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Questions about whether clinics should guarantee healthy babies emerge after Dane unknowingly spreads gene defect



Sperm banks hope that new scanning methods will help catch more illnesses than current screening procedures (Photo: Colourbox)

At least nine children conceived using sperm from an anonymous donor have been born with the potentially dangerous, inheritable disease Neurofibromatosis type 1 (NF1).

The illness, which is not routinely screened for in sperm donations, causes nerve tissue to grow tumours, potentially leading to nodules beneath the skin,

reduced vision and deformed bones.

The sperm derives from a young man who donated to the Danish sperm bank Nordic Cryobank between 2004 and 2006. The man, whose sperm was used up until 2009 and distributed to women in the US, Sweden and Belgium, did not know he carried the illness.

One of the children, two-and-half-year-old Andrea Søgaaard-Kristensen, must have a heart scan every six months to detect deformities.

Her mother, Lone Søgaaard-Kristensen, Fredericia, and her wife, were informed in a letter from their fertility clinic that their donor carried the disease NF-1.

Speaking to Jyllands-Posten newspaper, she said she was unaware of the risks associated with donated sperm.

"I was deeply, deeply shocked and sad. And I was also angry."

"I was sure it was completely safe," she added.

While it appears that Nordisk Cryobank has not broken any rules, director Peter Bower told Jyllands-Posten newspaper that they were looking into better screening options.

"We need to take a look at where the technology is going, because within the next few years it will be possible to perform a simple test, the so-called Next Generation Screening, that will make it possible to test for 500 illnesses at once, though we should be wary that we can never lower the risk to zero."

But not everyone agrees that increased screening of sperm is a reasonable option.

"Anyone who chooses to have children risks having a handicapped child. It's a part of life and as long as we continue to want to have children, we have to live with the risk that something may go wrong," Lotte Hvas, a member of the Danish Council of Ethics, told Jyllands-Posten.

"It's very fashionable to believe that you protect yourself against everything. But one cannot ask society to guarantee that you will give birth to a healthy child. Life is perilous, even having when having children with your own partner, and not sperm from a sperm bank."

Reports of children being born with genetic disease from donated sperm are not uncommon. In 2006 five children in the US were linked to the same sperm donor after all being born with severe congenital neutropenia.

If left untreated it can be fatal in children, though because it occurs in fewer than one in five million births it is not

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"The bottom line is, when you use a sperm donor you really don't know what you're getting," Dr Lawrence A. Boxer, from the University of Michigan, told MSNBC at the time.

Danish law allows sperm donors to father up to 25 children, more than in any other country. Some are now questioning whether that the number should be reduced in order to limit the spread of undetected illnesses.

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