

Newsweek

by [Fred Guterl](#) June 30, 2003

To Build A Baby



Molly Nash, her baby brother Adam, and Dr. John Wagner. Photo by Mark Engebretsen, University of Minnesota

The extraordinary thing about Molly Nash is that she seems like a typical second grader in Englewood, Colorado. "She can be as stubborn as an ox," says Lisa Nash, her mother, "and she smarts off now and then." But like most 8-year-olds, she has redeeming qualities--a round, cheeky face, a toothy smile, brown bangs. She also takes dance lessons and plays soccer, and she's a whiz in reading and math. "She's a bit small for her age," says Nash. "But not extremely small. There are kids in her class who are smaller."

Smallness is a vestige of Molly's tentative start in life. For a while Molly grew far too slowly, and the odds were good that she wouldn't live much beyond the age of 6. She had been born with a rare disorder called Fanconi's anemia, which was causing cells in her bone marrow--the ones that produce white blood cells and other defenses against infection--to fail. Molly needed new ones from a donor who was an almost exact genetic match. That meant that her parents needed to have another child, and fast. The trouble was, the odds of having one with the right genes and who didn't himself have the disease were only one in four.

Fortunately for Molly, there was a way of loading the genetic dice. Mark Hughes, a molecular biologist, has worked for the past 10 years building and perfecting the genetic equivalent of a one-hour photo-developing shop. If parents want a child with certain genes, doctors first use techniques of in vitro fertilization to make dozens of embryos--however many it takes to ensure that one of them has the desired genes. Hughes's technique, called preimplantation genetic diagnosis, then tells you which embryo to pick. What's more, Hughes can perform the test in 24 hours, with time to spare for implanting the embryo into the womb. The Nashes used PGD to conceive Adam, now 2-1/2, who successfully donated umbilical-cord blood to save Molly's life.

Molly wasn't the first child to benefit indirectly from PGD, and she won't be the last. While the world panics over false claims of human cloning, PGD is quietly transforming reproductive medicine by giving parents unprecedented control over what genes their offspring will have. So far the technique has been used largely, as in Molly's case, in laudable efforts to avoid passing along single-gene inherited diseases. But PGD makes some people nervous, because it also gives doctors a rudimentary ability to manipulate *traits*--the morally reprehensible practice of

eugenics. At present, manipulating complex traits like intelligence or athletic ability is impossible, but it may not always be. The fear is that as other aspects of reproductive technology improve, PGD may be misused. "There are 900 genetic tests available or in development," says Kathy Hudson, director of the Genetics and Public Policy Center at Johns Hopkins University in Baltimore, and a fellow of the World Economic Forum. "Determining which of these tests to offer to whom and at what point is really complex."

Are the benefits worth the risk? Hughes, Molly's parents and many others think so. PGD has in recent years moved into the mainstream of reproductive science. Clinics in London, Chicago, Tel Aviv and Brussels have recently begun to offer the procedure. Although Hughes doesn't keep count, his personal computer lists dozens of obstetricians who've sent patients to his lab.

The process starts with the arrival of tiny plastic tubes packed in ice, each containing a single human stem cell plucked a few hours before from a three-day-old embryo. The cells come from fertility clinics, where would-be parents have their eggs harvested, fertilized and grown in petri dishes. By day three a human egg cell has managed to divide, on average, into only six stem cells. To find out if it carries the genes for Tay-Sachs or cystic fibrosis or sickle-cell anemia, the lab's 60 researchers and technicians copy the sample cell's DNA and analyze it with a Willy Wonka assortment of specialized machines. The trick is in coming up with clever ways of finding specific genes quickly, starting with only a single sample of DNA. Behind panes of glass, robotic hands shuffle trays of a hundred tiny test tubes.

The technique has attracted controversy in the United States simply because it involves embryos. In 1997 Hughes was accused of using federal funds for embryo work. He lost his funding from the National Institutes of Health and resigned from Georgetown University in Washington, D.C. (Hughes had initially taken up Molly Nash's case, but was forced to abandon it. The Nashes eventually found a doctor in Chicago who performed the procedure.) Hughes moved to Detroit and set up the Center for Molecular Medicine and Genetics at Wayne State University.

