

Who's Your Daddy? Daddy?

BY BETSY STREISAND

Sperm donors rely on anonymity. Now donor offspring (and their moms) are breaking down the walls of privacy

Like many parents, Mia Lentz often looks at her 9-year-old son, Brandon, and wonders where on Earth he came from. Not in the usual alien-from-another-planet or raised-by-wolves kind of way that parents imagine when their kids behave like creatures from a parallel universe. Lentz's questions are far more basic, as in: Who is your father, and what was lurking in his DNA that might be hiding in yours? "Every time I look at him, I can't help but wonder who else he is," says Lentz, 46, an advertising and marketing executive in Boca Raton, Florida.

What Lentz does know is that Brandon's other half is sperm donor No. 1585: hazel eyes, college education, interest in architectural design, healthy family, piano-playing sister, and enough sperm donations to the Fairfax Cryobank in Virginia to father the von Trapp family several times over.

In the beginning of Brandon's life, those few tidbits were enough. But then came the autism like symptoms and the warning signs of precocious puberty, neither of which was part of Lentz's family history. Last year, Lentz learned--thanks to an Internet site that helps donor kids find their half siblings--that Brandon's half brothers and half sisters share some of the same physical attributes. But it's more than looks. The half siblings also share health problems, some of which are genetic. "I realize now I didn't do the right thing for my son by picking an anonymous donor," says Lentz, who most likely would have had little other choice in 1995. "The sperm banks have this information, and they're playing God with it. Our kids need the same rights as everyone else in this country to know their parentage."

Divine intervention notwithstanding, they may get them. Advances in the use of genetic medicine to predict and prevent disease, new DNA technology that makes it possible to trace ancestry, and the growing power of the Internet are galvanizing the

donor community. In turn, they are challenging the limits of donor anonymity and upping the pressure on sperm banks to make information about biological dads available to donor children.

It is only a matter of time before the courts step in, say legal and ethical experts. "As advances in genetics continue to raise the question of health risks due to heredity, more people made in non-traditional ways will demand to know about their biological ancestors," says Arthur Caplan, director of the Center for Bioethics at the University of Pennsylvania. "I have no doubt that children's interests will dominate, and the courts will break down the walls of privacy just as they did in adoptions." Most states, for instance, now make birth certificates available to an adopted child if a court finds there is a good cause.

Open donor. In several European countries, including Britain, Sweden, Norway, and the Netherlands, donor anonymity has already come to an end. It is illegal to sell anonymous donor sperm in those countries, and a few cases that would allow donor children access to birth records are making their way through the legal system. The same restrictions on the sale of donor sperm, which have been accompanied by a dramatic falloff in supply in Europe, are not expected in the United States anytime soon.

However, the nation's biggest sperm banks are responding to the growing demand from would-be mothers for donors who are willing to identify themselves. Last month, the Fairfax Cryobank, one of the largest sperm banks in the country, began an ID Consent Donor program. Donors must be willing to be contacted, via the sperm bank, by their offspring at age 18. Donors also agree to provide yearly updates on their whereabouts for 18 years following their participation in the program.

The California Cryobank, another of the nation's largest, began such an "open donor" program a few months back. "We are trying to encourage donors not to be anonymous," says Cappy Rothman, a urologist who started the California Cryobank in the mid-1970s and estimates it has been behind more than 75,000 births. The cryobank, one of more than 150 sperm banks nationwide, is upping its efforts to recruit ID donors by increasing its marketing on college campuses and paying more for contributions that come with a name attached. Right now, the typical sperm donor gives about a half-dozen times a month and earns from \$900 to \$1,500; ID donors can earn as much as 20 percent more. Cryobanks also are making more information about anonymous donors available to offspring for a price, such as supplying their childhood and teenage photos, essays, and audiotapes. But the shift isn't designed solely to please cryobank clients, who increasingly are single women and lesbian couples who tend to tell their children early on how they were conceived. (Married couples are considerably more secretive.) "A year ago, I felt sure that I could protect a donor's anonymity," says Rothman. "I'm not so sure anymore."

What has made Rothman and every other sperm bank, as well as many donors, unsure--and uneasy--is an enterprising 15-year-old boy, who shocked the donor world late last year when he tracked down his biological father by using a DNA sample and one of several genetic databases on the Internet. The boy sent a swab of his cheek to Family Tree DNA, a privately owned registry of more than 45,000 DNA samples, to see if his Y chromosome, which is passed down from father to son, matched anyone on file. Several months

later, he was contacted by two men whose Y's were a close match for his. The teenager then went to OmniTrace.com and used his donor's birth date and birthplace (which his mother had obtained from the sperm bank but are not available to all mothers) to buy the name of every person born in the donor's birthplace on that day. One man had the same last name as one of the two from the DNA registry. The boy contacted him.

