

Making Lives to Save Lives

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A story with international interest is unfolding at the University of Minnesota. Six-year-old Molly Nash seems to have been saved by the stem cell transplant Molly got from her infant brother, Adam. The human drama of the Nash case has been nearly overshadowed by the steps that were taken to create Adam and make the stem cell transplant possible.

Molly was born with Fanconi anemia (FA), so she needs a bone marrow transplant to survive. Before Adam's birth, Molly had no siblings, and neither of her parents were a close enough immune match to qualify as a bone marrow donor. Rather than try to find an unrelated marrow donor, the Nashes decided to use genetic testing to help them choose to have a child who would not inherit FA and who would also be a perfectly matched stem cell donor for Molly. Is this story an example of the genetic revolution going too far? Is it a case of creating one child to save the life of another? Or is it an example of using modern medicine to benefit everyone involved?

To make sure that the new baby would be a matched donor, the Nashes went through in vitro fertilization (IVF) to create embryos, and then applied 2 kinds of genetic tests on them. First, the embryos were tested for FA, and only the unaffected embryos were tested a second time. The second test was used to select only those embryos that were an identical human leukocyte antigen (HLA) match with Molly because the plan was to use the baby's cord blood for a stem cell transplant for her. The FA-negative and HLA-matched embryo was implanted, and 9 months later Adam was born. The process was complete

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when the cells from Adam's umbilical cord were used in a stem cell transplant for Molly.

The technology of preimplantation genetic diagnosis (PGD) has up to now been mostly used to help couples avoid passing on genetic diseases or illnesses—such as cystic fibrosis or Tay Sachs disease—to their future children. But this case applies PGD for a different purpose, and that raises new ethical issues. By selecting an embryo based on whether it was a genetic match for Molly, genetic testing crossed an important line. For many people, there is a moral difference between choosing characteristics that are meant to protect the health of the child that will be born, and choosing characteristics that are based on the interests or desires of somebody else—whether it be the future child's sibling, his or her parents, or for some other purpose. In Adam's case, the HLA factors chosen had no impact, good or bad, on his health. In fact, had the family not chosen for those factors, the probability is that Adam would never have been born. So from Adam's perspective, things worked out for the best. But what about couples that may want to choose other more controversial characteristics for their children, such as eye color, musical ability, height, or any number of others?

The only way to prevent couples from using PGD in unacceptable ways is to either create rules about what traits they can choose, or to review every couple's request for the use of PGD. But couples can have good reasons, bad reasons, or no reasons at all for having children, ranging from attempts to save a failing marriage, to creating more hands for working on the farm, or merely by accident. We neither ask nor judge peoples' motives for having children, a longstanding and understandable policy in most liberal societies. So it will take significant justification, such as risk of serious harms to future children, to change the presumption from reproductive liberty.

While we decide whether and what limits there ought to be on the use of PGD, many more couples will want to follow in the footsteps of the Nashes. But whether or not their motives are pure, PGD will be expensive, both monetarily and morally. The question is whether society is willing to pay its costs.

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