can be treated by HSC transplants (Boyce 2003). Only boys are affected by ALD since it is an X-chromosome-linked trait. But heterozygous girls have an increased risk of other health problems, meaning that only truly "normal" children are those without the trait. What this means is that the odds of finding an unaffected embryo that is also HLA-matched are much lower, so the parents are willing to implant heterozygous female embryos with the intent of aborting them after sixteen weeks. This would avoid bearing a child with the health risks associated with ALD trait, but allow the collection of potentially lifesaving hematopoetic stem cells from the liver of the aborted fetus. Whether this example qualifies as a mere means use depends on how we understand the status of the human fetus—the prohibition is on the mere means use of another person, and for many a human fetus does not qualify. Whatever the answer, it is a worrisome behavior that ought to be prevented if possible. In fact, the public law that allows the use of federal funding for fetal tissue research also bans the directed donation and use of discarded fetal tissue, making the scenario described a criminal offense.

Given this context and the realities of parents like the Nashes faced with ill children, what moral principles can we propose to protect future children while at the same time preventing the misuse of children 'created' not as ends in themselves but as means to the ends of others? At the very least, we argue first for the selection of characteristics that are in the best interests of the child who will be born, and second that the treatment of the child after he or she is born be limited in terms of the physical risks posed. To put it bluntly, we would hope to avoid the situation of couples literally creating children for the parts they can provide. It will be very difficult to prevent the case of a couple conceiving a child with the intention to put it up for adoption without something akin to licenses for parents, which are both an unacceptable infringement on procreative liberty and an impractical if not impossible to enforce option. More successful will be efforts to oversee the treatment of the children after they are born, and make sure that appropriate risk-benefit balance exists when children are used as donors. This is not an idle concern, since HLA-matched children can donate not only umbilical cord blood (which has no risk) but, in the event of a failed cord blood transplant, could also be used as bone marrow donors, which carries much greater risk of morbidity and even mortality. It is even expected that children treated by HSC transplants for Fanconi anemia will eventually likely need kidney transplants due to long-term use of immunosuppressive drugs, and their HLA-matched siblings will again be obvious potential donors. Since parents are in a position of conflict in deciding whether an HLA-matched child ought to be a donor for his or her sibling, third-party review offers a mechanism for ensuring that prospective donors are not exposed to greater than acceptable risks for the benefit of their siblings. Such review could assess whether there is sufficient medical and psychological benefit to the donor to offset the risks inherent in the donation.

**POLICY IMPLICATIONS**

What makes the Nash case and its implications so challenging? The case used a new combination of existing technologies—creation of embryos by IVF, use of PGD for selection of traits, and collection and use of umbilical cord blood for transplant. Each technology alone has been the subject of ethical debate and policy making, but when they are used in combination, the discussions become more complex and ultimately expose a policy gap. Put another way, the combination of technologies falls between the cracks of existing policy approaches for determining appropriate uses and controls of controversial medical technologies.

This policy gap exposed by the Nash case exists because there are few, if any, mechanisms for assessing the acceptable uses of each technique
employed in the case and a dispersion of responsibility for making such assessments. We have identified three components of this policy gap, each discussed in turn: (1) multiple sites leading to no locus of overall responsibility; (2) limited mechanisms for assessing acceptable creation and uses of human embryos; and (3) limited third-party oversight of the medical technologies involved.

No Locus of Overall Responsibility

The Nash case makes clear that whatever controls we might suggest, the fact that the various elements of the process can take place at different sites makes oversight difficult. In the Nash case, IVF was performed at a clinic in Denver, PGD in Chicago, and the cord blood transplant in Minneapolis. Rules or oversight dictated by the IVF clinic have little impact on behavior at the PGD clinic or in the transplant unit, and vice versa. The upshot of having multiple sites for the individual elements is that there is no locus of overall responsibility for the process, and creates an environment in which each of the individuals and institutions involved can claim that the implications are out of their control.

No Mechanisms for Assessing Creation and Uses of Embryos

There are few, if any, mechanisms for assessing the acceptable creation and uses of human embryos, particularly in the medical context. Part of the policy gap is related to the practice of reproductive medicine and the creation of human embryos. Since the vast majority of embryos created in the United States and abroad are the product of IVF, one potential area for control would be on the reproductive medicine clinics that perform IVF. Recent surveys suggest that there are more than four hundred thousand leftover embryos in the United States alone (Hoffman et al. 2003), and as numerous others have pointed out (Andrews 2000; Knowles 2002), reproductive medicine is among the least regulated or controlled areas of medicine.

