

NORDISK CRYOBANK

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<http://health.groups.yahoo.com/group/DonorSiblingRegistry/message/15345>

Full article: <http://cphpost.dk/news/national/sperm-donor-passed-disease-nine-children>

A sperm bank is facing criticism for not acting quickly enough after suspicions were first raised that one of their donors had passed on the disease NF-1

A sperm donor passed on an inheritable disease to at least nine of the 43 children conceived using his sperm in 14 different fertility clinics.

And at least two children were conceived using his sperm in the six months between when the sperm bank Nordisk Cryobank, which has offices in Frederiksberg and Aarhus, was first warned and when the sperm was withdrawn. One of those children was born with the disease.

The revelations, made last night on the TV news programme '21 Søndag' on public broadcaster DR, have led to the health authority, Sundhedsstyrelsen, tightening sperm-bank regulation.

The move is little consolation to Lone Søndergaard, mother of one of the affected children, however.

"I thought the system was designed to protect against inheritable illnesses," Søndergaard told DR. "It's just unacceptable that there is no oversight."

The nine children were born with Neurofibromatosis type 1 (NF-1), which creates non-cancerous lumps on the bodies of affected individuals. The severity of the illness can vary widely, but in its most severe form it can lead to learning difficulties, blindness and epilepsy.

According to Anne Marie Vangsted from Sundhedsstyrelsen, some of the illnesses could have been prevented if Nordisk Cryobank had withdrawn the sperm immediately after receiving the first warning.

"We know that children were conceived during that period and that could have been prevented if the sperm bank had acted correctly and stopped using the donor sooner," Vangsted told DR.

In June 2009, Nordisk Cryobank received the first warning that a child conceived using the sperm had been born with NF-1. According to Sundhedsstyrelsen's rules, the sperm bank should have immediately stopped using the sperm and contacted the clinics that had bought it.

But according to Nordisk Cryobank's CEO, Peter Bower, the sperm bank didn't act immediately because they thought the donor was not responsible for passing on the disease.