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'I didn't want children to die': A mother's mission to save sperm donor's 35 kids never told about his fatal, genetic illness

By Daily Mail Reporter

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When Rebecca Blackwell discovered her son Tyler had inherited a life-threatening heart defect via a sperm donor, she not only feared for his life but also the lives of 35 other children the man had fathered.

Ms Blackwell and Tyler,18, of Maryland were never warned about the condition that, if not corrected, could have resulted in a fatal aneurysm.

The single-mother began a medical crusade, calling for tighter regulations of sperm banks to avoid leaving children like Tyler without key-information about their medical histories.

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

Coverage of her efforts alerted Rebeca Price, who's son Stuart is Tyler's half brother, to the fact that her child also suffered from the same defect - essentially saving his life.

'I didn't want children to die' Ms Blackwell told People magazine.

On the mend: Tyler had corrective surgery for his rare aortic heart defect

The 59-year-old took it upon herself to inform the sperm banks where Tyler's father No. 832 had donated about his condition in the hope that they would pass that information on, according to the report.

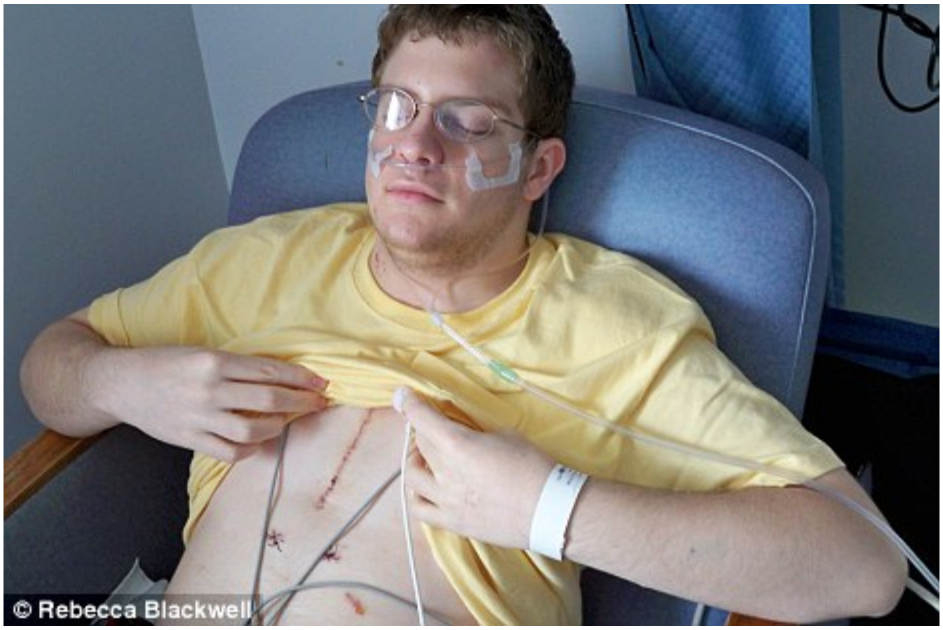
The fertility industry in the United States is one of the most unregulated in the developed world, said Wendy Kramer of the Donor Sibling Registry, a group that has matched some 8,400 donor offspring with their half siblings and/or donors.

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

When a donor develops a genetic disease after donation, families are very rarely told, according Ms Kramer who conceived her own son via sperm donation.

Ms Blackwell was only alerted to Tyler's condition and his 35 siblings when they tracked down sperm-donor 'John' three and a half years ago and spoke to his sister.

They discovered that John, two brothers and their mother all had an 'unnamed, never before seen genetic mutation' disorder.



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

John also had Asperger's syndrome, something Tyler and Stuart also have, which Ms Blackwell believed was passed on.

