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How far should



Jennifer Lester, 8 months pregnant, and daughter Abby, 3.

Testing can prevent babies from  
being born with genetic diseases,  
but how far is too far?

# CHILDREN BY DESIGN

STORY BY ROBIN HUIRAS ■ PHOTOS BY JOSH HAWKINS

As 3-year-old Abby Lester arced high through the air on her backyard swing set one sunny afternoon, her parents Jennifer and Brian looked on casually.

“That’s high enough,” the Aurora couple cautioned.

An exuberant, healthy toddler at play in her yard seems ordinary enough. But the little girl’s vigor might be considered amazing—Abby is healthy by design.

The Lesters’ first child could easily have been born with or carried a life-threatening bleeding disorder that would have made for a completely different existence.

“We definitely wouldn’t have a swing set in our backyard,” says Jennifer, who carries Hemophilia B, a genetic illness that hinders the body’s ability to clot blood, and whose father has the illness. “We’d have a very artistic, chess-playing 3-year-old and be living our life around cotton balls and planning. I think we would be totally overbearing. It would be very difficult—how do you keep a toddler from falling down and still let them be a kid?”

But four years ago, when the Lesters decided they were ready to start their family, they resolved to eliminate the 50 percent chance that a daughter would carry or son would have the

disease by undergoing pre-implantation genetic diagnosing, or PGD.

It’s a technology involving genetic testing, in-vitro fertilization and embryonic screening that has given the Lesters’ children—they’re expecting their second daughter in May—the healthy life of which all parents dream.

“If you have the opportunity to erase a genetic defect that you know causes injury and can sometimes kill, why not take advantage of that?” Brian says.

Using the technology to help parents bring healthy children into the world fosters a sense of accomplishment, says Dr. Randy Morris, the Lesters’ doctor and medical director of IVF1, which has offices in Chicago and Naperville.

“In some cases with parents that have genetic defects, there’s this sense that it’s just not going to be possible to have healthy offspring, so it’s a very neat thing when someone comes to your door and says, ‘You are our last hope. Can you help us?’ and you look at their case and are able to tell them, ‘Yes, we can,’” Morris says.

One of those patients is Vanessa Palcu, of Palos Heights, who carries X-linked Hyper IgM Syndrome, an autoimmune disorder that severely limits the body’s production of in-

fection-fighting cells and antibodies, leaving victims prone to a lifetime of infections and frequently early death.

“What a miracle it is that we could go through this, we’re so fortunate to have a healthy child,” says Palcu, whose daughter Madeleine was born free of the genetic disease nine months ago. “By doing this, we were hoping to eliminate this out of our family, so future generations don’t have to be concerned about it.”

Opponents of pre-implantation genetic diagnosing say screening for genetic traits—more than 1,000 genetic conditions can be identified through testing—is the first step down a morally murky path.

“There are some awful genetic diseases out there,” says John Hardt, assistant professor of bioethics at Loyola University Chicago Stritch School of Medicine’s Neiswanger Institute for Bioethics & Health Policy. “And you might find people saying that if we’re going to do PGD, let’s screen those out—like Huntington’s disease, that’s a terrifying genetic disease that we know to be fatal, without a cure, few treatment options. So there’s a lot of people saying, ‘Yes, that one is fine, let’s screen for that.’”

“But what if we found people saying they don’t want a baby with Down syndrome? Evidence tells us people

with Down's live full lives and rate very high on happiness scales. Or what about babies with deformed hands or missing fingers? Is that OK? Do people with deformities lead less full lives? Where are we going to draw the line of factors that we think make a life not worth living—this is one of the challenges that PGD faces us with.”

## Designer babies

Whether for or against PDG, both sides agree the social and ethical lines the reproductive technology crosses are fuzzy indeed.

Non-medical sex selection is already available to patients seeking to balance their families with opposite sex siblings.

“I just had a patient who for her and her husband it's important to have a daughter,” Morris says. “They had always imagined their family as having both sons and daughters and they had their first son, then a second and tried again and it was another boy. So they were at this impasse where they were asking themselves how many more children they felt comfortable attempting for and raising in the hopes of having a daughter.

“Gender selection isn't anything new, it's been practiced in various ways for centuries, it's just that now we do it more effectively.”

IVF1 is not alone in offering this service to clients. According to a 2006 study conducted by the Genetics and Public Policy Center at Johns Hopkins University, 42 percent of 137 fertility clinics surveyed provided PGD for non-medical sex selection.

“To choose the sex of offspring suggests to some people sexism,” says Mary Mahowald, professor emerita in the Department of Obstetrics and Gynecology and assistant director at the MacLean Center for Clinical Medical Ethics at the University of Chicago. “To many people, that's much more objectionable than selec-

tion intended to avoid an anomaly because sex is not an anomaly.”