In 1981, during the first Reagan administration, a ban, which continues to the present, was imposed on the use of federal funds for any research that harms or destroys human embryos (Public Law No. 105-277, 1998). While a research ban would seem to provide clear policy direction, it has in fact created a laissez-faire policy environment, or policy gap, related to embryo research. This may seem counterintuitive given the embryo research ban in place for more than twenty years, but it is precisely because of the ban that so few controls exist. When the federal government agrees to fund a particular program or area of research, the funding always comes with strings attached. In effect, the government says that if you want its money, then you must agree to follow its rules. This can be seen throughout government programs, from educational programs to large transportation projects to clinical trials. However, when there is no federal funding there are no funding-related rules or restrictions. This is the case with embryo research, since the government’s policy only bars federal funds being used for embryo research and therefore embryos can be created, destroyed, experimented upon, and used for any purpose so long as no federal dollars are used. This has led embryo research as one of the few areas of biomedicine that is carried out exclusively in the private sector and effectively unregulated.

Limited Third-party Oversight of the Technologies involved

Finally, there is very little third-party oversight of reproductive medicine by payers, the government, or professional organizations. Reproductive medicine has long enjoyed a market-oriented approach to oversight, in part because such a large proportion of the costs of reproductive medicine services are borne by patients directly and not by third-party payers. Since insurers pay so little of the costs of IVF and other reproductive medicine services, they have little say over the appropriate uses of the technologies involved. Instead, it is left to market forces to decide what restrictions ought to exist, if any. Likewise any attempts at self-regulation by reproductive medicine specialists are more influenced by what patients demand and are willing to pay for than by what the profession might deem as appropriate.

To summarize, there is a policy gap (which could easily occur again) when it comes to attempts to control the efforts to create immune-matched stem cell donors. This stems from the combination of multiple sites of responsibility and lack of any locus of responsibility for the overall process; the limited oversight of IVF and other reproductive medicine services owing in part to the embryo research ban; and the market-driven nature of reproductive medicine. This policy gap has implications not only for use of the individual technologies involved, but for how they might be used in cases like the Nashes and others in the future. Without reflective policy making, we are more likely to see policy made by reaction to scandalous cases and the “yuck factor” associated with them.

Some Implications

The policy gap revealed by attempts to create HLA-matched donors highlights concerns about the extent to which couples may use genetic testing to identify traits in their future children. Many of the media reports on the Nash case charged them with creating a “designer baby.” While the selection of the traits identified in a range of embryos is not the product of genetic manipulation or other technologies more akin to designing, the Nashes did select
from the genetic testing menu available at the time. That menu will only become larger and more detailed as genetic information and tests created from it proliferate. It is clear that some parents will use whatever tests are available, including tests for physical and behavioral characteristics. In fact, reports that some reproductive medicine clinics are offering and some couples are using PGD to select for gender is evidence that the use of genetic testing is limited by what is available rather than by what couples will use.

While the Nash case highlighted a two-stage process of genetic testing (testing for the FA mutation, followed by testing for HLA status), there are likely to be many people who test embryos for HLA status when there is no risk for genetic disease. Anybody with a disease that could be treated by an HSC transplant and could wait the nine months it will take for a matched donor to be born could use PGD to create a donor. This would apply to adult and childhood leukemia, rheumatoid arthritis, and numerous other diseases, greatly increasing the potential demand for combined technologies.

An increase in demand would create huge cost and access issues. The Nashes spent more than $100,000 for five attempts of both IVF and PGD before achieving a successful pregnancy. This costs did not include the cost of any treatment for Molly, and all the costs (IVF, PGD, and stem cell transplant) were borne by the family since their insurance refused to cover what they deemed to be experimental treatment. By their own admission, the Nashes were very fortunate to be able to afford the extraordinary costs of treating their daughter, but the vast majority of families would not be so lucky. If we conclude that the use of PGD to create stem cell donors is acceptable as a matter of policy, how then are we to ensure equitable access to the technologies? In the United States, we often end up paying for high-priced life-saving therapies when they are brought to the public’s attention. This ad hoc sort of resource allocation can work when there are only a few cases to address, but is irresponsible because it relies on a reactive process and is a poor way to spend increasingly limited health-care resources.

Change may be coming, however, in that third-party payers may find it increasingly difficult to deny coverage for the creation of stem cell donors for at least two reasons. First, the technologies being used—IVF, PGD and umbilical cord blood transplant—are all part of mainstream medical care. Second, many insurers deny coverage for IVF on the grounds (rightly or wrongly) that infertility is not an illness or disease. But in the case of creating a stem cell donor, IVF is not being used to treat infertility (the Nashes were not infertile) but as part of a treatment for the HSC transplant recipient, effectively creating a therapeutic use of IVF. The first appeals to insurers have been made on these grounds, and no doubt lawsuits will follow.