What happened between the two after that hasn't been made public. But no one believes the situation will be unique. The boy is part of an increasingly activist generation of donor offspring who are not content to be kept in the dark about their genetic heritage as a result of restrictions placed on their mothers, most of whom signed forms agreeing to honor a donor's privacy. "This is a generation of kids who want information, and they know how to get it," says Wendy Kramer, whose website, donorsiblingregistry.com, helps donor children, half siblings, and donors find each other. Kramer created the site in the hopes of uniting her son, Ryan, 15, with his half siblings and perhaps even his donor father. That hasn't happened yet. But since the site launched in 2003, more than 1,300 matches have been made between donor siblings and donors and their children. One group of half siblings had grown to more than 20 at last count. There are nearly 300 donors on the site who are willing to be found by their children, says Kramer.

Meeting place. For parents like Lentz, the site has been the next best thing to finding the donor. Through the DSR, Lentz met Mary Catherine Baechtel, whose daughter, Amelia, 8, was also conceived with an assist from Fairfax Cryobank donor No. 1585. Lentz and Baechtel then connected with two other families with 1585's children, although not all the children know the truth about their origins. Brandon got a half sister in Amelia (they met recently in Disney World and keep in touch by E-mail and letters), and Lentz, Baechtel, and the other mothers traded their offspring's medical histories.

Brandon, Amelia, and another of their half siblings, for instance, all experienced very early growth spurts. When Amelia was diagnosed with early-

onset puberty, which can be followed by an abrupt shutdown in growth, the problem had a name. As a toddler, Brandon would get hysterical in the presence of loud noises and bright lights and was on the verge of being diagnosed with autism. Then a speech therapist determined he had a sensory integration disorder that made it difficult for him to properly process certain stimuli. When another half sibling was said to be autistic, Lentz told the mother about Brandon's experience, and the boy was re-evaluated and diagnosed with the same sensory disorder. Three of the half siblings appear to suffer from celiac disease (an intolerance for gluten). One has been diagnosed; two others with symptoms are being tested. One half sibling has type 1 diabetes; two others have the precursors to type 2 diabetes. Both celiac disease and type 1 diabetes are believed to be genetic. "Yes, I'm driven to find out more about my donor," says Baechtel, 47, a retail wine manager in Derwood, Md. "But I'm not that curious to know his name, what he's interested in, or what he does for a living. I want medical information, and I'm willing to settle for that."

Few experts think that sperm banks will be forced by the courts to identify their donors in the near future, although DNA registries may make it harder for them to hide. And even if they were forced, the results might be less than satisfying. Other than a federal requirement to screen for a vast array of diseases such as HIV and cystic fibrosis, the donor industry is totally unregulated. Record keeping, although better than it once was, is still often spotty. Although some sperm banks limit the amount of sperm they will make available from an individual donor, there are no legal limits. The average specimen is good for about six inseminations, and men often remain in donor programs for years, fathering numerous children. "I could fill a banquet hall with my children," says one donor from Southern California, who, like many medical students in the '60s and '70s, donated sperm to help cover living expenses. Now he is trying to locate some of his children through the DSR, and so far he has found two whom he believes to be his sons. They're all scheduled for DNA tests later this month. Among the donor's concerns is what might happen if two of his offspring were to become romantically linked. "What's to keep them

from getting involved with each other?" he says. "They don't know they're related."

Indeed, the question of incest, although not the most urgent one for many offspring, is a real consideration. More pressing is family medical history. Most donors are in their early 20s, and the history they are required to submit goes back to their grandparents but is anecdotal. "It has always been about the donors and anonymity," says Kramer. "When are the policies going to be based on the best interests of people being born and their right to know and their children's right to know?"

Sperm banks, whose survival depends on being able to protect donor anonymity, argue that they do everything they can to ensure quality. Donor sperm is screened for certain genetic abnormalities, and fewer than 5 percent of applicants actually make the cut. "If we discover something subsequent about a donor, we would contact everyone who used that donor," says William Jaeger, vice president of the Fairfax Cryobank. But Jaeger acknowledges that such a discovery would depend on the cryobank's being contacted perhaps years later by the donor or by donor offspring who report a problem. Cryobanks do not check in with past donors to see how their health has progressed.

Even if the offspring could get a full medical report, it might not be enough. Many children want to fill what they describe as an emotional void created by not knowing their biological fathers or half of their ancestral past. They aren't interested in money (and their mothers signed away their rights to it anyway) or even an ongoing relationship. Finding their fathers is more about understanding a look, a mannerism, similar tastes, a connection. "I see Mom and me, and that's it," says Mary Catherine, a 21-year-old college student who was conceived with donor sperm and is hoping to find her biological father. "It would be wonderful to see that other part--even just to know what he looks like," she says. Now, as the barriers of anonymity are chipped away, it's a picture that many children of sperm donors may eventually be able to piece together.