The more substantial issue, though, is the specter of eugenics. At least one clinic in the United States is currently offering PGD services that allow parents to select the gender of their child, and more will surely follow. Hughes doesn't condone the practice. "We won't do gender selection," he says. "Gender is not a disease." What about fixing traits that make a good sibling donor? Are Hughes and other PGD specialists unwittingly turning children like Adam, selected to provide a transplant for his sister, into commodities? Hughes has struggled with this question and, he admits, has never managed to answer it unequivocally. He first confronted it when a case came up, before Molly Nash, while he was still working for the NIH in Washington. "I was very worried about it," he says. "We had meetings. We published in a serious bioethics journal." Hughes is not the kind of person who finds it easy to say no, and it's not hard to imagine him taking pains to avoid the impatient parents. One day the husband tracked him down at his lab unannounced. "I'll never forget what he told me," says Hughes. "He says, 'While you're running around the world sitting at mahogany tables debating the bioethics of this, our daughter is dying.'

"'People have children for all kinds of reasons,'" Hughes says, still paraphrasing. "'They have them for money, they have them for power, they have them to work on the farm. Mostly they have them by accident. What's wrong with our having a child we're going to love very much, but who also has the miraculous power to save our other child's life?'" It's not an easy question to answer.

Embryo genetic screening controversial - and successful

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By Lisa Nash

Molly Nash, on the ninth anniversary of her transplant.

By Dan Vergano, USA TODAY

A "slippery slope" to "a world of eugenics," as bioethics authorities [once worried](#), or a healthy life for a teenage girl?

Once at the center of a science controversy, Molly Nash, 15, represents the human answer to the debate over a genetic screening technique, "[pre-implantation genetic diagnosis](#)," (PGD) that made headlines a decade ago.

In Molly's case, her mother and father turned to PGD to pick out the embryo implanted to give birth to her brother, Adam, in an effort to save Molly's life.

"She's a typical teenage girl, she loves to dance, loves the theater," says nurse Lisa Nash of Denver, Molly's mom. "We never thought she would live to see 15."

A bone marrow transplant in 2000 cured Molly of [Fanconi's Anemia](#), a rare illness that kills many of its victims before the age of 7. The cord blood cells transplanted into Molly came from her then newborn brother, Adam. Now 9, Adam was the first reported case of baby selected as an embryo in a fertility lab for birth because his immune system characteristics made him an ideal transplant candidate for his sister. For the Nashes, giving birth to another child with those matching characteristics offered the only chance to save their daughter.

"Adam knows he helped his sister, that's all. They're normal kids," says Lisa Nash.

Of all the corners of science, fertility procedures have one of the longest track records for stirring controversy. In 1978, the delivery of the first "test tube" baby, [Louise Brown](#), in the United Kingdom gave birth to arguments that such procedures would harm children. Similarly, Adam Nash's birth raised worries at the 2002 President's Council on Bioethics meeting that pre-implantation genetic diagnosis (PGD) would lead to a widespread era of sex selection procedures at fertility clinics.

In particular, council members worried that embryos would be destroyed as families resorted to fertility clinic screening techniques to check embryos for hereditary diseases. In PGD, an embryologist plucks one or two cells from a few-day-old embryo, and destroys those cells in assays for Huntington's disease, cystic fibrosis, childhood cancer and many other ailments. In 2007, the most recently-available statistical year, about 5% of the 132,745 U.S. in-vitro-fertilization procedures included PGD, according to the [American Society for Reproductive Medicine](#).

"Parents are coming to us from all over the world with many kinds of rare genetic diseases," says Oleg Verlinsky of the Reproductive Genetics Institute in Chicago, which did the immune system screening on Adam Nash before his birth. Since then, RGI has performed more than 250 such screenings, Verlinsky says, for children whose birth led to the [treatment of an older sibling](#).

"Molly Nash is a wonderful story," Verlinsky says. "We worked so hard on her assay. The little girl was dying. Most patients come to us just for screening, but cases where parents come to you with an already-sick child are very hard."

Some bioethicists, such as former bioethics council chief [Leon Kass](#) of the American Enterprise Institute, raised worries that children born from such procedures would feel unloved, if they see themselves as exploited. The council also asked the public to weigh concerns about an era of "designer babies" [arriving through such techniques](#). The history of [eugenics](#), where 30 U.S. states passed mandatory sterilization laws during the 1920's, in a bid to weed out the "unfit," hung heavily over the debate.

"People are certainly entitled to their opinions. But we were doing what was best for our family," says Lisa Nash. She has become an advocate for cord-blood banking from newborns as a result of her experience. "I'd urge people to really think about it early in their pregnancy."

If you're interested, this video shows the Nash's in 2009.

<http://www.youtube.com/watch?v=xkT0CzcaXmo>