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Sometimes, it's hush-hush over donor eggs

Many parents don't tell the truth to children born of donor eggs.

By TERI SFORZA

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A generation or two ago, adoption was often a family secret. The rule was: Hush, hush. Don't tell. What they don't know won't hurt them.

But secrets have a way of slipping out. And when the truth was finally told – by a drunk uncle, an aging parent – the child, even if already an adult, experienced shock, confusion and betrayal.

Today, adoption experts almost unanimously agree that honesty is the best policy. There isn't as much consensus, however, when it comes to high-tech family-making.

Some 100,000 children have been born of donor eggs in America since 1984. The vast majority apparently don't know it.

Many fertility doctors counsel their patients to never tell children born from these arrangements that a donor egg was involved.

"We are more likely to recommend that people do not disclose," said Eli Reshef, medical director of the Bennett Fertility Institute in Oklahoma City. "If they cannot meet the egg donor, ever, who benefits by such disclosure?"

Mark Sauer, director of the Center for Women's Reproductive Care at the Columbia University Medical Center, is a pioneer in the field of egg donation. He recommends that his patients don't make any binding decisions – when they're in the midst of highly emotional fertility procedures.

"I say, 'Listen. I don't think you can really decide ahead of time what you're going to feel and what you should do. What you feel today as a non-pregnant, desperate, infertile person, you might feel very differently as the parent of a 3- or 4-year-old child,'" Sauer said. "There have been some patients who decide to be very open and disclose, but a great majority to this day don't tell their children."

Through the years, former patients have contacted him, asking to get in touch with their egg donors. He tells them that it's impossible, and they'd need a court order before he could divulge the information. "The donor's records are as private and protected as yours are," he said he tells them.

They became mothers in a most high-tech and unconventional way: never pregnant, never giving birth, never knowing the children born of their genes.

But many of the women who donated eggs to couples who so desperately wanted children made an implied contract for life: They'd be available through the years as the children grew up, they'd [illegible]

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consider requests to someday meet or correspond with their biological offspring.

"I am not looking for a relationship with these children," wrote Shawn of San Diego, whose five egg donations through now-defunct Options National Fertility Registry produced at least two children. "I personally did not think of future health issues, but did tell the recipients that they could contact me for any reason through Options.

"My father just passed of cancer, and my aunt just had a double mastectomy, so I think that would be information for the children to have. If these children were to need, for example, bone marrow, I would help."

Jennifer of Texas, another Options egg donor (donors are not being identified to protect their privacy), had promised to keep Options informed about children she later gave birth to, and where they were living – to guard against the science-fiction-like scenario of half-siblings inadvertently meeting, falling in love and wanting to marry. "Can you imagine finding out that the person you were dating was actually your biological sister or brother?" Jennifer wrote.

The last, fragile link between these and hundreds of other egg donors and the hundreds of children they helped produce may soon be broken.

In a scenario with little precedent, the bankruptcy of Options National Fertility Registry has concluded, and the fate of its files – 11 large storage cabinets filled with the names and addresses of donors and the names and addresses of couples who received their eggs – is in a strange limbo.

The files sit in a nondescript Orange County storage unit, paid for by the bankruptcy trustee, through the middle of October. The storage fee is $195 per month.

Teri Royal, the former president of Options, says she is ill and cannot afford to make those payments in perpetuity. But she believes the files are "potentially explosive" – showing that thousands of eggs and hundreds of embryos produced by her donors are unaccounted for – and should be preserved.

Melinda Lansford, Options' former medical records supervisor, has offered up her credit card to pay the storage bill for the short term. But she is in fragile health as well – recently treated for thyroid cancer – and can't afford a long-term commitment.

Lansford fears that the highly sensitive records could eventually end up alongside furniture and clothes and other junk from unpaid storage units. At the swap meet or on the auction block, the records could get sold to the highest bidder, who could then do whatever he or she wished with the "potentially explosive" information.

Should such records be preserved? Are they truly valuable?

In Canada and the United Kingdom, the answer is yes. Regularly-updated donor databases are kept by the government. But in America, there are no laws governing such records, even after 23 years and some 100,000 babies born from egg donations. This booming slice of the high-tech, high-profit fertility industry is still what some medical ethicists call the Wild, Wild West.

To a great many parents, the files in that nondescript Orange County storage unit are, indeed, explosive. Many fertility doctors counsel their patients to never tell the children born of such arrangements that a donor egg was used. Such children go through life assuming the physical

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the women who gave birth to them are, indeed, their genetic mothers.

The files in that nondescript storage unit could unravel highly sensitive, and carefully-kept, family secrets.

