ABSTRACT. During the nearly 10 years since its introduction, 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 IVF-created embryos 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 hematopoietic stem cell transplant. This article describes the case, raises some ethical and policy issues, highlights gaps in U.S. policy, and finally makes some 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 the present 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.

The Nash case involves the use of 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 policymaking; but when they are used in combination, the discussions become even more complex and ultimately expose a gap in existing public policy. Here we examine the issues raised by the case and make some recommendations regarding the growing need for oversight mechanisms.
The Nash case relies on the relatively new technology of preimplantation genetic diagnosis, or PGD, which allows for genetic testing of very early-stage human embryos prior to their implantation. Embryos are created using IVF techniques and then “biopsied” at the eight-cell stage, two to three days post-fertilization. The biopsy is performed by nicking the outer membrane and 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 the 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—i.e., 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, incomplete gut, and most important for this story, the children become leukemic at six to eight years of age (Wagner, Davies, and Auerbach 1999). To treat the leukemia associated with FA, the children require a hematopoietic stem cell (HSC) transplant for their survival. Hematopoietic stem cells either can be donated through the collection of bone marrow or peripheral blood stem cells or can be 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 the first and only child, so no sibling donors were available. The next best donor source would have been other relatives, but no family member 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 a HSC transplant.

In children with FA, research has shown that sibling transplants have a substantially higher success rate than transplants from unrelated donors (Wagner, Davies, and Auerbach 1999), so the Nashes hoped that a future child would be a close enough match to be 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) immune-matched to their sick child. The results of the prenatal testing would lead to a potential abortion decision if the developing fetus was found to be carrying the FA mutation, and, 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 decided to use PGD to test embryos made in vitro rather than going through the process of prenatal testing and potential abortion of the developing fetus. The PGD would be a two-stage process, testing first for the FA mutation, and then testing for HLA compatibility with Molly among those embryos that tested FA-negative. During 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, five separate times 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 in which one of Adam’s ribs 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 hematopoetic 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 THE NASH CASE MATTER?

The Nash case raises a range of ethical and policy issues and highlights the types of social issues that will continue to arise as biotechnology advances. It challenges society to consider the limits of ethical acceptability for the application and combination of new medical technologies. This case is particularly useful because it is far from hypothetical, with real people whose names and story could be any of 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 also serves as an object lesson for why society needs 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 to inform responses in other controversial policy areas such as other reproductive technologies, stem cell research, and even cloning.

SOME ETHICAL ISSUES

The Nash case is interesting both as a human interest story and for the ethical and policy issues it raises. In the publicity surrounding the case, many pundits questioned both the characteristics the Nashes selected using 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 the Characteristics Chosen Matter?*

Some of the concerns raised in the popular press 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 be used only to test but not to alter the genetic makeup of an existing embryo. Any sort of genetic manipulation would be akin to gene therapy, a technology yet to show successful application aside from a very few patients. In the Nash case, however, a line was crossed in the way PGD was used to test the genetic makeup of embryos. In the years since PGD had been developed and introduced, its use had been restricted to avoiding disease in future children for couples at risk of passing on genetic disease. The most common use was, and is, 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, the distinction between testing for a disease and testing for some other, nondisease trait was ignored. The first stage of PGD in fact was used to avoid disease—i.e., the embryos were screened and only those that were Fanconi negative proceeded to the second stage of testing. The second stage, however, crossed the line between avoiding genetic disease and selecting for some nondisease trait by testing the remaining embryos 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 for the purpose of benefitting somebody other than the child who would be born. For some,
the concern about selecting traits for this purpose 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. In other words, if the Nashes had selected an embryo only based on its FA-negative status, in all probability a child other than Adam would have been born since numerous FA-negative (but HLA incompatible) embryos were available earlier in the process. On this argument, the choice of a nondisease trait to benefit Molly actually also carried the ultimate benefit to Adam of his being brought into the world (Robertson 1994; Robertson, Kahn, and Wagner 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, as have others (Wolf, Kahn, and Wagner 2003), that such arguments ought to have limits.

