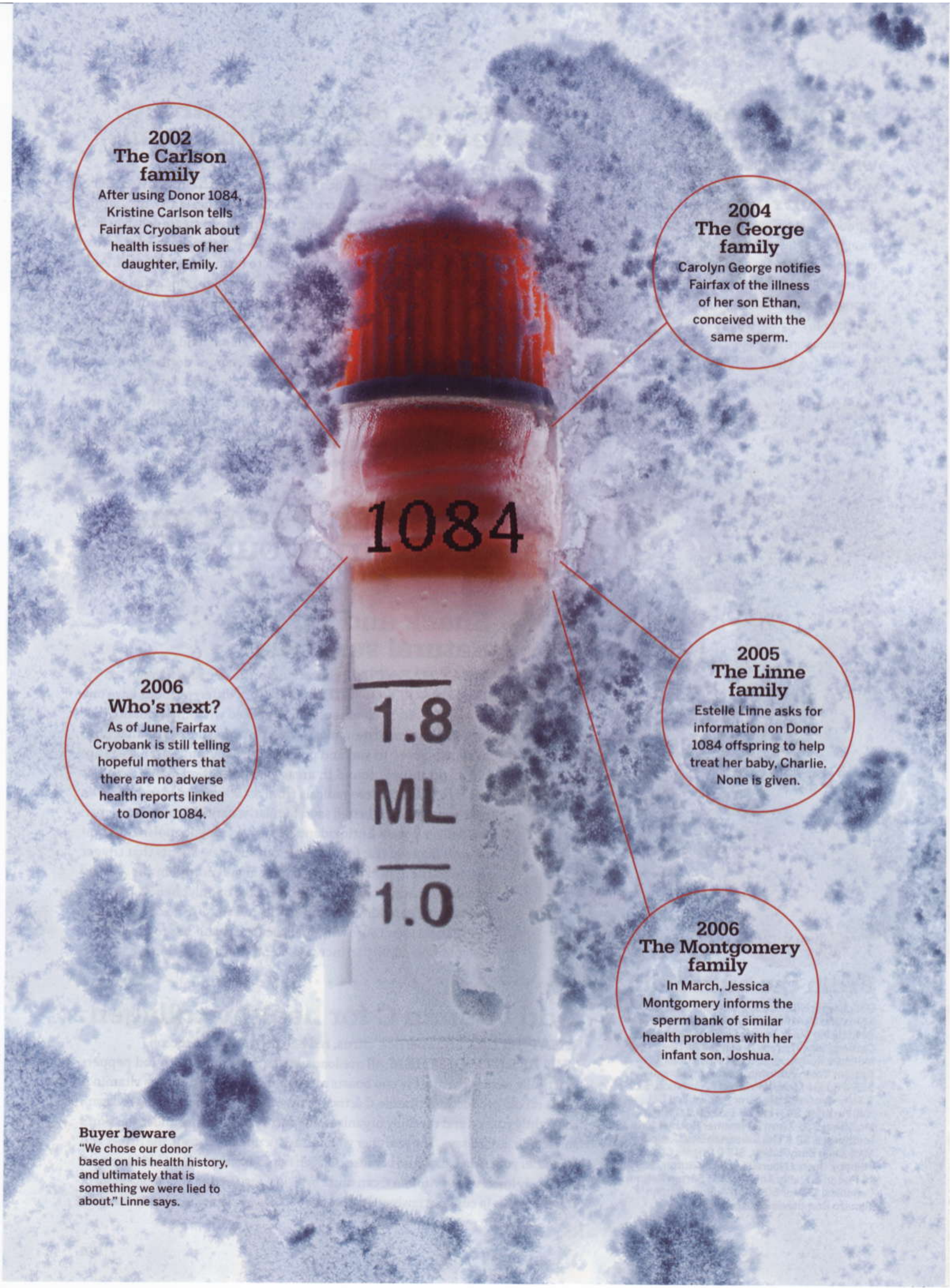

2002
The Carlson family
After using Donor 1084, Kristine Carlson tells Fairfax Cryobank about health issues of her daughter, Emily.

