

LOCAL

Colorado Expert Calls For Better Regulation Of Sperm Banks

Parents Sue Cryogenic Center Over Child's Cystic Fibrosis

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What's this?



Sharine Kretchmar holds her son Jaxon (credit: CBS)

NEDERLAND, Colo. (CBS4) – Every expectant parent knows the anxieties that accompany the birth of a baby.

The Kretchmars, a Texas couple, were no different when their son Jaxon arrived two years ago.

Jaxon is battling cystic fibrosis. He was diagnosed just days after he was born. Breathing treatments and up to 20-pills a day are all part of fighting the pulmonary disease,

which will only get worse.

"Nobody wants to think about outliving their child," says Sharine Kretchmar. Sitting next to her husband, Brian, they hold hands and explain, "There is not a day that goes by that we don't think about it."

In 2009, the Kretchmars turned to the New England Cryogenic Center, NECC, near Boston, when they needed help conceiving Jaxon. The sperm bank's website talks about having a "healthy baby." It states: "No specimens are released until it has been tested" for a list of diseases including cystic fibrosis.

The Kretchmars chose donor N170. The questionnaire they received described him as a dad, a criminal justice major, and a Catholic man with clean family health history. The Kretchmars bought three vials of N170. And, on April 17, 2010, Jaxon was born.



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But days later, doctors diagnosed Jaxon with cystic fibrosis. "His stomach hurt so bad, he would be in so much pain," said Brian thinking back to the surgery and days that followed right after his birth.

The Kretchmars doctor wrote a letter to NECC calling this an "unexpected outcome." The doctor cited NECC's website and paperwork which "shows that cystic fibrosis carrier screening is performed."

The Kretchmars had one of the remaining vials of N170 that they had purchased tested. Lab results given to CBS 11 show the man who donated the N170 vials of sperm did carry the cystic fibrosis gene. In order for a child to develop cystic fibrosis, the gene must be carried by both parents. The Kretchmars say there was no way for Jaxon to have the disease without receiving a gene from Sharine and the donor, N170.

"My first thought was I don't know how anyone could have sold something that wasn't tested for that." Brian says he is still in disbelief.

NECC updated its website. It now states: "Cystic fibrosis (please note that not all donors have been tested for the same number of CF mutations. Please call and speak with an NECC customer representative to find out the specific number of mutations tested on your donor of choice)."

The Kretchmars hired Dallas Attorney Dean Gresham, who has filed suit against NECC. Gresham learned the sperm the Kretchmars bought was not donated to NECC. Donor N170 had donated to a bank in Wyoming called Rocky Mountain Cryogenics in 1993.

"NECC purchased all 10,000 vials of Rocky Mountain inventory and brought it to Boston and put in their inventory making it the largest sperm pool in the United States at the time," says Gresham. But, "there was a problem with a lot of it."

CBS4 sister station CBS 11 learned that some regulators were aware of problems with N170 and other donors long before little Jaxon was conceived.

WATCH: CBS 11's report on the Kretchmars

Gresham showed CBS 11 documents from the New York State Department of Health where it cited a "number of deficiencies" at NECC particularly with the sperm from the Wyoming bank. In April of

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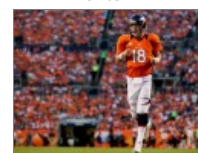
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2008, the New York Department of Health inspected NECC and cited that some “donors are not appropriately screened and tested.” And, some vials of semen are “not tested” for infectious diseases including syphilis and gonorrhea. The sample vials it referenced were from the Rocky Mountain Cryogenic inventory purchased by NECC.

In response to its findings, the New York Department of Health sent NECC a letter stating that it could not “distribute” sperm received from Rocky Mountain Cryogenic to the state of New York. Gresham showed CBS 11 documents he said he obtained which show NECC, internally, marked all donor sperm acquired from Rocky Mountain Cryogenic: “DO NOT SHIP TO NY.”

Sharine Kretchar now asks, “Why was it okay for my baby to get this disease but it’s not okay for a baby in another state to get it?”

As of this month, the state of New York still has a ban on shipments into New York on Rocky Mountain sperm bought by NECC. CBS 11 also learned that New York never reported its findings to the Food and Drug Administration. The FDA is the regulatory agency for reproductive tissue banking; however, CBS 11 also learned that the FDA has only inspected NECC once in the last five years.

“Nobody is watching over the industry,” says Wendy Kramer of Nederland.

Kramer runs the Donor Sibling Registry. The website connects families with genetic ties.

“We know a lot of cases where sperm banks are selling sperm that has not been properly tested.”

Kramer says the Kretchmars are not alone because sperm banks have been allowed to self-regulate for too long. “This is a highly unregulated industry. There is no oversight. Nobody is watching and it is motivated by profit.”

“I don’t ever want another mother to sit in my shoes and go through what I’ve been through if it could have been prevented and this could have been prevented.”

Infectious disease testing is mandated by the FDA. Industry standards require genetic testing and most banks claim to test for genetic disorders but it is not a legal requirement.

The FDA inspects reproductive tissue banks but there is no set law requiring when and how often those inspections must be performed.

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CBS 11 repeatedly asked the FDA for answers about the Kretchmar case and the NECC/Rocky Mountain Cryogenic inventory, but a spokesperson only cited rules under which the FDA regulates reproductive tissue. The agency has refused to specifically answer all questions.

Jacalyn Fallman, a spokesperson with NECC provided a statement to CBS 11:

“The New England Cryogenic Center is proud of its 30 year history of innovation and excellence in cryogenic preservation. In this capacity, we have helped thousands of families fulfill their dream of parenthood.

When screening donors, NECC does not conduct its own genetic tests, but engages outside laboratories to conduct such testing. The sperm that was purchased from Rocky Mountain Cryobank is no longer sold by NECC and is now being used for research purposes. Our thoughts are with the Kretchmar family. We are encouraged by advances in the treatment of cystic fibrosis and are hopeful that the Kretchmars will benefit from modern treatments. While we sincerely appreciate the opportunity to comment for this story, we feel that it would be inappropriate to say anything further while the litigation is ongoing. Further, maintaining the privacy of its clients and donors is a priority for NECC.”

LINK: Donor Sibling Registry



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