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Doctor blames profit motive for sperm-donor diseases

The Journal of the American Medical Association (JAMA) recently highlighted the case of a sperm donor who had 24 children, nine of whom became sick with an inherited heart condition. One child, 2, died.

Dr. Kirk M. Maxey is chairman of the board of directors for the Donor Sibling Registry (DSR), a nonprofit organization that serves donor-conceived individuals and families. Dr. Maxey is also a former sperm donor who has met two of his biological daughters, and founder of Cayman Biomedical Research Institute, a nonprofit organization that offers genetic testing.

In a detailed response to the JAMA article on the DSR Blog, Dr. Maxey said there are many cases of inherited genetic disease in donor-conceived children, and reform is needed. Washington Times staff writer Cheryl Wetzstein recently spoke with Dr. Maxey.

Q: Why did you write a response to the JAMA article? A: I wrote the letter because ... the authors of the article said, "Wow, this is so amazing; we have found a sperm donor who had a congenital heart disease and he passed it on to nine children, including one who died. And isn't that remarkable because we've never heard this before."

So I was responding, saying, "First of all, you guys are pretty dense because ... there's multiple published reports of donors passing bad things to children. And second of all, this is a good reminder to everyone that we should open up and eliminate anonymity in donor gamete collection. And we should stop the profit system - for-profit sperm banks - because that's basically what drives this."

Q: What is your interest in this issue?

A: I am a former donor and I have a vested interest in trying to see that there is some reform of this particular branch of medical living-tissue donation.

If you step back and you say, "From time to time, patients need living medical tissue," everyone says, "Yes, that's true - kidneys, hearts, lungs." OK, everybody gets that.

And then you say, "And let's take one branch and completely cover it in secrecy, with no open records, no ability to find out who did what, and let's make the people running that system really rich." And then everyone's eyebrows would just hit the ceiling and say, "Why would you ever do that?"

But that is actually the case [with sperm banks]. Blood products and other tissues are handled in this sort of calm, boring, nonprofit manner, and then gamete (reproductive tissue) is handled in this other way - Wild West, crazy, no one knows what anyone is doing. And I find that just so inappropriate from a public-health standpoint.

Q: Just a ballpark figure - how much are the men paid for their sperm, and how much do women pay to get it?

A: [In the 1980s], I was paid $20. Donors now get closer to $80 to $100 for a donation. And my biological daughters' mom was charged $1,500 for the first one and $2,000 for the second one. So I didn't get a very big cut of the gate, if that's what you are asking.

Q: I think most Americans really have no idea of the profit markup on these particular exchanges.

A: One-hundred fold.

Q: Tell me about your solution, the "5 and 2."

A: It's a very simple solution. Take the current situation, which is that the sperm bank sells as many vials of the donor semen as they feel like. There's no limit; they can sell 4,000 if they feel like it.

As an alternative to that, you set up a situation where as soon as they introduce a new donor, they actually have to follow each outcome ... and they have to monitor each baby that's born.

When there's been five babies [from a specific donor], they have to stop selling his vials, and he's retired for two years ... until that youngest baby gets 2 years old, and all [five of his offspring have gone] to the pediatrician.

And you get two outcomes. Either some of these kids are having problems, and in that case, you carefully work through - is this from the mother? Is this from the father? Is this a very rare thing? Is this a common thing? And is it genetic? If the kid has bad allergies, for instance, it may have nothing to do with the donor. But either you get a clean bill of health or not. And if it's a clean bill of health, he gets to have two times [of new births, based on] the last number. So, if he had five pregnancies before, the second time out, he gets 10. Basically, you start him out fresh, selling his vials. And when he gets to 10 [babies], you stop again, and those kids have to have physicals.

So it's sort of a start-and-stop process that allows you to fully check whether you're introducing unnecessary health problems into the human population, in spite of everyone's intentions. I don't think any parent would say, "Oh, I've been dreaming of a kid with a congenital heart defect."

Q: Aren't inherited health conditions screened for in sperm?

A: There's almost nothing screened for. Like I've seen sperm banks say, "Tested for cystic fibrosis." But there's 1,000 different mutations that cause cystic fibrosis and I know they have not run 1,000 tests on their donor; they have probably run one or two of the tests that are most common. Frankly, there's no law to require testing, and there's not very much done.

Q: I know the Food and Drug Administration (FDA) calls for screening for sexually transmitted disease in sperm.

A: Right. That's what the FDA's response to the entire donor question has been - they decided that it's under their purview to prevent sexually transmitted diseases by donor tissue, so they do require the banks to do quite a few infectious-disease tests. But that started when I was a donor, in the mid-80s, right about when AIDS started coming in - and that's quite different from testing for genetic illness.

Q: What would you want to see screened?

A: Fragile X ... should definitely be tested [in both sperm and egg donations]. But the first genetic test everyone should do is a karyotype; that's a visual look at the chromosomes. Then, you can sequence the genes for cystic fibrosis [inherited lung disease], Thalassemia and sickle cell [inherited blood disorders], Tay-Sachs [fatal degenerative genetic disorder], and do BCRA 1 and 2 [genes that increase risk of breast cancer], APC [a gene involved in colon cancer], and autosomal kidney disease.

My ideal world is one where there would be genetic counseling of people who are going to do donor-assisted reproduction, so you can make sure you're matched up. You don't want two people with really strong diabetes risk factors joining together.

Q: It sounds like science can help married couples too.

A: Yes, but I think there is such a clear distinction. When couples get married and find they have genetic risks, because they are in a relationship, they can make very careful decisions about whether they are going to take those genetic risks.

But if your relationship is to a donor, you just want healthy offspring. And as soon as you have true information that the donor's not healthy, I think you drop him like a hot potato.

That's the difficulty - there's a vested profit motive [in sperm banks] not to drop those donors ... The banks hold on to them because they've invested in them, paid them for their donations, and they really want to keep selling it. And as long as nobody knows that donor has sickness involved, they just keep selling ... and I think that's really something that makes people queasy.