THE BIG PICTURE

It was 1984. Reagan was president. "Ghostbusters," "Splash" and "Amadeus" were the year's big movies. The Olympics were in Los Angeles. And the nation's first egg-donor baby was born in California.

Back then, the procedure was seen as a fix for women who couldn't make their own eggs due to disease, chemotherapy or the like, according to literature from the American Society for Reproductive Medicine.

But as women increasingly put off marriage and children to pursue education and careers, egg donation became much more popular. After age 35, the quality of women's eggs declines precipitously – even though their bodies can nurture healthy pregnancies well into the golden years. Enter the egg donors, who granted men the gift of genetic offspring (donor eggs are usually fertilized with a husband's sperm) and granted women the gift of biological – if not genetic – motherhood, complete with morning sickness, swollen ankles and the rigors of childbirth.

The lure of donor eggs is obvious. Freshly donated eggs from young women produce children more than half the time, compared to just one-third of the time when a woman's own eggs are used, according to statistics kept by the Centers for Disease Control and Prevention. That success rate is even more pronounced with women over 42, whose eggs produce children only about 3 percent of the time.

In 2004, donor eggs or embryos were used in 12 percent of all fertility procedures in the United States, and produced 17 percent of the children born, according to the CDC. That year alone, 8,386 babies were born from donor eggs.

Twenty years ago, egg donations were handled mostly through university hospitals and donors only earned about $500 for their trouble, which is considerable – daily injections, swollen ovaries and surgical retrieval of the eggs.

Today, however, independent brokers handle the bulk of egg donations. Donors often earn $5,000 to $10,000 per "cycle," as each round is called – and ads in Ivy League student newspapers have offered $50,000 to young women with the right mix of brains, beauty and ethnic background.

Who pays? The fertility patients receiving the eggs – $18,000 to $30,000 for a single donor cycle.

Debora L. Spar, a professor of business administration at Harvard University who wrote a critical book about the egg donation industry, estimates that about $38 million a year is spent on donor eggs.

BANKRUPTCY

This leaves many in the fertility field wondering how Options – an agency that connected egg donors with fertility patients – could possibly go bankrupt.

According to its bankruptcy petition, Options of Santa Fe Springs was forced out of business in 2003 after getting caught up in a legal tangle in Texas.

An Options donor, identified only as "Elizabeth," had contracted to donate her eggs to one infertile couple, and later learned that the doctor gave some of her eggs to a second couple without her

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permission, the bankruptcy documents say.

In the wake of this revelation, Options combed through every "post-cycle" report it received from doctors over a dozen years of business. Those reports were supposed to detail how many eggs each donor produced and what became of those eggs. "To put it simply, there are many eggs and embryos that are unaccounted for," Options' bankruptcy petition said.

An audit of Options' records suggested that 596 embryos and 2,189 eggs were unaccounted for. The FBI and other enforcement agencies were notified, but nothing was pursued.

The post-cycle reports Options based its suspicions on – meant to track the success of an egg donor's cycle, not the disposition of every egg and embryo – were not authoritative enough to stand as evidence in court, officials said.

Options filed for bankruptcy in 2005, and the case closed last month. That's when its sensitive records were moved into storage.

SAVE OR DESTROY?

Mark Sauer is director of the Center for Women's Reproductive Care at the Columbia University Medical Center. He's responsible for the world's first donor egg pregnancies in menopausal women, and casts an unromantic eye on the commercialization of egg donation.

The high demand for egg donors has led to escalating costs and long waiting lists, he and his colleagues wrote in a recent journal article. American fertility programs bid against each other for the services of young women who are "often motivated as much by financial reward as altruism." And even though more than 100,000 treatment cycles involving egg donors have been done in the U.S., "no meaningful longitudinal studies detailing the long-term effects of treatment on donors, recipients, children born, or families created have been published," they wrote.

Does Sauer think Options' records are so valuable that they should be preserved? Not necessarily.

"As best I can tell, these brokers don't have any medical or legal obligation to maintain these records," he said. "They're not physicians who have an obligation to maintain a medical record for a period of years."

Concerns about preserving the records so children might someday get updated medical information from their genetic mothers are exaggerated, he said. Prospective egg donors answer lengthy questions about family medical history, and those with problematic backgrounds are not accepted.

"I'm not sure the child would want to know that the egg donor's mother developed breast cancer or had heart attack," Sauer said. "Even if a condition turns out to be genetically predisposed, it's still a small percentage of people who will actually develop it. With things like breast cancer, most are sporadic events. You don't have a history.

