

Are Sperm Donors Really Anonymous Anymore?

DNA testing makes them easy to trace.

By Rachel Lehmann-Haupt

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When Donor 3066 signed up with the California Cryobank, he offered some basic information about himself on a piece of paper: that he had a BA in theater; that his mother was a nurse and his father was in the Baseball Hall of Fame; that his birthday was Sept. 18, 1968. He made it clear that he didn't want to be found by signing a waiver of anonymity.

The sperm bank protected his anonymity, just as it promised. But that did not mean he couldn't be found. In an age of sophisticated genetic testing, the concept of anonymity is rapidly fading. With some clever sleuthing—tests that can track down ancestral origins, donor numbers, and bits of biographical information—parents and offspring can find out the donors. "With DNA testing and Google, there's no such thing as anonymity anymore," says Wendy Kramer, the founder of the Donor Sibling Registry. "Donors are choosing anonymity because they're not educated," adds Kramer. "If they were properly educated on the consequences, then many would choose not to donate."

Donor3066 was being sought out by

Michelle Jorgenson, a 39-year-old waitress from Sacramento, Calif., whose daughter, Cheyenne, was born in 1998.* When her daughter turned 5, Jorgenson joined the Donor Sibling Registry and began searching for other mothers and donor offspring who used Donor 3066. She was concerned because her daughter was sensitive to sounds and walked on her toes, and she wanted to know if other half-siblings were displaying similar behavior. Through the registry, she met a number of other mothers and half-siblings. She discovered that two had autism and two other showed similar signs of sensory disorder. Over the years, the group, which grew to 13 families, formed a bond around this anonymous man who was their biological link. They had unions and reunions and exchanged holiday cards, but none of this socializing answered any of Michelle's

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questions about the donor's identity. Because he signed a waiver, the California Cryobank would not release his identity. And because genetic testing is not part of their protocol or an FDA requirement, they could not offer any clues to his genetic history that might have caused these traits.

Jorgenson began talking to Wendy Kramer, the founder of the Donor Sibling Registry. Kramer suggested that she try to find her donor through an ancestry company such as Family Tree DNA, which helps people trace their ancestral heritage through cheek-swab cell scrapings. Her son had recently found his sperm donor this way. Because we get half of our DNA from our mothers and half from our fathers, almost all DNA gets shuffled and remixed every generation, making it impossible to trace what comes from whom. There are, however, two bits of DNA that are more pure and therefore easier to read. Mitochondrial DNA is located in the cytoplasm of the cell and is passed from mother to daughter, without recombining with anything else. The other, the Y chromosome, passes directly from father to son. Just like a condensed computer file, scientists unzip the cells to obtain the DNA, which tells a story about a person's ancestors and their migration roots and can lead to discoveries about personal identity and family history.

Jorgenson began her search by approaching a mother in her group with a son named Joshua and suggested he do a cheek swab so she could explore his paternal roots through a Y chromosome test. The mother agreed. Through the test, Michelle learned about some of Joshua's genetic markers. A few weeks of searching on the Family Tree DNA Web site using these markers lead to two families with matching DNA. Through one of the families, she met a woman who mentioned that she found the obit of a relative who was a former baseball manager, and three children were listed. Michelle suspected that this might be her donor's father, so she looked up the phone number of his listed son. When Michelle called the number, the deceased man's son answered the phone. She began to ask him questions: *Was your father in the Baseball Hall of Fame? Were you born in Illinois? Did you ever donate*

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sperm? When the man said yes, she asked him if his birthday was Sept. 18, 1968. When he answered yes, she burst into tears. "You're the biological father of my daughter," she said. He was shocked but agreed to talk to Cheyenne on the phone—and eventually allowed the two to come visit him in Los Angeles.

"I e-mailed the group when I found him and said I thought you would want to know," she said. "Once they found out, everyone wanted to know who he was, and now he knows about all the kids. I talk to him a few times a year, but I'm the only mom who he's agreed to talk to, and we're the only family he's met."

Stories like Jorgenson's are profound on several levels. Sperm banks are not bound by the FDA to do genetic testing of donors, but if they were, these new tests could offer a way for donor offspring to learn not only about their ancestry but about origins of specific genetic traits that could be linked to disease.

They also challenge the long-cherished idea of donor privacy. Most sperm banks now offer identity-release sperm, which means that donors have agreed to let their offspring contact their donor when they turn 18. But the great majority of donors still prefer anonymity, and profits hinge on ensuring it. College students are lured by the promise of easy money for

doing what they would do for free. Few banks advertise—or even counsel their donors—that one day this easy money could result in dozens of children who might be curious about their genetics and ancestral routes, and a genetic family that could rival the size of one on *Big Love*.

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This new science is now forcing sperm banks to reconsider their policies and the education of their donors. "At this point, it's hard to know how much it means, since the science is changing so quickly and we don't know how many are actually looking for their donor," says Alice Ruby, the director of the Sperm Bank of California, the only not-for-

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profit sperm bank in Berkeley, Calif. Ruby, who was the first to spearhead the idea of the identity-release donor, says that her bank's research has shown that the majority of families are not interested in finding their sperm donors. In 2008, the bank presented a research study at the conference of the American Society for Reproductive Medicine that found that only about 30 percent of families in their first class of identity-release donors have come looking for their donors. "We now tell donors that we'll protect their identity, but that we cannot promise that future medical or technological advances will not make it possible for someone to identify who they are," she adds.

Some sperm banks are changing their policies for fear that anonymous donors might withdraw from the program and hurt their bottom line. Cryos International, a sperm bank based in Copenhagen, Denmark, that claims to be the largest bank in the world, has started to offer a new program that it's dubbing "Invisible Donors." It's a system where donors can offer very few registered characteristics so they will be more difficult to track, and the bank keeps track of them by fingerprints instead of donor number.

"I'm fully aware of the future child's needs, and I fully understand and support children who will search for

their donor [and] half-siblings, but the fact is that it is wrong to search for a donor who claimed anonymity," says Ole Schou, the director of Cryos International.

She may be right that it will become increasingly difficult for a donor to hide, which means the moral decision of whether to trace him and ignore his request for anonymity will rest less on the banks and more on the parents and offspring. If DNA testing does become more ubiquitous, it may be that even a very few traits will make the men traceable. What will they do then? wonders Kramer. "Create men without DNA?"

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***March 1, 2010:** The piece originally said Michelle Jorgensen lived in Nederland,*

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Colo. She lives in Sacramento, Calif. (Return to the corrected sentence.)

Rachel Lehmann-Haupt is the author of In Her Own Sweet Time: Unexpected Adventure in Finding Love, Commitment, and Motherhood. Her Web site is www.lehmannhaupt.com.

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