

CASE STUDY

MOLLY AND ADAM NASH

USING PREIMPLANTATION GENETIC DIAGNOSIS TO SAVE A SIBLING¹

Bonnie Steinbock

Molly Nash was born on July 4, 1994 with multiple birth defects due to Fanconi anemia, a deadly genetic disease that causes bone marrow failure, eventually resulting in leukemia and other forms of cancer. Her best chance for survival was a bone marrow transplant from a perfectly matched sibling donor. Lisa and Jack Nash had considered having another child, not as a source of bone marrow but because they very much wanted another child. They had decided against it because there was a one-in-four chance that the infant would have the same illness as Molly, and aborting an affected fetus was not an option Mrs. Nash would consider. Then they learned about preimplantation genetic diagnosis (PGD), which would enable them to screen embryos for the disease, and implant only the healthy ones. Moreover, the embryos could also be tested to find which ones shared Molly's tissue type. The baby would be not only disease-free, but could also provide bone marrow to Molly. Moreover, because blood cells saved from the baby's umbilical cord and placenta could be used, there would be no need to extract the bone marrow from the baby's body, a procedure which is both painful and carries some risk.

The odds of producing an embryo that is disease-free, a perfect match, and capable of initiating a pregnancy are daunting. In January 1999, Lisa Nash produced 12 eggs, 2 of which were healthy matches. She became pregnant, but miscarried. In June she produced only four eggs, one of which was a match, but she did not become pregnant. In September, she produced eight eggs, only one of which was a healthy match, but again she did not become pregnant. Molly was getting sicker and her physician recommended proceeding with a transplant from a nonrelated donor, although the odds that such a transplant would work were virtually nil. The Nashes decided to try a different IVF clinic, one known for being more

aggressive. Lisa's hormone regimen was changed and in December 1999, 24 eggs were retrieved. Only one was a match, but this time she became pregnant. She was confined to bed to prevent a miscarriage. On August 29, 2000, after 52 hours of labor (Lisa resisted a cesarean section because more cord blood could be collected during a vaginal birth), Adam Nash was delivered by C-section. In October 2000, doctors at Fairview-University Hospital in Minneapolis, which specializes in bone marrow transplants for children with Fanconi anemia, successfully transferred tissue from Adam's umbilical cord into Molly's body. Molly, by all accounts, is doing very well. She is back at school, or rather a visiting teacher, who must wear a mask during lessons, comes to her home. She takes ballet lessons. Her transplant did not cure her of Fanconi anemia, but merely prevented her developing leukemia. She is likely to suffer Fanconi's other complications, particularly cancers of the mouth and neck, but that is far off in the future.

Adam Nash was not unique in being conceived to save a sibling. Ten years earlier, another couple, Abe and Mary Ayala, decided to have Abe's vasectomy reversed, in the hopes that Mary would become pregnant with a child who could be a bone marrow donor for their daughter, Anissa, aged 17, who had been diagnosed with leukemia. Surprisingly, the reversal worked and Mary, aged 42, became pregnant. Moreover, the baby, Marissa Eve, born on April 3, 1990, turned out to be a compatible donor. At the time, the reaction from medical ethicists was generally negative. Philip Boyle, an associate at the Hastings Center, said, "It's troublesome, to say the least. It's outrageous that people would go to this length." Alexander Capron, professor of law and medicine at the University of Southern California, suggested that having a baby to save another child was ethically unacceptable because it violated the

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Kantian principle that persons are never to be used solely as a means to another person's ends. Others, however, challenged the view that Marissa was being used as a means only, or that she was not given the respect due to persons. The crucial thing, they argued, was that her parents and siblings intended to love the new addition to the family as much as her older brother and sister, whether or not she could donate bone marrow. The risk to Marissa was minimal; indeed, if Anissa already had a baby sister with compatible marrow, no one would have questioned using the infant as a donor. Why should the moral situation be different if the choice is to create a child in the hopes that she will be a donor?

Unlike the Ayalas, who thought they had completed their family, the Nashes wanted another child. When they were told that the same technique that could prevent the birth of a child with Fanconi might also identify a compatible donor for Molly, they jumped at the chance. As Mrs. Nash put it, "You could say it was an added perk to have Adam be the right bone marrow type, which would not hurt him in the least and would save Molly's life. We didn't have to think twice about it."²

Are there ethical objections to what the Nashes did? Some oppose PGD even for its ordinary use, to prevent the birth of a child with a serious disability.³ Others do not oppose PGD in principle, but think that it should not be used to save the lives of existing children. One concern is that the parents of fatally ill children will be unable to refuse to go through IVF if it is presented as their only chance for saving their child. Furthermore, not every story of a Fanconi child has the happy ending afforded the Nash family. Some women go through cycle after cycle of IVF, only to fail to produce a compatible embryo, or to suffer repeated miscarriages.⁴ It may be argued that this is not a choice that doctors should offer desperate parents, given that the odds of success are relatively low. At the same time, many women choose to undergo the rigors of IVF to have babies. If it is not unethical to give them this choice, is it unethical to give them the chance to save their child's life, if they

are fully informed about the burdens and risks, and the odds of success?

Some ethicists object to the idea of having a baby for "spare parts." Clearly it would be wrong to create a baby for spare parts if that would be harmful to the child. One could not create a baby for his heart or lungs or even kidney. In what sense has Adam Nash been harmed? He owes his very existence to the fact that he was a perfect match for Molly. Of course, many embryos were discarded and this is considered immoral by those who view preimplantation embryos as tiny children. This, however, is not an objection to using PGD to create donors, but to PGD generally, and indeed to all of IVF.

Finally, many are profoundly disturbed by the possibility of "having babies to spec," of choosing who will be born based on their genetic characteristics. "If we can screen an embryo for tissue type, won't we one day screen for eye color or intelligence?"⁵ Some ethicists fear that the use of PGD to get compatible donors today will lead to a world in which parents will be able to select their children's physical, mental, and emotional traits. From one perspective, PGD offers parents of desperately ill children the hope of a miracle. From another, it opens the door to "genetic engineering" and a new eugenics.

NOTES

1. Much of the factual material in this case study comes from Lisa Belkin, "The Made-to-Order Savior," *The New York Times Magazine*, July 1, 2001.
2. Denise Grady, "Son Conceived to Provide Blood Cells for Daughter," *The New York Times*, October 4, 2000, A24.
3. See Adrienne Asch, "Prenatal Diagnosis and Selective Abortion: A Challenge to Practice and Policy," *American Journal of Public Health*, Vol. 89, no. 11 (November 1999): 1649-1657. In this volume, pp. 609-619. Though Asch does not specifically discuss PGD, her objections to selective abortion extend to embryo selection and discard as well.
4. See Belkin, *op. cit.*
5. *Ibid.*