

Found on the Web, With DNA: a Boy's Father

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Like many children whose mothers used an anonymous sperm donor, the 15-year-old boy longed for any shred of information about his biological father. But, uniquely, this resourceful teenager decided to try exploiting the latest in genetic technology and the sleuthing powers of the Internet in his quest.

By submitting a DNA sample to a commercial genetic database service designed to help people draw their family tree, the youth found a crucial clue that quickly enabled him to track down his long-sought parent.

"I was stunned," said Wendy Kramer, whose online registry for children trying to find anonymous donors of sperm or egg helped lead the teenager to his father. "This had never been done before. No one knew you could get a DNA test and find your donor."

While welcomed by advocates of children trying to locate anonymous donors, the case -- apparently the first of its kind -- has raised alarm among sperm banks and some medical ethicists. They are concerned it might start a trend that could violate the privacy of thousands of sperm donors and discourage future ones.

The case has also underscored how the growing number of genetic databases being established by governments, law enforcement agencies, private companies and research organizations could be used in unintended ways, potentially invading personal privacy and raising a thicket of social, ethical and legal questions.

"When you create these databases, you're creating something that has a lot of power -- far beyond what they were originally designed for," said David M.J. Lazer, who studies the legal implications of genetic databases at Harvard University's John F. Kennedy School of Government. "This seems like one of those scenarios."

The database involved in the sperm donor case was set up by Family Tree DNA of Houston, a private company that has accumulated more than 45,000 DNA samples. For a fee, clients hoping to learn more about their heritage can have their DNA tested to see if it matches anyone in the database.

"We provide services for genealogists. That's what we do," company spokesman Max Blankfeld said. "We really didn't have anything like this in mind."

In this case, the teenager scraped some cells off the inside of his cheek last year and sent in the sample with \$296 to see if his Y chromosome, which is passed down from father to son, matched anyone on file.

"At first he just wanted to get a little more information about his paternal side, like countries or origin. That kind of thing helps people who want to know: 'Where am I from culturally? Where are my people from?' Any bit of information is so welcomed," Kramer said.

The youth has declined to be identified, revealing just the outlines of his case through Kramer's registry to protect the identity of his newfound biological father. The case was first reported by the British magazine *New Scientist*.

About nine months after submitting his sample and agreeing to be contacted by other clients, the U.S. youth heard from two men with Y chromosomes that closely matched his, Kramer said. Neither man knew the other, but the analysis indicated there was about a 50 percent chance that all three had the same father, grandfather or great-grandfather, Kramer said. The men also had similar last names, spelled differently.

Because the youth's mother had obtained the donor's date of birth and birthplace from the sperm bank, he paid another online service, *OmniTrace.com*, to buy the name of every person born there on the same day, Kramer said. One man with the same last name appeared on the list, and within 10 days the youth contacted him, said Kramer, who declined to reveal details about the donor's reaction.

"I think this kid would love to come out with his story, but for the time being those are the wishes of the donor," Kramer said.

Since word of the case emerged, several other offspring registered on Kramer's site, <http://www.donorsiblingregistry.com/>, have clicked the link to the Family Tree DNA site (<http://www.familytreedna.org/>) in hopes of locating their biological father, she said.

"Given this case, more people will be putting their DNA in the pool so that potential connections can be made," Kramer said. "Not everyone who puts their DNA in is going to find their biological father, but now we've seen this as a distinct possibility. The DNA databases are just going to grow and grow, and this is going to be more and more common."

That scenario is likely to concern thousands of men who have donated sperm anonymously -- often college students or other young men who saw it as an easy way to make money -- according to sperm bank officials and ethicists. There are no reliable estimates of the number of Americans who have been born using donated sperm, but it could number in the hundreds of thousands.

"A fair number will be quite perturbed," said R. Alta Charo, a University of Wisconsin bioethicist. "They well may be wondering, 'Am I next?'"

Several experts said the relatively small number of people whose DNA is on file means the approach remains a long shot.

"The sperm bank involved in this case disclosed a lot more information than we do," said William Jaeger of the Genetics and IVF Institute of Fairfax, one of the nation's largest sperm banks. "In cases where the donor does not want to be identified, we do everything we can to protect them."

Nevertheless, Jaeger and officials at several other of the nation's largest sperm banks said the development is disturbing.

"Protecting the identify of our donors is paramount for us," Jaeger said. "It would become a problem if it became common. It would really reduce the number of donors available, and I think you would be doing a disservice to people who want to use sperm donors."

Many sperm banks offer donors the option to donate without anonymity and allow recipients to chose those donors. But those who opt to remain anonymous should be protected, officials said.

"I think it's unethical. It's an invasion of the donor's privacy and a breach of contract," said Cappy M. Rothman of the California Cryobank of Los Angeles, another large sperm bank. "If we were to expose our donors to being known, we would have many fewer donors."

Some ethicists said the rights of offspring outweigh those of donors.

"I have no sympathy for someone who wants to have a child but doesn't want the child to find out who their father is," said George Annas of Boston University. "If you're worried about it, you shouldn't be selling your sperm."

Other ethicists said the case illustrates the need to find ways to balance both interests.

"The overall issue is the importance of some offspring of donors to learn about their biologic parentage, which is a strong impulse in some children and needs to be taken seriously, with ways to accommodate that that are respectful of the privacy of the donors," said John A. Robertson of the University of Texas School of Law.

"At the very least, we may now need to inform donors that we may no longer have a foolproof way to protect them," Robertson said. "If the system is as porous as this case indicates, then at least we need to inform them that someone may track them down."

Moreover, the case illustrates that when people put their DNA on a database, it provides information about more than themselves, several experts said.

"DNA is the ultimate identifier," said Kathy Hudson, director of the Genetics and Public Policy Center at Johns Hopkins University. "I don't know to what extent these databanks are taking their responsibility seriously to make sure people are aware of the possibility of these unintended disclosures."

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