2004
The George family
Carolyn George notifies Fairfax of the illness of her son Ethan, conceived with the same sperm.

2005
The Linne family
Estelle Linne asks for information on Donor 1084 offspring to help treat her baby, Charlie. None is given.

2006
The Montgomery family
In March, Jessica Montgomery informs the sperm bank of similar health problems with her infant son, Joshua.

2006
Who's next?
As of June, Fairfax Cryobank is still telling hopeful mothers that there are no adverse health reports linked to Donor 1084.

Buyer beware
"We chose our donor based on his health history, and ultimately that is something we were lied to about," Linne says.

the truth ABOUT DONOR 1084

Angry mothers say sperm banks are hiding evidence of donors' genetic defects. A SELF investigation

By Jennifer Wolff Photographs by Plamen Petkov

Carolyn George admits that looks were a top priority when she went about choosing a sperm donor to help conceive her second child. She wanted someone with blond hair and green eyes, features her ex-boyfriend had passed down to their 11-year-old son, Noah. "I thought that then there would be less of a chance the baby would grow up to feel like a stranger in his own family," says George, a 35-year-old accountant living in Jenks, Oklahoma.

From Fairfax Cryobank in Fairfax, Virginia, one of the country's largest sperm banks, she chose Donor 1084 for his coloring and also for his health. Asked on his donor profile about his history of disease, from heart problems and cancer to allergies and eczema, he mentioned none. Her baby, named Ethan George, was born in April 2001 with a thatch of red hair and blue eyes. He couldn't have resembled his brother—or his brown-eyed, brown-haired mother—any less. "You just never know what games genetics will play," George muses.

Indeed. When Ethan was 1 week old, he developed eczema on his face. After six weeks, George says, her son's face, cheeks, hands and wrists were oozing and bloody. "I put socks on his hands so he wouldn't rub his skin raw, but every morning his crib sheets were covered with blood," she says. By the time he was 18 months old, Ethan had severe asthma and an egg allergy that caused facial swelling, hives and vomiting. Then his body began to bruise in places he had never injured. George feared she'd be reported as an abusive mother. "On his worst days, he has about 60 black-and-blue marks on his body," she says.

One of Ethan's doctors suggested leukemia—"that was too devastating to think about," George says. Several blood tests later, doctors diagnosed him instead with delta storage pool deficiency (delta-SPD), a rare genetic platelet disorder that causes bruises and bleeding from the slightest bump or cut. Ethan will have a normal life span, doctors have told George, but he must avoid contact sports or anything that might cause a blow to the head, leading to a brain bleed. Meanwhile, he has had a spate of staph infections in his open wounds and by last year had tested positive for allergies to corn, tomatoes, pork, peanuts, grass, dust, mold, ragweed, dogs and had reactions to several of the medications used to treat him. "It's just one illness after another. It doesn't stop," George says.

In July 2004, George contacted Fairfax to report Ethan's medical problems. Because she had no family history of blood disorders, eczema or egg allergies, she worried Donor 1084 had passed them down to Ethan—and might do it again to other offspring. "I felt the information would be useful to families who had used this donor or were considering using him," she says. "If people choose to take a risk, that's fine, but I felt an obligation to inform them the risk existed."

Three months later, Estelle and Audrey Linne, partners in St. Petersburg, Florida, ordered 12 vials of sperm from Fairfax Donor 1084. "He and his family appeared to be in terrific health, and that was essential to us," says Estelle, a 24-year-old insurance agent. Like Ethan George, Charlie Linne was born with reddish hair and blue eyes. And like Ethan, he developed severe eczema soon after his birth. At 5 months old, Linne says, "his skin was peeling off like an onion. He had to be hospitalized in isolation lest he get an infection."

As with Ethan, Charlie's doctors were at a loss and wondered whether leukemia might be the cause. Desperate for answers, Linne reached out to Fairfax several times starting in November 2005, seeking information about Donor 1084's other children that might help doctors diagnose Charlie. "I said not only do *you* need to know about Charlie's illness for your records, but *I* need to know if his siblings are sick, too," Linne says. "All [Fairfax] would say is that there are no issues."

