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# WETZSTEIN: Sperm donation testing falls short

[Cheryl Wetzstein](#)

News broke a few weeks ago about a sperm donor who passed congenital heart disease to nine of his 24 offspring.

One of the children, a 2-year-old girl, died of the genetic mutation.

The case "underscores the potential risk" of inherited disease transmitted by sperm donation, Dr. Barry J. Maron and colleagues wrote in the Journal of the American Medical Association (JAMA).

This problem is "largely unappreciated" by the medical community and agencies regulating tissue donation, they added.

That's for sure, said Wendy Kramer, who, with her donor-conceived son, created the Donor Sibling Registry (DSR) in 2000. The 25,700-member registry helps donor-conceived children connect with their donors, half-siblings or other biological family members.

It also serves as a sounding board for issues surrounding donation, and genetic health is one of the biggies, Ms. Kramer said.

"I've got a list of probably 60 fairly serious [genetic issues], all the way to severely serious genetic issues that people have reported on my Web site," she said.

Some of these cases involve "very, very sick children," and "it didn't have to be that way, if simple genetic testing was done," she said.

Sperm banks, of course, tout the health of their products.

Idant Laboratories, one of the oldest, largest and best-regulated sperm banks, says it evaluates medical and genetic histories of all prospective donors, and no man is accepted if his family history reveals a condition that "poses a risk of producing offspring with a birth defect and/or a genetic disease in the general population."

In addition, any man "found to be a carrier for a genetic condition for which Idant screens" is not accepted as a sperm donor. All donors are tested for cystic fibrosis and Thalassemia blood disease, and men of certain ancestries (e.g., Jewish, African, French-Canadian) are tested for sickle cell disease, Tay-Sachs disease and Canavan, a degenerative neurological disease.

These are reassuring words, especially when sperm banks note that they also screen for HIV/AIDS, chlamydia and other infectious diseases, as required by the federal government.

But these words don't tell the whole story, said Dr. Kirk Maxey, a former sperm donor, chairman of DSR's board and founder of a nonprofit organization that conducts genetic testing.

There are all kinds of inherited diseases, and DSR members have reported donor-conceived children with albinism, cystic fibrosis, Williams-Beuren syndrome (which typically causes mental retardation) and immune system disease, Dr. Maxey wrote in a letter to JAMA, which was posted on the DSR blog.

Perhaps there is selection bias in the DSR, but the percentage of congenital disorders among these offspring "actually seems to exceed the population average," Dr. Maxey wrote.

Dr. Maxey recommends sperm banks begin tracking outcomes (births) of their donors, and quarantine donors' sperm until some of those children reach their second birthday. If the toddlers are pronounced healthy, their donors' sperm could be sold once again.

This temporary quarantine system could prevent hidden or rare diseases from being passed along en masse, because donors can have dozens and even hundreds of offspring, Dr. Maxey said. It also would be good to give prospective donors extensive genetic testing, such as karyotyping or genetic sequencing, to ensure healthy sperm.

Sadly, it seems sperm banks are content with their current testing policies. "You know what they're touting?" Ms. Kramer asked. "They're touting, 'We have donors that look like Brad Pitt.'"

I raise the issue of sperm banks and genetic health because intentional single motherhood and lesbian motherhood are becoming more socially acceptable. Height and intelligence may always top the list of desirable qualities in male gametes, but without a full report card on genetic health, it is buyer beware.

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