

Genetic selection gives girl a brother and a second chance

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From staff and wire reports

MINNEAPOLIS, Minnesota -- Six-year-old Molly Nash has a chance at a better life, thanks to her 5-week-old brother Adam. He was born after genetic testing showed he would be a match for a transplant that could help her survive Fanconi anemia, a rare genetic disease. Jack and Lisa Nash had Adam through in vitro fertilization in order to produce a child who was both a transplant match for Molly and free of Fanconi anemia. The deadly condition prevents Molly Nash from creating her own bone marrow and could lead to leukemia.

"I was going to save Molly no matter how," said Lisa Nash, "and I wanted Molly to have siblings."

Doctors at the University of Minnesota last week infused stem cells from Adam's umbilical cord blood into his sister. They expect to know within a week whether the blood is helping Molly develop healthy marrow cells. It's the first time that parents have used genetic testing to select a child who is both free of a disease and is the best tissue match for a sibling who needs a transplant to fight that disease, said experts.

"What's new here is not the use of umbilical cord blood in the treatment of a life-threatening disease, but it's the way the transplant was engineered and the way the baby was conceived," said Dr. John Wagner of the University of Minnesota, and expert in cord blood transfers and Fanconi anemia.

The Nashes wanted more children, but were afraid to conceive because both carry a faulty version of the Fanconi gene. Each child would have a 25 percent chance of developing the disease. About 98 percent of people with the anemia have bone marrow failure by age 35, and half have it by 7. The best treatment is a transfer of stem cells found in the umbilical cord of a sibling, because the recipient's body is not likely to reject them, said Wagner.

Ethical questions

The Nashes employed a technique called pre-implantation genetic diagnosis to give birth to Adam. Embryos were created in the laboratory through in vitro fertilization. Three days later, they were genetically screened to find one that was free of Fanconi anemia and a match for Molly. That embryo was then implanted in Lisa Nash.

"What this technology did was take away the guesswork," said Wagner. "It allowed them to have -- and know that they were going to have -- a healthy child and one that would be matched."

This screening procedure has been used in about 300 children worldwide. But the technology also raises a difficult question -- is it ethical to select traits of a future child? It is widely considered ethical to screen embryos for genetic diseases because it is best for the child, explained Jeff Kahn, director of the University of Minnesota's Center for Bioethics. But the case of the Nash family is different because the embryo that became Adam was also selected for traits that would benefit someone else -- his sister.

The survival rate for a patient with Fanconi anemia is 31 percent after a transplant from someone who is not related, but jumps to 85 percent with blood from a sibling, Wagner said. However, the transplant will not cure Molly completely. She will still have other symptoms she'll have to live with.