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## Parents Sue Cryogenic Center Over Child's Cystic Fibrosis

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**NORTH TEXAS (CBSDFW.COM)** – The Kretchmar home is filled with the hum of a breathing machine and the sounds of Mario racing around a television screen watched by 22-month old Jaxon.

"MMMMaaarrrioooo..." he mutters under the clear mask which covers most of his tiny face. He's yelling, but it's hard to understand, because his voice is so muffled and his body is shaking. The shaking is a good thing. The special vest he is wearing, while he getting his breathing treatment, helps shake the congestion loose inside his little body.

Jaxon is battling cystic fibrosis. He was diagnosed just days after he was born. The new vest, breathing treatments, up to 20-pills a day. It's all part of fighting the pulmonary disease. The disease will only get

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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.

"We really liked what it said, " Sharine Kretchmar thought back.

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.

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."

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

Gresham showed us documents from the [New York State Department of Health](#) where it cited a "number of deficiencies" at NECC

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particularly with the sperm from the Wyoming bank. In April of 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.

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In response to its findings, the New York Department

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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 has 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 has also learned that the FDA has only inspected NECC once in the last five years.

"Nobody is watching over the industry," says Wendy Kramer. [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. CBS 11 repeatedly asked the FDA for answers about the Kretchmar

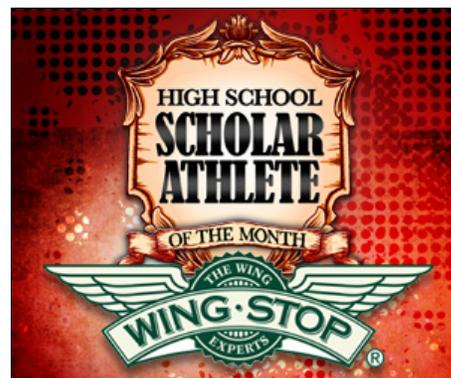
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case and the NECC/Rocky Mountain Cryogenic inventory, but a spokesperson only cited rules under which the FDA regulates reproductive tissue. The agency has refused to specifically answer all questions.

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."

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politicaljules · 9 months ago

I am horrified by these comments of judgement. I am a conservative prolife supporter, and I support this couple. I also have a child with cystic fibrosis. I am not sure I agree with the judgement that is being thrown at this couple. My child has cf, and I would never ever trade her for anything. she is the light of my life. I am one of the biggest prolife supporters you can get. This couple is not saying they would throw away their child either.

If you can be as prolife, and still have a family if you are a cf carrier, that is ideal. Cf is not like down's syndrome or cerebral palsy. Just for information sake, not to say this should be a reason to kill, it is not! I am grateful to science that may extend my daughter's life. I do not advocate babies being killed in the womb for a diagnosis of any kind. But bear with me until the end. It has been compared to breathing through a straw for most of your life. If you could make a prolife decision about starting a family with a sperm donor, it would be a good thing. I do not know if that is why this couple chose this route, but they still have every right to sue.

Many couples who find out they are carriers choose to use a sperm donor that is not a carrier rather than fertilize eggs & sperm from the two carriers to figure out which ones will have cf and which ones wont. Then fetuses are destroyed.

When you are both carriers you have a 1 in 4 chance of producing a child with cf. Perhaps this couple did not want to go the route of destroying life, and decided to go with a sperm donor.

I think this is a touchy subject that yall should tread lightly and not vilify this couple. If you have seen this disease you would understand why a couple would try to do the right thing that is still the prolife thing to have a child. I am in Texas too, and if I could reach out to this family I would. Please do not politicize this families pain.

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Heidi → politicaljules · 9 months ago

Thank you! In their case after having one child, they found that He was no longer fertile. It was a medical issue so they went this route. They wanted to give their child a sibling and lead normal, happy lives. I know they are prolife and would never have given this child up for anything. However, they did choose a donor based on many factors, including medical history. To be outright lied to by the bank is just horrifying. As far as those saying they were creating a designer baby, this is absolutely not true. They chose a profile that closely match the husband and son, but there was no deep digging into the donor past. All they needed was a brief description and medical information. If that is "designing" what they think is the perfect baby than the majority of humans are guilty of this just by choosing a life partner that they feel is a compatible match. I chose my husband because he was good looking and healthy. Now I have healthy, adorable children. I didn't "design" them.

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Tom · 10 months ago

This is another example of why sperm donation should be banned.

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Heidi · 10 months ago

Sharine, I love you and my heart and prayers are with you! Hug the boys tight for me.

0 ^ [ v · Reply · Share &gt;



NiteNurse · 10 months ago

I'm a believer that if you can't conceive naturally that you should adopt. With a world full of unwanted and needy children why try and manufacture a made to order one.

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Heidi → NiteNurse · 10 months ago

Sounds like you are projecting your own agenda.

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NiteNurse → Heidi · 10 months ago

No, I just feel sometimes when we try to do something that nature or god has decided shouldn't be possible we end up with problems.

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Heidi → NiteNurse · 10 months ago

So you feel we should stop trying to find a cure for all diseases then.

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Linda of TXX · 10 months ago

I am very sorry that they had a sick baby. My nephew and his wife had a baby of their own with left heart syndrome. It is a strain on a family to have a sick baby. However, it bothers me to hear the media and others challenging why the government or this or that other group isn't doing more to protect people. The couple had no problem having a specimen checked themselves after the fact, so for something this important, why didn't they take care themselves instead of blaming everybody else for their misfortune. Not only that, both parents have to be carriers, which means the mother is also a carrier of the gene, and if they had a child naturally they could have potentially had the same issue. Did they do tests on themselves before trying to procreate to see if maybe they shouldn't even have children because they might bring a child into the world that might have some genetic defect? See how ridiculous this all sounds. We don't want big brother watching over everything we do, but as soon as something goes wrong, we point the finger and holler foul.

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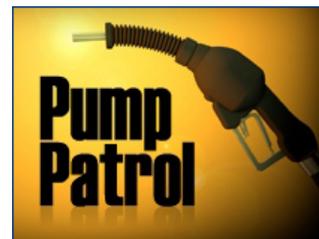


Heidi → Linda of TXX · 10 months ago

Wow, so heartless. They trusted that everything they were told is legitimate. This process is expensive enough. Why should they have the specimen tested when in a contract it state that it was already tested? I know this family and know of the entire process they went through. They have a perfectly healthy child that they were able to conceive before their problems started. There was no reason to test further on their part. These parents are the best people I know and the best parents. This was done to them, not them doing it to themselves. How dare you pass judgement when you don't know them or understand the years of struggle to even have a child only to reach out to the medical community that they trusted. If someone gave you a blood transfusion with HIV tainted blood you wouldn't have it tested first, you would trust that the blood bank already tested it. Similar situation.

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