In January, Linne joined the Donor Sibling Registry, an online community launched six years ago to help children of sperm donors locate their half siblings, and maybe even their donors. There, Linne exchanged notes with George and two other women who used Donor 1084. All four children suffer from some combination of eczema, allergies and asthma. Kristine Carlson of Bridgeport, Connecticut, says she reported the skin problems of her daughter Emily, then 2 years old, to Fairfax in 2002. Jessica Montgomery of Schaumberg, Illinois, reported her infant Joshua's eczema and food and drug allergies in March 2006. Yet when SELF called to inquire about Fairfax Donor 1084 in April and again in June and asked if there had been any adverse health reports from other parents of his offspring, the customer service representative replied, "No, none at all."

Now the mothers wonder: What else might the sperm bank be withholding about donors and their offspring? "You're never going to get a perfect donor," George says. "Diabetes and heart disease run in my family, so it doesn't anger me that he has health issues. It does anger me that Fairfax knows about them but refuses to inform prospective parents."

How much information do sperm banks owe their customers? The industry,

which has thrived since sperm donation was commercialized in the 1970s, relies on the promise of anonymity to attract donors and fiercely defends any intrusion on donors' privacy. "What made me decide to be a donor were the financial benefits," says one anonymous donor to California Cryobank in Los Angeles. "Not being anonymous would definitely make me think twice about it. Not protecting yourself seems naive."

But parents of children conceived with the help of sperm donors are starting to demand more information, sometimes for pressing reasons: Their children are sick. As SELF has discovered, sperm carrying serious genetic diseases has been distributed to potentially hundreds of women, who could pass their donor's lineage down many generations. With some donors fathering dozens of children—rather than the two or three offspring the average man might have—relatively rare genetic diseases may end up touching many more families than they would have before sperm banking. So who should be accountable if something goes wrong?

In May, *The Journal of Pediatrics* reported the case of Donor F827 at International Cryogenics in Birmingham, Michigan, who passed down a serious genetic defect, congenital neutropenia, to at least 5 of the 11 children born from his donations. The defect was discovered by sheer serendipity; all five children were patients of the same doctor at C.S. Mott Children's Hospital at the University of Michigan at Ann Arbor. Further analysis of the sperm can't be done without the donor's permission, and the sperm bank cannot locate him even to warn him that he risks passing the disease to any children he might have in the future.

In another incident, twin girls born to a couple in Sciota, Pennsylvania, who used Fairfax Donor 2148 fell ill within a year of their birth in April 2003. The mother (who asked that her name not be published) says she called the bank in December 2003 to get more information on the donor but was given nothing. Eventually, both twins were diagnosed with familial hemophagocytic lymphohistiocytosis (FHL), a rare genetic immune disorder, and one of them died in August 2004. The mother sent medical records, hoping the sperm bank would pull Donor 2148 off the market. They did not, but restricted his use only to parents who already have children with his sperm and agree not to sue Fairfax if their child is born with any genetic problem. Fairfax management says it contacted Donor 2148 clients or their physicians about the risk of disease in 2004. But the twins' mother, who is a member of a support group of 18 mothers with 23 children by the donor, says that many of the families haven't been alerted.

Some recipients don't care to know anything more about their donor than the fact that his sperm helped create their beloved child. But others can feel cheated and betrayed by an industry with little oversight that offers even less recourse for its sometimes tragically dissatisfied customers. George grew so infuriated that Fairfax Cryobank wasn't informing clients of the disorders related to Donor 1084 that in February 2006 she again contacted the sperm bank, this time sending copies of Ethan's medical records. "It became clear that Fairfax was withholding this information," she says.

Fairfax Cryobank management says that it logs and investigates all complaints, and restricts semen if necessary to protect the health and safety of sperm users and their offspring. In a letter to George dated February 16, 2006, Fairfax laboratory director Stephen H. Pool, Ph.D., wrote that Ethan's

Lifelong ordeal "Sometimes I am angry," Brittany Johnson says of her genetic illness.

diagnosis "most likely represents a new mutation [of delta-SPD] without significant recurrent risk." The sperm bank says that it received two complaints about skin problems but concluded that the conditions likely came from a combination of places, not simply the biological father. So Donor 1084 continues to be sold without any restrictions.

