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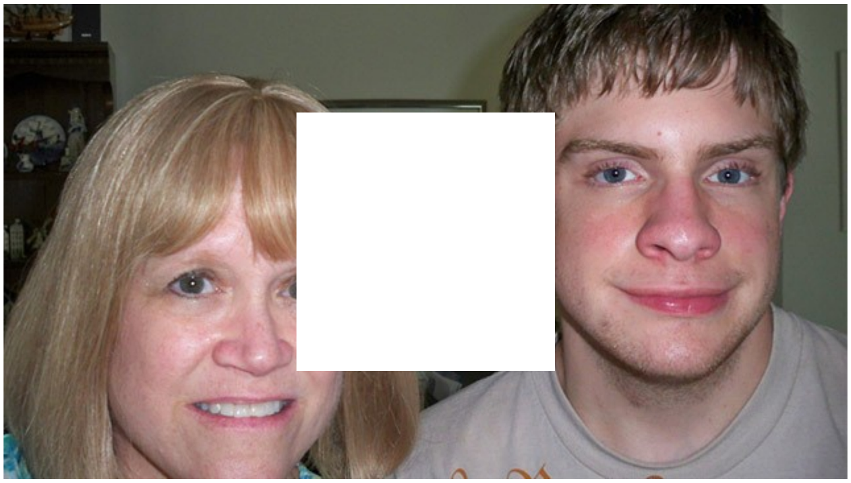
Sperm Donor's 24 Kids Never Told About Fatal Illness



A Son's Search for Sperm-Donor Father

By SUSAN DONALDSON JAMES
July 21, 2011

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Rebecca Blackwell and her 15-year-old son Tyler were curious about his sperm donor father, whose identity had been anonymous since the moment of conception. Through good detective work, they were eventually able to find "John" three years ago.

What they didn't expect to learn was that Tyler had inherited his father's medical condition -- a connective tissue disorder called Marfan's syndrome and a heart defect that could have killed him at any moment.

Tyler's father never responded to their letter to make contact, but just last year, John's sister found the Blackwells online building on a family tree and immediately told them that John had nearly died when his aorta ruptured at the age of 43, and two brothers and Tyler's grandmother had the genetic disorder.

John had never notified any of the three sperm banks where he had fathered at least 24 children -- 50 percent of whom could inherit the disorder.

"Tyler had a time bomb ticking in his chest," said Blackwell, a 59-year-old special education teacher and single mother from Frederick, Md. "It didn't occur to anyone to tell us."

Tyler, now 18, had surgery in June after doctors found a defect in his aorta, but Blackwell wonders why the fertility clinic was never required to update them on John's medical history when so many lives were in the balance.

But Friday, Washington will be the first state to grant rights to donor-conceived people to gain access to crucial health information about their biological parents.

A new law requires donors to provide, "at a minimum," identifying information and medical history to the fertility clinic. And their offspring

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can seek them out when they are 18, unless the donor has signed an affidavit of nondisclosure.

Until now, offspring were not entitled to any information about their donor and medical information was rarely updated or shared among donors and recipient families. The law is not perfect, say advocates, but the new law opens the door to national recognition of rights for these children.

Exact numbers are not known, but experts speculate that there are about 1 million donor-conceived children in the United States, according to a 2003 report in the journal Nature.

The fertility industry in the United States is one of the least-regulated among developed nations, according to Wendy Kramer, co-founder of the Donor Sibling Registry, a web-based organization that has helped match more than 8,400 donor offspring with their half siblings and/or donors.

"There are no rules or regulations about donor identification, testing donors, monitoring numbers of children or medical records," said Kramer, who conceived her son through sperm donation. "No one is watching. There are no laws. They don't keep track."

Food and Drug Administration guidelines indicate that donated sperm cannot have any "relevant communicable disease or agent," but there is no limit on how many donations can be made by one person nor is there any sharing of medical information between the donor and the child's family.