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

One approach would be to choose characteristics based on the best interests of the child who will be born, not merely to benefit someone else—parents, siblings, and so on. In the Nash case, a particular HLA status was selected to help save Molly’s life rather than directly to benefit the child that was Adam. However, having one combination of HLA antigens versus another has no apparent effect one way or the other on Adam’s health, so its selection is effectively neutral for him. Given that testing also was used to ensure that the embryos selected, including the one that became Adam, were negative for Fanconi Anemia, we think that 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 is the suspect nature of the parents’ motivation for having Adam in that he was brought into the world at least partly to save the life of his sister. The concern is that parents could use predictive genetic testing technologies like PGD for reasons that serve themselves or their existing children but have very little to do with the interests of the future child. But why should the Nashes’ motivation(s) be open to this sort of second-guessing and assessment of moral propriety and while those of other parents are not? Were one to have access to the true reasons that people have children, one would 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 to 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, truly honest answers would also include pregnancies that were not planned at all. In many cultures, including some agricultural areas of the United States, families historically have had many children, partly 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, one needs to think hard about whether there are wrong reasons for having children, and if there are what one might do about it. Given the wide range of reasons and motivations for having children, it is difficult to argue convincingly that having a child to save the life of an existing sick child is such a bad parental motivation.

All this being said, society still imposes limits on what parents may do with the children that they bear, and such limits may be instructive for developing limits in the use of PGD. Parents are prevented from abusing or neglecting their children, with the state stepping in and even removing children from their parents when their health and safety are threatened. We unfortunately can envision cases in which parents might 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 mere means to the ends of others.
Consider two examples that arguably cross the line of treating someone as an end in him/herself. One possibility is that 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 Nashes effectively would have brought Adam into the world solely for the cells in his umbilical cord—not for him, but for his parts. This seems to be an example of using Adam as a mere means to his parents’ and Molly’s ends rather than treating him as an end unto himself (Pennings et al. 2002).

The second potential scenario is less clear. Some couples have learned that the same cells that are present in the umbilical cord blood at birth already are present in the fetal liver after approximately 16 weeks of development. So rather than waiting for the baby to be born, the fetus could be aborted after 16 weeks and the hematopoetic stem cells collected from the fetus’ liver. Rather than being a purely 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). ALD affects only boys since it is an X-linked trait, but heterozygous girls have an increased risk of other health problems, meaning that the only truly unaffected children are those without the trait. Consequently, the odds of finding an unaffected embryo that is also an HLA match are much lower, so these parents are willing to implant heterozygous female embryos with the intent of aborting them after 16 weeks. This approach would avoid the birth of a child with the health risks associated with the ALD trait, but still allow the collection of potentially lifesaving hematopoetic stem cells from the liver of the aborted fetus. Whether this example qualifies as a meremeans use depends on how one understands the moral status of the human fetus—the prohibition is on the meremeans use of another person, and for many a human fetus does not qualify. Whatever the answer to the question of fetal moral status, our view is that the scenario described is sufficiently morally worrisome in its motivation of intentional pregnancy with the plan to abort that the behavior ought to be prevented if possible as a matter of social policy. In fact, the public law that allows the use of federal funding for fetal tissue research also bars the directed donation and use of discarded fetal tissue regardless of funding source,
and the law provides criminal penalties for the scenario described (Public Law 103–43, sec. 112 (National Institutes of Health Revitalization Act of 1993)).

Given this context and the harsh realities faced by the parents of seriously ill children like the Nashes, what moral principles can protect the interests of seriously ill children while at the same time preventing the misuse of children “created” not solely as ends in themselves but also as means to the ends of others like their sick siblings? We propose first the selection of characteristics that are in, or do not run counter to, the best interests of the child who will be born, and following others (Wolf, Kahn, and Wagner 2003), that the physical risks posed by any procedures performed on the child after he or she is born be limited. To put it bluntly, we hope to avoid the situation of couples literally creating children for the parts they can provide. It would be virtually impossible to prevent a couple from conceiving a child with the intention of putting it up for adoption. More successful would be efforts to oversee the treatment of the children after they are born, and to make sure that an appropriate risk-benefit balance exists when children are used as donors. This is not an idle concern, since HLA-matched children not only can donate umbilical cord blood—which poses no risk to the child—but in the event of a failed cord blood transplant, also could be used as bone marrow donors, which carries a much greater risk of morbidity and even mortality. In addition, it is expected that children treated by HSC transplants for Fanconi Anemia eventually will need kidney transplants due to long-term use of immunosuppressive drugs, and their HLA-matched siblings again will 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, we endorse Wolf, Kahn, and Wagner’s (1993) recommendation for third-party review of proposed transplants requiring invasive donations as a mechanism to ensure 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/or psychological benefit to the donor to offset the risks inherent in the donation.

