

The children of Donor H898

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The Washington post, September 14

BARTLETT, III. —



Danielle Rizzo poses for a portrait with her boys, 6 and 7 years old, outside of their group therapy appointment. (Taylor Glascock/For The Washington Post)

Danielle Rizzo's son is screaming. He is planted in the middle of the lobby of his elementary school, clinging to rainbow-colored blocks as she gently explains that she is here — off schedule, in the middle of the day — to take him to a doctor's appointment. But the first-grader is not listening.

“Happy Meal,” he repeats over and over again. “Happy Meal!”

His little brother, who is also going to the appointment, is nearby, not moving. Rizzo is relieved that the two of them are not melting down at the same time, which happens all too often, and firmly guides them out the door.

Rizzo's children, ages 7 and 6, were at the center of one of the most ethically complex legal cases in the modern-day fertility industry. Three years ago, while researching treatment options for her sons, Rizzo says she made an extraordinary discovery: The boys are part of an autism cluster involving at least a dozen children scattered across the United States, Canada and Europe, all conceived with sperm from the same donor. Many of the children have secondary diagnoses of ADHD,

dyslexia, mood disorders, epilepsy and other developmental and learning disabilities.

The phenomenon is believed to be unprecedented and has attracted the attention of some of the world's foremost experts in the genetics of autism, who have been gathering blood and spit samples from the families.

Autism, which affects an estimated 1 of 59 children in the United States, is a "spectrum disorder" characterized by difficulties navigating social situations and restricted or repetitive behavior. Some people who have it never speak and need daily care, while others, like actress Daryl Hannah and Pokémon creator Satoshi Tajiri, are highly successful in their fields. In recent years a growing movement has been challenging the notion that autism is a disorder at all. Rather, advocates argue, it's a difference that should be celebrated as adding diversity to human communities.

Rizzo hopes her children will cope better as they grow older, but for now, she knows they are suffering.

When she first found out about their many half-siblings, she consulted a genetic counselor, who she says told her the odds of so many blood-related children with autism occurring spontaneously was akin to all the mothers "opening up a dictionary and pointing to the same letter of the same word on the same page at the same time."

"It was the donor," Rizzo remembered thinking. "It had to be."

A quick online search for the donor's profile showed that sperm from a man matching his description was still being sold by at least four companies. She called them all, asking for information about his medical history — and to inform them of the autism cluster — but she says the representatives she reached told her she didn't have any "evidence" that his sperm was responsible for the autism cases.

She turned to health-care regulators in New York and California, where the sperm banks were based. The response, Rizzo said, was that cases like hers are not part of their responsibility. (A spokeswoman for New York State said her department had no record of Rizzo's complaint but urged her "to reach out." A California spokesperson said the state would consider investigating her case as an "adverse event" related to a sperm bank.)

The Food and Drug Administration told her its oversight of the sperm-donor industry is limited to screening for sexually transmitted diseases.

So, after a year of fruitless phone calls and letters, she sued.



Rizzo watches her sons look for their lost frog in their backyard. (Taylor Glascock/For The Washington Post)

Motherhood

Rizzo turned to a sperm bank when she was 27 years old and a business banker at a JPMorgan Chase branch. She and her partner, who asked that her name not be used to protect her privacy, had been together for eight years. They met while Rizzo was attending community college on a softball scholarship. Rizzo was the team's pitcher; her partner was an assistant coach. In June 2011, when Illinois began issuing civil union licenses to same-sex couples, they were the first in line at the Kane County courthouse.

Rizzo says they were eager to start their family and decided that Rizzo, younger by two years, would carry the baby. For months, the couple scoured online profiles to find just the right sperm donor.

Donor H898 from Idant Laboratories looked like a winner.

He was blond and blue-eyed, 6-foot-1, 240 pounds, and appeared to be smart and accomplished. His profile said he had a master's degree and was working as a medical photographer. His hobbies included long-distance running, reading and art.

And most important, Rizzo says, he had a clean bill of health, according to his profile — having scribbled “NA” and a strikethrough line on all but one of the more than 100

medical questions, including mental health ones, posed by sperm banks. (His paternal grandfather had had prostate cancer at age 85.)

Over the next few months, Rizzo purchased several vials of sperm. The bill came to about \$500.

Rizzo's first son, conceived via in vitro fertilization, was born in September 2011, and the first year of his life was bliss. He hit all his milestones on time — sitting up, rolling over, crawling and waving, saying “hi” and “bye.” Rizzo was “mama,” and her partner “mommy.”

“He was the happiest baby,” she recalled. “We knew we wanted one more kid.”

Doctors transferred another embryo, and their second boy was born about 14 months after the first.