The American Society for Reproductive Medicine (ASRM) has 15 pages of guidelines for gamete donation.

"Donors should be healthy and give no history to suggest hereditary diseases," the guidelines say. "Some institutions offer chromosomal analysis on all donors, but it is not required."

Although the FDA only mandates that clinics keep records for 10 years, ASRM recommends that record-keeping be permanent. Those that don't are "removed from our membership," said ASRM spokesman Sean Tipton.

But Tipton said that the state shouldn't "change the rules in the middle of the game."

"We think that it's important that parents be allowed to make decisions on how to build their families," he said. "I don't think there's a way to make human reproduction perfect."

"It's unfortunate that anyone who has ever developed a disease or disorder, but they will and all you can do is use the best and most practical screening available at the time of donation," he said. "You can't screen for everything."

By law, donors need only screened for sexually transmitted diseases and some communicable diseases.

At the very least, advocates say sperm and egg donors should have "vigorous" face-to-face medical screening and genetic testing for diseases like cystic fibrosis, Tay-Sachs disease, Fragile X syndrome, among others.

Donor Child Advocates Say End Anonymity

Unless donors have a relationship with the child's parent, the donor is anonymous and only has a number. Advocates say that practice should end.

To find a donor, offspring like Tyler have to have a birth date and try to figure it out.

Tyler's mother contacted the California sperm bank she had used to get pregnant, learning John's level of education, degree, and work history. She knew he had lived in Delaware when he went to college.

His work history lined up with an internship program and when she reached them, they provided a public brochure with John's picture.

"It was my son's face," said Blackwell. "They are identical."

When Tyler was 2, doctors thought he had neurofibromatosis and the sperm bank had contacted John to see if anyone in the family had ever had the disease.

"He never responded, and they did not follow-up," said Blackwell. As she later learned from his sister, John has Asperger's syndrome, just like Tyler, a disorder that can make it difficult to initiate social contact.

Eventually, Blackwell found John was living in San Francisco and sent a certified letter but never heard back from him.

But in 2010, John's sister found Blackwell on Ancestry.com and asked why the mother and son had been searching for her brother. She never even knew John had donated.

"She told me right away she told me about the possibility of Marfan's syndrome," said Blackwell. "John's brother Joe had been diagnosed, without the aortic defect, and his grandmother and brother Bob also had the heart defect."

When a sperm or egg donor develops a genetic disease after donation, the medical history is almost never reported to donor families, according Kramer, who has helped thousands of families share medical information.

One California donor passed on hypertrophic cardiomyopathy to nine of his 22 known offspring and one died, she said. A 3-year-old developed Rasmussen's encephalitis, resulting in seizures and brain damage.

"[John] should never have been a sperm donor," said Kramer. "How could such a thing happen in this era of medical advances and an explosion of genomic information about the causes and inheritance of disease, especially in the most medical advanced country in the world?"

In May, a Supreme Court in British Columbia struck down provincial legislation that protected the identity of sperm donors. The judge also prohibited the future destruction of any records and ordered the province to draw up new legislation, extending the rights of adopted children to donor-conceived children.

Washington Law is 'First Step'

Washington state lawyer Mark Demaray, who works with many couples seeking assisted reproductive technology (ART) and is president of the American Academy of Adoption Attorneys, said the American fertility industry should also look to the adoption world as a model.

When a child is adopted, all details on the social and medical history of the biological parents must be kept in court records in case of a medical emergency.

"That hasn't been required with ART, where a child may not have the ability to find a donor or medical information," he said. "What about when he needs a bone marrow transplant or a blood transfusion? The donor child is at a disadvantage."

"And when the clinic goes out of business and where are those records?" he asked. "There are many practical problems."

Demaray said the Washington law has problems, including the waiver of disclosure. And the term "identifying information" is also not adequately defined. Social Security and privacy laws may also impede getting donor information.

But, he said, the new law is a "first step" and may lead to a national donor registry to keep track of donors and their offspring.

