

BIRMINGHAM CASE RAISES QUESTION ...: Do banks find out enough about donors?

BY TAMARA AUDI
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With only limited regulation, U.S. sperm banks set their own rules on a host of sensitive issues -- from how many children a donor can father, to what donors and prospective parents can learn of one another.

But one of the thorniest areas involves genetic testing, an issue underscored by last week's revelation that five children had contracted a rare and potentially deadly disease from a donor to a Birmingham bank.

While the federal government sets standards on testing for communicable and genetic diseases and on the shipping and storage of sperm, banks largely make their own decisions on the extent of genetic testing they offer.

Most banks generally screen only for common illnesses such as cystic fibrosis, but not for more obscure diseases.

Banks say it's impossible to screen for every defect -- there are too many. They try to hit the big ones and ask for medical histories in hopes of spotting a genetic fault.

"On the whole, the industry has a very good track record of safety and not communicating diseases and not giving people HIV or other diseases," said Arthur Caplan, director of the Center for Bioethics at the University of Pennsylvania.

But Caplan said important pieces are missing in sperm bank regulation: Banks are not required to verify key donor information, including family history and personal information, and how banks "promote ... and advertise is not regulated at all."

Caplan said banks "are not intentionally deceptive, they just don't bother to check very hard. And they know that and they don't admit that."

As it happens, only a few banks verify donors' personal information. Instead, they largely rely on the donors -- whether for crucial family medical histories or seemingly insignificant information about hobbies or interests.

Banks counter that they are highly selective, turning away more than 95% of potential donors who do not meet health criteria. Although bank directors concede they generally do not independently verify personal information that donors provide, they note that they screen donors through a rigorous interview process.

"The way we talk and talk and talk to them, and the fact that they're not getting paid much, we have found donors are very honest with us," said Mary Ann Brown, president of International Cryogenics in Birmingham, Michigan's only major sperm bank.

Charles Sims, medical director of California Cryobank, acknowledges there are "huge gaps" in government regulation on several key issues.

For example, most banks try to limit the children each donor can produce to prevent half-siblings from inadvertently mating, but the number is not regulated, leaving banks to follow their own consciences.

The Birmingham sperm bank allows only 20 births per donor worldwide, but may make an exception if a woman wants to have another baby with the same donor.

Some banks roughly follow an informal guideline that suggests no more than 20 births in any region of about 800,000 people. California Cryobank uses its own formula, allowing up to 52 children from one donor. Sims estimates the average donor from his bank has between 20 and 30 children.

There is a catch to all of these equations: Women are not required to report pregnancies.

"The problem with saying we're going to limit the number of children to 10, 20, 30 is that you get underreporting," Sims said. "You could go considerably over that and think you are well within it."

Sims, who is also the chairman of the Reproductive Council for the American Association of Tissue Banking, which offers to accredit sperm banks, is pushing the industry to develop better reporting and uniform standards "rather than have a scandal that causes laws to be passed."

Still, Caplan said sperm banks can figure out the birth rates by limiting how long a donor can donate. Some banks, he said, "tend to be callously indifferent" when it comes to how much a donor is used. "They will use the same donor 10, 15, 20, 30 times and that's inexcusable. ... They're creating potential interbreeding problems so offspring won't be aware of it."

Even now, as half-siblings find each other through the Donor Sibling Registry, a Web site that connects half-siblings, families are finding up to 25 children from one donor.

"It's very clear to me that we need to do what the right thing is," Sims said. "But what's the right thing?"

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