Warning other customers of the possibility of an inherited disorder is "the least they can do," argues Mark Aronica, M.D., an asthma and allergy specialist at the Cleveland Clinic in Ohio. Dr. Aronica has not treated any of Donor 1084's offspring. But he says there exists a strong genetic component to asthma and eczema; given that three of the four mothers did not have a history of these conditions, "that certainly suggests the sperm donor is the culprit."

Most sperm banks test their donors for common genetic diseases such as cystic fibrosis, and the FDA requires testing for infectious diseases such as HIV and hepatitis. But with 30,000 genes identified, time and cost make it impossible for cryobanks to test for everything, notes Harvey Stern, M.D., medical director of Fairfax Cryobank. No organization or government agency mandates that sperm banks maintain contact with donors. Nor are cryobanks obligated in any way to inform new clients of health problems among a donor's previous offspring or to provide families with sick children any medical intelligence about their donor. "You can get nutritional information whenever you buy a bag of potato chips and a mechanical history when you buy a used car. At the very least, you need the assurance of good health information when you buy sperm," says Debora L. Spar, a professor of business administration at Harvard Business School in Boston and author of *The Baby Business* (Harvard Business School Press). "Nobody can offer guarantees in this industry because, regardless of the technology, it's still controlled by Mother Nature. But it's bad business for a sperm bank to ignore this stuff. In some cases it could be malpractice."

In December 1986, a young law clerk began making donations

to California Cryobank. In four and a half years, Donor 276 delivered some 320 specimens for $35 each. He made $11,200 for himself and exponentially more for the sperm bank, which divided the samples into approximately 1,600 vials and priced them at $130 apiece. In 1988, Diane and Ron Johnson, a couple in Santa Barbara, California, who had struggled to become pregnant due to Ron's low sperm count, bought two vials and used them to conceive their first child, a daughter named Brittany. Now 17 years old, Brittany Johnson is a tall, strikingly pretty and deeply contemplative teenager, an accomplished artist who recently interned at the Santa Barbara Museum of Art. For more than a decade, she has also been the poster child for sperm gone wrong, having inherited a life-threatening kidney disease from California Cryobank Donor 276.

In 1995, 6-year-old Brittany came home from gymnastics class with blood in her urine. Doctors diagnosed her with autosomal dominant polycystic kidney disease (ADPKD), a genetic disorder that causes slowly growing cysts on the kidneys; because her mother tested negative, doctors are certain her sperm donor passed it to her. The disorder can lead to high blood pressure, vascular disease, brain aneurysms and, ultimately, renal failure. At least half of patients need a transplant by age 50. "I know there are no miracle cures, but I still hope for one," Brittany says. She gets jabbing pain in her right side—"like being stabbed with a knife"—so powerful that she sometimes has to lie down when she's out with friends. "Kids my age have no idea what it means to be sick," she says. "I don't like telling them because I don't feel like having to go into long explanations."

The Johnsons first learned that Brittany might be at risk for kidney disease in 1991, four years before she showed any symptoms. The couple had decided to

(continued on page 228)

PROP STYLING, SARA WACKSMAN. THIS PAGE: NATHAN PERKEL; HAIR AND MAKEUP, KENDRA RICHARDS FOR CLOUTIERAGENCY.COM.

The truth about Donor 1084

(continued from page 205) try to conceive a second child, and Diane called California Cryobank about using the same donor. Marilyn Ray, manager of the genetics department, told her that due to a history of kidney disease in his aunt, Donor 276 was available only to parents who already had a child with his sperm. Johnson says that Ray reassured her about Brittany's risk: A 1991 ultrasound of Donor 276's kidneys had shown no kidney disease. (Regardless, the couple used a different donor to help conceive their son, Brandon, now a healthy 13-year-old.)