"Almost everyone agrees that there should be a way to get in touch through the clinic or a confidential intermediary," he said. "Egg donors who are in their mid-20s who donate ovums may have kids of their own some day with half siblings. What if her child needs a bone marrow transplant?"

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As for Tyler Blackwell, finding out his biological father's medical history saved his life. Although he had no symptoms of Marfan's syndrome, his mother took him to Johns Hopkins Medical Center in Baltimore to get a baseline screening of his heart and found he had an aortic aneurysm just waiting to rupture.

"Tyler is fine now," said his mother. "He's got an ugly scar on his chest, but he's a girl magnet."

She has since discovered that one of Tyler's 23 half-siblings -- another donor-conceived child who lives in Seattle -- also has Marfan's syndrome. She wonders how many more are affected.

"Sperm banks need to make an effort to collect updated medical information every couple of years," said Blackwell. "They made no effort until I came up with a problem. And I don't think sperm donors should be anonymous. We didn't get to the truth until his sister called me. It shouldn't be secret."

"There is no one who knew about it," she said. "If I could foretell the future, I would have picked a different donor. I didn't know."

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Learn more about the Donor Sibling Registry

Read gamete donation guidelines from the American Society for Reproductive Medicine (ASRM)

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hueygunner69
10:19 AM EDT
Jul 21, 2011

Father your children the old-fashioned way: ####! Then take responsibility by at least signing on the birth certificate that you're the biological parent. Go to jail when you cannot afford to pay child support because you're un-employed. Try to be a dad even when the mother hates your guts and has you locked up every chance she gets. Earn the title DAD! Be there for your kids if you can. I'm not the perfect father but my daughter calls me "Dad." And I'm there for my handicapped son, trying to help him get on his feet and make it in this tough old world.

meemsosa
10:18 AM EDT
Jul 21, 2011

In response to all the people who commented that "that's what you get when you don't want to have a relationship and get married", I'm guessing you are all the same kind of people who are anti-gay as well. For what it's worth, I'm a lesbian and have been in a long and loving relationship with my partner for ~7 years. When we decided to go with a donor, we had planned it for at least 2 years. Trust me, people who go to donors give this process (and parenting as a whole) a LOT of consideration because we have to PLAN and PAY for it. I think the main point of this article is stating that "sperm banks do genetic testing for a very wide array of pre-disposed genetic defects (and for the amount of money you are paying for the sperm, sometimes tens of thousands of dollars depending on how long it takes you to get pregnant, they SHOULD be testing very thoroughly) *so why didn't they test for this very threatening disease?*"I do think the donor's anonymity should be protected from the recipient, however I think there also needs to be a process whereby the donor keeps in contact with the bank should any life threatening disease *that can be prevented or treated medically* can be reported to the recipient.Regardless of how the child was conceived, your child is still your child and you love them with all your heart. Even those who think "she got what she deserved" would share her feelings as a parent about wanting to do anything possible to help her sick child.

Eleonora27
10:18 AM EDT
Jul 21, 2011

I don't think women who go the artificial insemination route should be condemned. Sometimes a woman really wants to become a mother but there is no potential husband in sight. Is it really so terrible that she should seek out an insemination clinic when there is no possibility of marriage on the horizon and when her biological clock is ticking away? As for medical information, this donor must have known, from his own family experience, that he might have been in danger of passing a defect to a child. He had an obligation to be upfront about this, and the law should insist that known information should be provided at the time of donation. However, many medical problems could crop up in donors later. Right now, with a full genetic analysis at the time of donation, mothers and their children simply cannot be sure of what might show up down the line. Donors can't reasonably be tracked for the rest of their lives, so those who choose insemination simply have to accept that they be playing a form of medical roulette.

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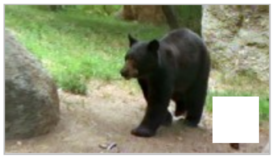

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