"I lost my father last year to lung cancer and he never smoked. Everybody is going to have illness in their family, and most of the time – not all the time – you can't predict that. And when they do happen, you're not going to find a clear genetic reason for it. … I think it's silly that people maintain these registries for illnesses which aren't necessarily going to have any bearing on this child's life."

Many doctors counsel their patients to never tell children that they were born from a donor egg. Others, however, find that abhorrent.

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"Especially as we age, many of us have many questions about our genealogy and where we came from," wrote Jennifer, the egg donor from Texas. "Wouldn't you want to know if your mother was your (genetic) mother?" Arthur Caplan, director of the Center for Bioethics at the University of Pennsylvania, thinks Options should have to keep all the records, and should be carrying insurance to permit it to do so. "Options is absolutely responsible for all records," he said. To ensure that this sort of scenario doesn't keep repeating itself, he thinks the government should draft regulations mandating minimal requirements for egg banks and brokers, including bankruptcy and disaster/catastrophe plans.

"You have an industry that rose up with no oversight regulations or requirements at all," he said. "It was handled as a kind of in-the-gray-zone, mom-and-pop business despite the fact that you're talking about intimate and personal details of people's lives. Incredibly, there aren't any requirements for what to do if there's a bankruptcy, a disaster, a fire that destroys all the records."

Spar, the Harvard professor of business administration, agrees.

"To my mind, this is exactly the kind of story that demonstrates why we need better oversight of the fertility industry in this country – and at a minimum, much better record-keeping," she wrote in an e-mail.

SECRETS HARD TO KEEP

A Perfect Match is a business much like Options was – an online database of potential egg donors and surrogates. Infertile couples search the database to find a donor with the traits they desire – ethnic background, high intelligence, artistic or athletic leanings, etc.

Darlene and Tom Pinkerton of San Diego started A Perfect Match in 1998, after their own child was born via a surrogate. There are now 350 egg donors in its database, and it has helped bring hundreds of children into the world.

Darlene Pinkerton keeps backups of her files in a safe deposit box, she said in an e-mail. Files from the early days – 1998 to 2004 – aren't as complete as the newer files, as it just wasn't standard practice to have parties agree to keep in touch, she said. Files from 2004 onward are much more complete, and parties were asked to alert Pinkerton about address changes for 18 years.

If she sells the business, she's obligated to contact her post-2004 clients at their last known address to inform them of the pending sale, she said. They would then have the choice of paying a service to hold the information, or the information would most probably be destroyed.

"I also feel this is very important information, so I also may choose to turn it over to an attorney who could be trusted to keep the information on the off chance that someone contacts us after I close," she wrote. "I haven't really made a final decision on that."

Why the change toward greater openness in 2004? "I think people started realizing it was in the best interest of the child, much like adoption," she wrote. "Also, in this day and age of DNA testing, eventually there will be no room for hiding if someone really wanted to find you."

That's what many are hoping.

Almost 12,100 people have signed up with the Donor Sibling Registry – apparently the largest of the private databases springing up to help connect egg donors, sperm donors and the children born from such futuristic arrangements.

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About 18 years ago, Wendy Kramer and her then-husband decided they wanted to have a baby. Ryan was conceived with sperm from an anonymous donor, and, unlike many parents in similar situations, they eventually told him the truth.

"He was always very curious about his origins, his donor, the invisible side of himself," Kramer said. "It's one-half of his genetic identity."

Kramer asked the sperm bank for more information, and learned that Ryan's donor had fathered at least nine children. Who and where are they? "We asked, but quickly found out no one would help us here. It's a closed system," Kramer said.

In 2000, she started a Yahoo group, hoping to connect folks in a similar situation. A few years later it had grown so large she built a Web site and incorporated as a nonprofit. Of the 12,100 people on the Donor Sibling Registry, 541 of them are gamete donors – 414 sperm donors, and 127 egg donors – and the rest are offspring born from such arrangements.

So far, nearly 4,000 genetic relations – many half-brothers and sisters – have found one another through the registry. Her son Ryan, now 17, found a half-sister, 14.

"Nobody in the industry is keeping track or updating medical records," Kramer said. "It's really irresponsible, the way that things are being handled right now. No one is educating donors as to the true ramifications of their donations – nowhere does it say, 'You may be creating a human life that might someday want to know who you are.'

"As these kids are getting older and having more of their own voices, it is an issue. We've served, until now, the needs of the couples who wanted children and the donors who wanted anonymity. What we would like to see is for the industry as a whole to say, 'What's in the best interest of the child being born?'"

Staff writer Blythe Bernhard contributed to this report.

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