THE NASH CASE AND THE POLICY GAP

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 policymaking; 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 of and controls on controversial medical technologies.

The policy gap exposed by the Nash case exists because few if any mechanisms exist for assessing the acceptable uses of each technique employed in the case, and there is a dispersion of responsibility for making such assessments. We have identified three components of the present policy gap: (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 payer oversight of the medical technologies involved.

**No Locus of Overall Responsibility**

First, 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 coordinated review and 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, which creates an environment in which each of the individuals and institutions involved can make decisions at their own discretion and then claim that the implications resulting from the combination of technologies are out of their control.

**Limited Mechanisms for Assessing Creation and Uses of Embryos**

Second, 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. Reproductive medicine clinics in the U.S. and abroad create embryos as part of routine, high-tech medical care for infertility. Such creation is subject to little if any oversight or review. Recent surveys suggest that in the U.S. alone there are nearly 400,000 frozen embryos in storage, leftover from IVF procedures (Hoffman et al. 2003). These so-called “spare embryos” are subject to private contracts
with the lab and infertile couples and individuals, but otherwise are subject to few legal restrictions, if any, on their future use, including experimental uses.

In the research context, U.S. policies and practices for decades have effectively prohibited the use of federal funds in any research that harms or destroys human embryos. This funding limitation has a complex policy history that has been well-documented elsewhere (Parens and Knowles 2003; Mastroianni 1999; Charo 1995), and is a reflection of the political and moral controversy surrounding abortion. However, in the absence of federal research funding, funding-related rules or restrictions do not exist: embryos can be created, destroyed, experimented upon, and used for any purpose so long as no federal dollars are used. In addition, much of the work that takes place in reproductive clinics typically has not been classified as research, but rather as innovative clinical practice, an area that in law and policy historically has been left to the discretion of individuals and institutional policies (Parens and Knowles 2003). Indeed, as numerous others have pointed out (Andrews and Elster 2000; Knowles 2002; Parens and Knowles 2003), reproductive medicine is among the least regulated or controlled areas of medicine.

**Limited Third-Party Payer Oversight of the Technologies Involved**

A third component of the policy gap is a product of the limited third-party payer oversight of reproductive medicine. Reproductive medicine long has enjoyed a market-oriented approach to oversight, in part because such a large proportion of the costs of reproductive medicine services are born by patients directly and not by third-party payers. Since insurers pay so few of the costs of IVF and other reproductive medicine services, they have little say over the appropriate uses of the technologies involved. Instead, market forces decide the restrictions, if any, that should exist. Likewise any attempts at self-regulation by reproductive medicine specialists are more influenced by patient demand and willingness to pay than by any criteria that the profession might deem appropriate.

To summarize, efforts to control or oversee the creation of immune-matched stem cell donors falls neatly into a policy gap, a gap that could easily occur again in other overlapping technology uses. This policy gap 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 em-
bryio research ban; and the market-driven nature of reproductive medicine. This gap has implications not only for the use of the individual technologies involved, but also for how they might be used in combination in cases like the Nashes’ and others in the future.

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 media reports on the Nash case charged the parents with creating a “designer baby.” Although selection from the range of traits identified in a number of different embryos is neither genetic manipulation nor any of the other technologies more akin to designing, the Nashes did select embryos based on the list of traits identifiable at the time through genetic testing. This list 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, a controversial use that also highlights the absence of policies in reproductive medicine clinics, is evidence that the use of genetic testing is limited only by what is available. Although 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 with diseases that could be treated by an HSC transplant who, if they could wait the nine months for a matched donor to be born, will be motivated to create and then test embryos solely for HLA status when there is no risk to the embryo of genetic disease. This situation would apply to patients with 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 IVF plus PGD before achieving a successful pregnancy. These costs did not include the cost of any treatment for Molly, and all the costs (IVF, PGD, and stem cell transplant) were born by the family since their insurer refused to cover what was deemed to be an experimental treatment. By the Nashes’ own admission, they 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 society concludes that the use of PGD to create
stem cell donors is acceptable as a matter of policy, how then will it ensure equitable access to the technologies? In the U.S., health insurers or government-funded programs often end up paying for high-priced lifesaving 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 in terms of policy both because no reflective process underlies it and because it is a poor way to spend increasingly limited health care resources.