In fact, Donor 276's aunt wasn't the only family member with kidney disease: His maternal grandmother had died of ADPKD and his mother also had the disease (and would later die of it). Some of this history had been alluded to on the donor questionnaire he filled out in 1986—but no one had ever shown that information to the Johnsons. "In California Cryobank's brochure, they say that donors' medical histories are checked for problems going back three generations," says Johnson, a 46-year-old nurse. "I trusted them."

The Johnsons would later learn that the 1991 ultrasound had actually revealed that both kidneys were enlarged and had multiple cysts consistent with ADPKD. Charles A. Sims, M.D., California Cryobank medical director, says that Donor 276 "had a few cysts on his kidneys, but not enough to say he had PKD." But Stanley C. Jordan, M.D., director of nephrology at Cedars-Sinai Medical Center in Los Angeles and one of Brittany's doctors, says the sperm should never have been sold. "If a donor has a strong family history of kidney disease," he says, "the sperm bank shouldn't accept him, plain and simple."

The typical ADPKD sufferer starts having symptoms in her 40s or 50s. That Brittany got sick so young was a marker for potential disaster. "The most important issue when first treating Brittany was to learn what kind of gene she had," Dr. Jordan says. "Did anyone in the donor's family progress to renal failure, and at what age? Did they have strokes, vascular diseases, lesions in their liver or ovaries or aneurysms in their cerebral arteries? All of these are symptoms of ADPKD and indicators of how it might progress in Brittany. They are also pieces of information that we didn't have."

In 1996, the Johnsons sued California Cryobank, in part to get information from Donor 276 that would shed light on his family medical history. The donor fought hard to avoid testifying. But in the first case of its kind, the California Supreme Court ruled that an anonymous donor could be forced to testify in a lawsuit against the cryobank where he sold his sperm. Donor 276 finally gave a closed deposition in 2001 but refused to provide the information Brittany's doctors needed and would not submit to a blood test to help isolate the strain of ADPKD he had passed down. (The case was settled out of court in 2003.) "This was someone the donor was intrinsically connected to, and he wouldn't do a thing," says R. Richard Farnell, the Newport Beach, California, attorney who represented the Johnsons. "Even more frightening is that his sperm had produced other children."

In fact, court documents suggest that as many as 1,480 vials of Donor 276's sperm may have been sold before the cryobank restricted sales in 1991. And management apparently waited at least seven years before reaching out to the physicians of Donor 276 families, warning them of the risk sometime in or after 1998. "We had no proof he had carried the gene, and we still don't," Dr. Sims says, adding that he is no longer in touch with the donor. "The original hope was that we could get a definitive answer. If he didn't carry the gene, there would be no point in raising fears."

Women get far more information from a sperm donor than they would likely get from a husband or other partner. Donor profiles are lengthy treatises, sometimes 25 pages long. A sample profile from California Cryobank, for instance, will tell you the hair color and texture, education level and profession for the donor and his parents, aunts, uncles and grandparents. Donors answer questionnaires about their families' history of disease in the circulatory, gastrointestinal, nervous, *(continued on page 230)* (continued from page 229) respiratory, skeletal, genital and urinary systems.

But do most college kids, who make up the bulk of donors, know the answers to those questions? "If a donor says his Aunt Pearl died of a heart attack, we take him at his word," says Sheridan Rivers, communications director for Xytex Corporation, a sperm bank in Augusta, Georgia. "We hope our donors are honest, but it is a risk we run. Sometimes we have kids who are adopted or who are sperm-donor kids themselves and they don't know. You do the best you can with the information you have."

A donor's blood is tested for general health, but not for drug and alcohol use. Nor do cryobanks run criminal background checks, a problem that emerged recently in Denmark, where it was discovered that a donor had been imprisoned for murder. And few surveys can confirm beyond a doubt a donor's bona fides. Most sperm banks ask for student ID or diplomas and proof of employment if they are working. But verification typically stops there. California Cryobank's Ray notes that prospective donors are asked the same questions by as many as six different interviewers. "We check to see that their answers are consistent," she says. "Every once in a while, we'll feel someone is not being straight with us, and we'll disqualify him."