At least two lawsuits have already been brought (though unsuccessful) against physicians on the grounds that they failed to inform families of the option of using PGD to create stem cell donors that could have saved the lives of their sick children. It is only a matter of time before similar suits are brought against genetic counselors and others, with the associated costs they will bring.

Finally, attempts to create HLA-matched stem cell donors have the unintended consequence of creating a potentially large number of leftover or “spare” human embryos. First, couples who would otherwise not avail themselves of reproductive medicine services use IVF to create embryos that can be tested by PGD. Second, these couples create far more embryos than in “regular” use of IVF since it takes a relatively large number of embryos to get even one that is both disease-negative and HLA-matched. The Nashes reported that they created upward of twenty-five embryos, many of which remain frozen. Other couples who unsuccessfully attempted to create a matched donor have created upward of one hundred leftover embryos. While this problem is not unique to the creation of stem cell donors, it highlights the fact that there is no policy for the disposition of leftover embryos in the United States—where recent reports placed the number of frozen embryos at upward of four hundred thousand (Hoffman et al. 2003).

SOME POLICY RECOMMENDATIONS

How can we improve the policy environment for intervention and oversight in the creation of stem cell donors? A few concrete recommendations follow:

1. Move the debate from the clinic to the public policy arena. Ethical and policy issues are currently addressed by individual physicians in discussion with individual patients. While this is an appropriate model for much of health care, the making and testing of human embryos has societal as well as personal implications, and the societal issues should be addressed as matters of public policy. There are many potential fora for such discussion and debate, including the Institute of Medicine (IOM), National Institutes of Health (NIH), and others.

2. Avoid reactive policy making. One of the well-founded worries in the medical community is that a very provocative and controversial case will make its way into the news media and result in reactive and potentially knee-jerk policy making. The only way to avoid this is through organized public policy debate and institutional commitments to local review until wider policies are promulgated.

3. Create local mechanisms for review and advice of controversial uses of biomedical technologies. Institutions can do their part by establishing processes for at least advisory review of new and controversial applications of biomedical technologies. One example is the University of Minnesota’s Stem Cell Ethics Advisory Board, which exists to provide advice to any university faculty or staff involved in the use of stem cell technologies. The
board's membership is a combination of internal and external experts in medicine, science, law, ethics, and religion, and is linked to the university's internal review board (IRB) by ex officio membership of the IRB executive chair. The board's conclusions and recommendations are advisory but not binding, and the university strongly encourages but does not require that stem cell researchers consult the board.

4. Consider lessons from others. There are policy models in other countries that can be instructive for moving forward in this discussion. The United Kingdom's Human Fertilisation and Embryology Authority (HFEA) offers strong central control of any creation and use of human embryos. In so doing, it can limit the uses of embryo creation and testing as the authority rules and can review requests for uses that fall outside of existing policy. The same mechanism allows for more liberal research uses of embryos than U.S. policy. Such a centralized approach would require a wholesale shift in not only embryo research oversight but also the structure of reproductive medicine in the United States, making this approach very unlikely. What is instructive is that while centralized control is most often viewed as a restrictive approach to oversight, in practice it can actually allow for more liberal policies than diffuse controls.

CONCLUSION

It is clear that cases like the Nashes' raise significant and challenging ethical and policy issues, and that we lack sufficient mechanisms for addressing them. The case pits fundamental core principles such as procreative liberty and prohibition of mere means uses of individuals against each other, so it is no wonder that the issues are so difficult to address. But the issues won't go away, and we must address them since the beneficial uses of these medical technologies are at stake. Reactive policy making is not the answer, nor is unchecked uses of existing and new technologies. The challenge before us is to create a robust ethics and policy framework for addressing them, and to do so quickly and in a way that is flexible enough to respond to technological advances. This might be achieved by an approach similar to the NIH's Recombinant Advisory Committee (RAC). The Nash case was a success story, but others have not been so successful. Other couples endured years of IVF and PGD in an attempt to create an immune-matched stem cell donor for their sick children, often spending their life's savings, but never had the Nashes' success. Many others will continue on similar paths in the hope of their own success—we need to create a path for success on the policy front, as well.

NOTES

1. A version of this chapter was published previously as "Creating a Stem Cell Donor: A Case Study in Reproductive Genetics," Kennedy Institute of Ethics Journal 1(1) March 2004; reprinted here with permission.
2. We are sensitive to concerns about patient and family confidentiality. The Nash family has been very public in their discussion of their daughter Molly's illness, giving many interviews for prominent print and television stories. They have explained their willingness to share their story in order to advance the medical and policy discussion of cases like theirs and to bring attention to needed research on Fanconi anemia.
3. Jeffrey Kahn is a current member of the board of directors of the NMDP.
4. Jeffrey Kahn is the current chair.

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