Change may be coming for families like the Nashes, however. Third-party payers may find it increasingly difficult to deny coverage for the creation of stem cell donors for at least two reasons. First, insurers typically exclude coverage of experimental therapies. However, the individual technologies being used in this case—IVF, PGD, and umbilical cord blood transplant—are no longer considered experimental and have become part of mainstream medical care. It is their combination that still is considered experimental by many insurers. 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. Indeed, the first successful appeals to insurers have been made on these grounds (personal communication with J. Wagner, M.D., University of Minnesota Medical School).

Consumer awareness of these procedures and the potential for legal remedies are already stimulating medical malpractice challenges. At least two lawsuits have been brought (albeit unsuccessfully) against physicians on the grounds that they failed to inform families of the availability of PGD to create stem cell donors, a procedure that might have saved the lives of their sick children (Grewal et al. 2004). It is only a matter of time before similar suits are brought against genetic counselors and others, along 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 that 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 the use of IVF to treat infertility 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 upwards of 25
embryos, many of which remain frozen. Other couples who unsuccessfully attempted to create matched donors have created many more leftover embryos (Belkin 2001). Although this problem is not unique to the creation of stem cell donors, it highlights the fact that the disposition of leftover embryos in the U.S. is decided between couples and the reproductive medicine clinics in which the embryos are stored.

POLICY RECOMMENDATIONS

What can be done to improve the policy environment for intervention and/or oversight in the creation of stem cell donors? We offer four concrete recommendations, which, while not settling the issues, should help to stimulate further discussion.

(1) Move the debate from the clinic to the public policy arena.

Ethical and policy issues involving reproductive medicine currently are addressed by individual physicians in discussion with individual patients. Although 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 forums for such discussion and debate, including the National Institutes of Health, the Institute of Medicine, and others.

(2) Avoid reactive policymaking.

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 policymaking to the detriment of legitimate uses of the technologies. The only way to avoid this sort of response is through organized public policy debate and institutional commitments to local review until wider policies are promulgated.

(3) Create local mechanisms for review of and advice on controversial uses of biomedical technologies.

Individual institutions can do their part by establishing processes for at least advisory review of new and/or 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 the Board is linked to the University’s IRB by *ex officio* membership of the IRB executive chair. The Board’s conclusions and recommendations are advisory, not binding, and the University strongly encourages but does not require that stem cell researchers consult the Board.

(4) Consider lessons from others.

Finally, there are policy models in other countries that can be instructive for moving the discussion forward. 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 and can review requests for uses that fall outside of existing policy. The same mechanism allows for more liberal research uses of embryos than current U.S. policy permits. Adopting such a centralized approach in the U.S. would require a wholesale shift not only in embryo research oversight but also in the structure of reproductive medicine in the U.S. These reasons, along with real questions about the constitutionality of federal regulation of private sector research and the ongoing association of the issues with the abortion debate, demonstrate the need for significant foundational policy work before proposals for centralized oversight can go forward (Parens and Knowles 2003).

CONCLUSION

It is clear that cases like the Nashes’ raise significant and challenging ethical and policy issues and that the U.S. lacks sufficient mechanisms for addressing them. But the issues will not go away, and they must be addressed since the beneficial uses of the medical technologies are at stake. Reactive policymaking is not the answer, nor is the unchecked use of existing and new technologies. The challenge 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 goal might be achieved by an approach similar to NIH’s Recombinant DNA Advisory Committee (RAC), along the lines of a Reprogenetics Technologies Board as recently suggested by one working group on reproductive genetics (Parens and Knowles 2003). The Nash case was a success story, but others have not been so successful. Other couples have endured years of IVF and PGD in attempts to create immune-matched stem cell donors for their sick children, often spending their life’s savings, but never having
the Nashes’ success (Belkin 2001). Surely many others will continue on similar paths in the hope of their own success—we, as a society, need to create a path for success on the policy front as well.

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NOTES

1. 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.

2. Jeffrey Kahn was a member of the Board of Directors of the NMDP from 1999–2003.

3. Jeffrey Kahn is the current chair.

REFERENCES


