

# MailOnline

## Sperm donor's 24 kids never told about his fatal, genetic illness

By [Daily Mail Reporter](#)

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A mother and son were devastated to find out the man who donated sperm for his conception had a genetic illness - and they were never warned.

Rebecca Blackwell and her 18-year-old son Tyler of Maryland tracked down sperm donor 'John' three years ago.

While he didn't respond to their letter for contact, John's sister found them online via Ancestry.com and, unaware her brother had donated sperm, asked why they wanted to get in touch.



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**Rebecca Blackwell and 15-year-old son Tyler were devastated when they found out the sperm donor had a rare, genetic mutation and the family wasn't told**

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When she found out he had a son, she told them of the fatal genetic disorder that had ruptured John's aorta at the age of 43.



**On the mend: Tyler was treated by Dr Hal Dietz for his rare aortic heart defect**

She said John, two brothers and their mother all had an 'unnamed, never before seen genetic mutation' disorder, the 59-year-old special education teacher told MailOnline.

John's father, who didn't die from the aortic dissection suffered a stroke due to a lack of oxygen to the brain, Ms Blackwell said.

John also has a family condition of the connective tissue disorder Marfan's Syndrome.

'Tyler had a time bomb ticking in his chest,' she said.

'It didn't occur to anyone to tell us.'

Though Tyler has since had surgery on the defect in June, questions are raised as to the Blackwells weren't informed.

The fertility industry in the United States is one of the most unregulated in the developed world, said Wendy Kramer of the Donor Sibling Registry, a group that has matched some 8,400 donor offspring with their half siblings and/or donors.



**'Time bomb ticking in his chest': Tyler Blackwell after his surgery in June at Johns Hopkins Hospital**

'There are no rules or regulations about donor identification, testing donors, monitoring numbers of children or medical records,' she said.

Ms Kramer conceived her own son via sperm donation.

## **MARFAN SYNDROME**

According to Gretchen Oswald of the John Hopkins Genetics Institute:

- Affects 1 in 5,000 to 10,000
- Caused by mutations in the Fibrillin1 gene
- Often leads to Aortic root dilation - a life threatening complication. If it is undiagnosed, the aorta can tear
- Therefore individuals are often monitored with blood-pressure lowering medication and lifestyle modification to avoid putting stress on weak aortic tissue
- 60% of patients have eye-lens dislocation which also needs to be monitored
- Skeletal features can often be signals that a person has it. For example: scoliosis, pectus anomalies, if they are unusually tall, with long limbs and long, thin fingers and long flat feet
- In two thirds of cases it runs through families, the other third is spontaneous
- Genetically inherited as a dominant trait: that is, if you have inherited the defective gene from either parent will have Marfan's

'No one is watching. There are no laws. They don't keep track.'  
But laws are changing.

Come Friday, Washington is set to be the first state to give donor-conceived people the right to crucial health information about their biological parents when they turn eighteen.

Previously, they were not entitled to any information and medical records were rarely updated.

Advocates say the new law is imperfect but it's a 'first step' in allowing these children to be nationally recognised.

There are approximately 1 million children in the US born via a sperm donor.

Law at present requires donors only be screened for sexually transmitted diseases and some communicable diseases.

Advocates say there should also be testing for genetic diseases such as cystic fibrosis, Tay-Sachs disease and Fragile X syndrome.

Advocates say the anonymous donors, identifiable only by number, should end.

When a donor develops a genetic disease after donation, families are very rarely told, according Ms Kramer.

In a case in California, a donor passed on hypertrophic cardiomyopathy to nine of his 22 known offspring -one died, she said.

A 3-year-old developed Rasmussen's encephalitis, resulting in seizures and brain damage.



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**Wendy Kramer and her son Ryan formed a Donor Sibling Registry and work to make information more available to donor-conceived children**

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'[John] should never have been a sperm donor,' Ms Kramer told ABC.

'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?'

'When the clinic goes out of business and where are those records?' Washington reproductive lawyer Mark Demaray asked. 'There are many practical problems.'



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**Lobbyists: want donor-conceived children to be able to receive more information on the medical history of their donors**

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It is far better regulated in the case of adopted children - all social and medical records are kept by the courts - but not with sperm donation.

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

The single mother has since found out another of his half-siblings who live's in Seattle has the same disorder .

She worries about how many more of John's children may have the condition.

'Sperm banks need to make an effort to collect updated medical information every couple of years,' said Ms 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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Ok, yes, what happened to this lady is awful, but she should be thankful regardless of what had happened, because she

has a son thanks to "John". There is no place now for "I would have picked a different donor". Tyler is who he is thanks to his biological, sperm donor father.

- Elizabeth, Fas, far away..., 21/7/2011 19:48

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It is wicked that sperm donors are often anonymous. The results of their sperm are people who like everyone else have a right who their biological parents are.

- Sarah, uk, 21/7/2011 19:45

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This is why it continues to be a good idea to know just exactly who the father of your children is.

- Lynn, NJ, 21/7/2011 18:35

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