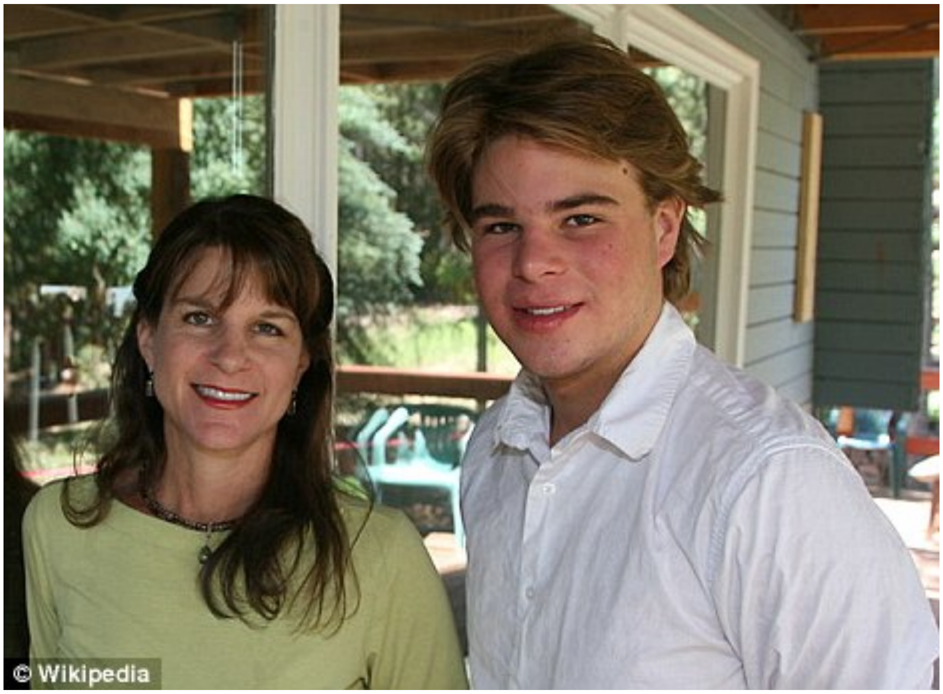
‘Tyler had a time bomb ticking in his chest,’ she said. ‘It didn't occur to anyone to tell us.’

The college freshman had corrective heart surgery on the defect in June but will have to be monitored for the rest of his life.

In February Tyler and Ms Blackwell met with Stuart, the only half-sibling Tyler has met so far, and his parents at his home in Santa Fe.

Ms Price, 53, told People magazine that she was thankful to Ms Blackwell for having alerted her to her 17-year-old's son condition.

'I don't think I will ever be able to to express how grateful I am to Rebecca Blackwell.

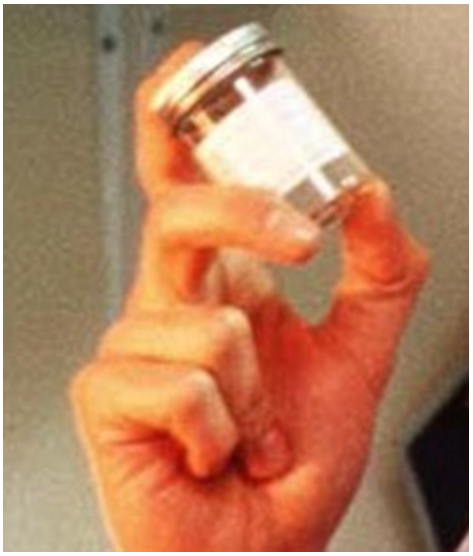


Wendy Kramer and her son Ryan formed a Donor Sibling Registry and work to make information more available to donor-conceived children

'She's a life saver in every sense of the word,'

Both mothers were struck by how similar the half-brothers were. 'They stand alike. They walk alike,' says Ms Blackwell.

Tyler told People that he has no desire to meet his other half-siblings but said he was glad to have found a brother.



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

'We got along well, it was pretty cool. I'm glad my children will have an uncle now.'

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 and that donors should no longer be anonymous.

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

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

‘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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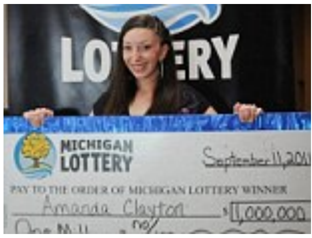
- 

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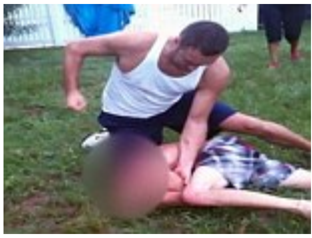
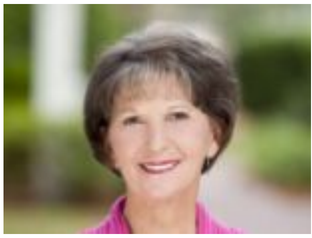
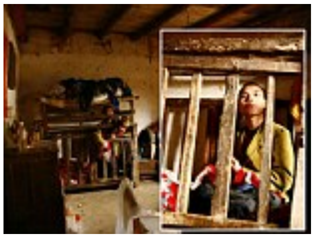
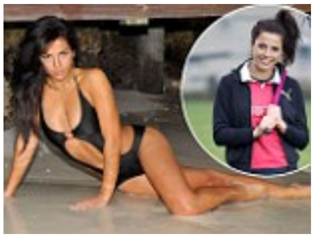
-  Father who beat 16-year-old boy in Youtube brawl faces ten...
-  Headmistress shot dead at private Florida high school by...
-  Heart-breaking plight of the Chinese man who has spent his...
-  'Tomboy' hockey player swaps trainers for stilettos and is...

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