The U.S. is one of only a handful of countries accepting of sex selection, she says.

“The rationale of those who support it in the United States say that it's the couple's choice to choose who they want, it supports the autonomy of the parent,” Mahowald says. “Then the question becomes, what would it lead

generations ... that they become a project of expectation?”

This concept isn't science fiction—3 percent of the clinics surveyed by Johns Hopkins reported using PDG to screen for certain traits, such as dwarfism or deafness.

Unlike deafness or dwarfism, which can be identified at the chromosomal level, most physical attributes, such as height and weight and cerebral traits,

## Screening for disease: how it works

1. Through a simple blood test, the DNA of the affected parent and grandparent, if available, is analyzed to determine the characteristics of the affected gene.
2. The mother receives fertility treatments, hormones called gonadotropins, to stimulate ovulation.
3. Mother's eggs, or oocytes, are retrieved—between 10 and 20 per cycle—by passing a hollow needle, which is guided by a vaginal ultrasound probe, through the wall of the vagina into the ovary.
4. Father's sperm is collected.
5. Each viable egg is injected with a single sperm.
6. The following day, injected eggs are inspected to determine which have fertilized.
7. When the embryos become blastomeres, which are clusters of eight identical cells, one or two cells are removed during a blastomere biopsy and undergo genetic testing. These tests include looking for the same genetic abnormalities present in the affected parent or sex selection.
8. Five days after fertilization, two to three of the healthiest, non-affected embryos, now comprised of hundreds of cells and called blastocysts, are transferred to the uterus.

to, a predominance of boys over girls? I believe it can be done for non-sexist reasons and unless it is, I believe it's wrong.”

Hardt, whose perspective is rooted in the Catholic Church, says that while gender might seem insignificant, placing more importance on one—in the same way that a parent might place importance on height, weight or intelligence—sets the child for a life grounded in meeting parental expectations.

“Are we running the risk for turning procreation, the continuation of our species, into a project more than a simple fact of life, where we begin to assert so much control over future

such as disposition and intellect, are not found on any one specific gene.

“Let's say a parent wants a tall baby, so he'll be a basketball player,” Morris says. “That is so much more complex because we're not just looking at one gene or chromosome. There's going to be a huge number of interacting genes, not to mention the environment, contributing to height. Eye and hair color, intelligence and height, things that people worry about from a eugenics perspective, these are far more complicated and just aren't going to be doable, at least with the technology that we have today. We're really going through the first baby steps.”

The cost to society

Technological infancy or not, the price society will pay for PDG could outweigh its individual benefits, critics argue.

“My starting point is that every person born has the same value as every other person,” Mahowald says. “We’re all different with different sets of abilities and disabilities and, while we don’t live according to that, treating each other with the same value is something we aspire to. So the idea of promoting a designer baby is in a sense necessarily assigning greater value and I find that troublesome.”

The fact that not everyone has access to the technology could create another level of distinction between social and ethnic groups.

“One thing we have to think about is that this technology is more than likely restricted to people who have the money to get it,” Hardt says. “Are we going to now see babies born with genetic disorders limited to those who are poor because the wealthy can screen out the disease, so we’ll be widening another gap between the rich and the poor? Will we see a browning

of Down syndrome, where it becomes a genetic disorder of people of color because that follows the economic disparities in our society?”

Morris says the typical cost for in-vitro fertilization at his agency is \$10,500. Depending on the genetic screening and number of tests involved in the PDG process, that cost could increase by several thousand dollars.

The Lesters are by no means rich. In fact, their insurance covered the \$6,500 cost of the PGD process, Jennifer says.

“The cost of one blood transfusion far outweighs the cost of genetic testing,” she explains.

Further, as a parent facing the painful decision of whether to remain childless, bring a sick child into the world or screen out for the disease, having a healthy baby is the obvious choice and ethical choice.

Because Palcu and her husband John were aware of the 50 percent chance their child would have or carry the disease, they felt bound to prevent it.

“We didn’t even consider having a baby naturally because of this dis-

ease,” Vanessa says. “Because we were aware of that situation, we were not comfortable with the idea of putting a child through this.”

Brian Lester says: “It would be one thing if you could have kids and they would be fine, but it’s not like we could have kids on our own and ensure they would not have the disease.”

The Lesters and Palcu, neither of whom feel their children are designer babies, could have delved further into that complex realm by choosing gender or by asking their doctor to look for other genetic abnormalities.

“There are other things that could happen to Abby, and some of those things you just have to take on,” Jennifer says.

“The designer baby thing boggles my mind—I can’t imagine being so fussy as to want a certain hair or eye color. But, as a parent, it makes sense to avoid having to watch your child bleed to death.”

*Robin Huiras is a writer living in Evergreen Park.*