Lea, a 37-year-old Midwestern attorney (who asked SELF not to publish her full name), wonders how the sperm bank she used three years ago vetted her donor, a man she suspects of lying on his profile. When her daughter was 1 year old, Lea began to worry that "she's going to be bitter when she's older because she won't know where she comes from." She knew her donor's age and college major from the profile he had filled out the year he started donating. So Lea began her search by making an open records request for commencement programs over a four-year period at the university near the sperm bank she used. Because she also had the ages of the donor's parents and his siblings, she was able to use Internet people-search engines to narrow the pool to six students, and then found their pictures online. Only one of the men matched her donor's ethnic background and profile and looked "uncannily" like her daughter.

But there were discrepancies. On his profile, the donor claimed he had a 3.5 grade point average, one of the key reasons Lea chose him. "My family is academic, and I wanted a smart child," she says. Students need a GPA of 3.2 or above for honors at this university, yet Lea's donor hadn't qualified. Immigration records revealed that one of his grandparents had been legally blind since the 1950s, and that a relative was 6 inches shorter than he had claimed. Lea is miffed the profile wasn't more accurate. "I think we have to assume that sperm donor profiles have about the same rate of falsification as résumés," she says. "But no one wants to learn that she's the child of a liar."

As happened to adoption agencies before them, sperm banks are learning how difficult it is to safeguard anonymity when clients are determined to breach it. The cryobank Lea used recently posted a note on its online message board urging clients to report anyone who compromises the anonymity of a donor. It has also added a clause to its release forms that bars clients from making any effort to contact or gather information on their donors; if they do, they become responsible for damages of up to $10,000.

Completely stripping away donor anonymity could have dire consequences, if what happened in the United Kingdom is a guide. A law enacted there in April 2005 ending anonymity for donors has contributed to a sperm shortage, with women left on five-year waiting lists. To address the demand for more information, U.S. sperm banks have started "open donor" programs, in which the donor volunteers to make himself available for contact after his offspring turns 18. "Many of our open donors have waiting lists of up to 10 to 15 people," says Rivers of Xytex, which charges $100 more for a vial of open-donor sperm and pays the donors an extra $35 per specimen.

Harvard's Spar suggests sperm banks could maintain anonymity—but still provide families more information—by making efforts to update medical records periodically. "A donor who has a heart attack at 42 should be required to pass that information to his offspring," she says. Fairfax Cryobank charges a premium for sperm from donors with Ph.D.s; Spar proposes cryobanks should charge clients for health updates and pay more to donors who stay in touch. "What major the guy had at Harvard or if he played Frisbee isn't as important as accurate genetic information," she says.

In 2005, two former egg donor counselors founded GenetiSafe, a company in Las Vegas that stores medical information from anonymous sperm and egg donors and their offspring. Recipients pay GenetiSafe to send their donor a yearly health questionnaire. If someone in the donor's family gets breast cancer, for instance, the child could take precautions. And if the child becomes ill, the donor can help without GenetiSafe blowing his cover, says cofounder Darci Steranko. The company has about 100 clients so far, all of them donor-egg recipients. Sperm banks, Steranko says, have been more resistant to partnering with the company. "Often an egg donor knows there is a person tied to her donation in real time, while sperm donors have no idea when or to whom their sperm is sold," she says. "I think that knowledge makes egg donors more cognizant than sperm donors that they have a genetic tie to another human."

That kind of awareness could turn angry mothers into grateful customers. In April, a mother in a Northwest state contacted her sperm bank and asked its management to forward a letter to the donor: Her daughter had a blood disorder and might need a bone marrow transplant. A genetic relative, such as her donor or his offspring, could be a match. The cryobank refused. "Here was a child with a serious health issue, and they weren't willing to help," she told SELF. "I feel like they are making me out to be a liar who wants to get in touch with the donor just for the sake of it."

She persisted, and on May 18 posted to the website that the sperm bank had not only agreed to contact her donor but also that the donor agreed to be tested and was already on the National Marrow Donor Program Registry. Once infuriated with the cryobank's apparent callousness, she wrote, "We are so thankful to them for working with our family in regards to saving my baby's life." ■