



Sperm donor with genetic illness speaks out

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The government health agency has been criticised for not looking for children who may have been born with a cancer-causing illness inherited from an anonymous sperm donor

A former sperm donor may have passed on a heritable and treatable cancer-causing illness to half of the children created with his sperm, but they will never know if they are harbouring the illness.

Henrik Koch, 60, came forward to Berlingske newspaper to express his concern that not more was done to look for the children who could be carrying a genetic illness known as Lynch Syndrome.

"For many years I have felt bad that a number of children have probably inherited my illness without knowing it," Koch told Berlingske. "I don't

care that I am drawing attention to myself. If one woman has her child genetically tested and that test prevents a deadly illness, then it's worth putting myself forward."

Koch tested positive for the illness in 1997 and subsequently informed the health authorities with the hope of tracking down the children. Children fathered by Koch's sperm have a 50-50 chance of being carriers of the illness and risk developing an aggressive form of cancer typically between ages 30 and 50.

But even though the mortality rate can be significantly reduced with early treatment and diagnosis, the health authorities decided not to search for the five to ten children who may have inherited the disease.

The major problem is that sperm donors are protected with absolute anonymity, meaning there was nothing connecting Koch with any of the children that he fathered – he's not even sure how many children that may be.

After Koch first voiced his concern in 1997, a panel of doctors examined whether it was worth looking for the families. The panel estimated that Koch likely fathered five to ten children but concluded that, due to the anonymity of sperm donors, around 500 families would have needed to be found through the media if their children were to be offered genetic tests.

Given the potential worry to so many people, the panel, with the approval of the health agency Sundhedsstyrelsen, decided against the search.

"We knew that we could drastically improve the children's chances of survival by finding them. But the search was cancelled, partly because it was difficult and partly because of the principle of anonymity," Finn Cilius Nielsen, the head of genetic medicine at Rigshospitalet and a member of the panel of doctors, told Berlingske.

While Berlingske reports that the members of the panel still stand by their decision, parliament's ethical council, Det Etske Råd, thinks more could have been done.

"The seriousness of the illness, the treatment opportunities and size of the risk means they should have



No one is sure how many children Henrik Koch fathered but the government health agency estimates that between five and ten children could be affected (Photo: Colourbox)

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tracked [the children]," spokesperson Thomas Ploug told Berlingske. "It would have been the most respectful action in order to allow the children, who are now adults, to adjust their lives. In my view, it's a scandal they were never contacted."

Former city medical officer Claus Lundstedt, who was also on the panel of doctors, argued however that the search for the children would have caused more harm than good.

"I completely understand the man's concern," Lundstedt told Berlingske. "But our inability to uncover who his children were without alarming many people is the result of the anonymity principle."

Koch said he recognised the concern, but after reading in an article in Berlingske this January that he could have fathered as many as 100 children, he felt compelled to come forward.

"Of course I can understand the dilemma - how much trouble is it worth creating in order to help someone?" Koch told Berlingske. "But if it were my child or spouse that was suddenly diagnosed with a serious cancer, and I then discovered it was known that a donor had passed on a genetic illness that causes preventable cancers, I would have thought: Why the hell didn't you look for us?"



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