It was around that time that Rizzo says they started noticing unusual behaviors in their first son. He had stopped looking his mothers in the eye. He no longer responded to his name. He wouldn't interact with other children, and when he played with toys he would line things up or turn cars upside down and just spin the wheels, over and over again. She was devastated when her second child, at around age 2, began to exhibit the same behaviors.

Rizzo sought help from the state's early-intervention services and a developmental pediatrician, and both boys were diagnosed with autism. She soon found herself thrown into the frenzied world of special-needs parenting.

She and her partner took turns running the boys to therapies. But the more months that passed, the more help the boys seemed to need. Instead of one day off, she started taking two, then three.

“The screaming, the hitting, the yelling, the pinching, the punching, the pulling my hair when I'm driving,” she said, describing her days. After three nannies quit, Rizzo left her job, and her relationship collapsed.

Rizzo received primary custody, and with two preschoolers with severe needs, she says she was financially strapped. Her ex had been fulfilling her obligation to pay child support, but Rizzo says it wasn't enough to cover the mortgage. The house went into foreclosure. Rizzo went on Medicaid, and in July 2018 she and the two boys moved into her parents' basement.



Rizzo's sons walk in their backyard. (Taylor Glascock/For The Washington Post)
The lawsuit

Sperm donors tend to be taller, better looking and better educated than the general population. But they have the same chance of carrying a gene for an inherited condition as anyone else.

And because of their unusual role in modern reproduction, the effect of those mutations can be amplified. Popular donors can father 10, 20, 100 or even more progeny — each potentially carrying the same genetic risk factors.

Rizzo has never had contact with the donor, who is now in his early 40s and from the New York area. But two other mothers who have met him said in interviews that he is clean-cut and polite. One described him as “hot.” Another said her first impression of the donor, who showed up wearing khakis and a nice shirt, was that he is “brave” and “generous.” The parents had happily connected on Facebook and Yahoo groups for “donor siblings” — and then were shocked to discover that many of their children seemed to have the same types of developmental challenges and diagnoses.

Donor H898's sperm was offered through multiple sources. According to the mothers, court documents and genetic testing through 23andMe and Ancestry.com, he sold anonymously to at least four sperm banks (which typically pay about \$100 per visit), donated to a high-end agency that matches parents with donors they can

meet face-to-face, and offered his sperm for a low fee or even free on sites such as KnownDonorRegistry.com or privately.

His profile stood out in many ways, women who used his sperm said, citing the thoughtful answers in his essays and audio interview. “I dislike dishonest and wasteful people,” he wrote in one statement. “I have my own garden and go to the Met when I can.”

Rizzo filed a lawsuit in U.S. District Court for the Northern District of Illinois in July 2017. In her complaint, she alleged that his online profile was a lie and that he was not an “appropriate candidate for sperm donation.” She sued Idant and Daxor, Idant’s former parent company, under the state’s consumer fraud and deceptive practices act.

She says in the complaint that research, based on public documents and calls to his relatives, showed that the donor had no college degrees, had been diagnosed with ADHD, and “went to a school for children with learning and emotional disabilities.” (Idant, and other sperm banks, generally do not verify their donors’ medical and educational backgrounds.) Moreover, her attorneys wrote in the filing, “Donor H898 is a prolific sperm donor who has fathered at least 12 children through sperm donation, and that each of those children has either been diagnosed with Autism, or suffers from signs and symptoms associated with Autism.” In court documents, other mothers corroborated the story.

Guidelines from the Society for Assisted Reproductive Technology, which represents fertility clinics in the United States, call for mandatory genetic testing for only one disease: cystic fibrosis. But most clinics say they test for several hundred. There is no test for autism.

Idant was one of the nation’s oldest sperm banks until it shut down around 2015 . In 2009, it was sued by a woman whose child had Fragile X Syndrome, a developmental disorder that is among the conditions typically detected in genetic tests. The suit was dismissed because the plaintiffs could not define a “legally-cognizable injury.” In 2004, state inspectors found that Idant had ignored the requirement that sperm donors be tested for genetic and sexually transmitted diseases. It was temporarily closed by New York state regulators in 1995 for failing to pass along information about “high-risk social and sexual behavior. And in the 1990s, Idant settled a lawsuit from a white mother who said it gave her the wrong sperm, from a black donor.

Officials from Daxor, Idant’s former parent company, said in a statement that Rizzo’s lawsuit was “meritless.” In court filings, Idant attorneys called the accusations by Rizzo “inflammatory, specious and dangerous,” and said her claims did not establish that the company “knew any of the alleged representations to be false.”

Citing privacy concerns, the sperm banks declined to contact the donor regarding a request for an interview, and he did not respond to messages left on an online profile.

Rochester Cryobank, which also sold sperm from the same donor, has gone out of business. Manhattan Cryobank, now part of California Cryobank, said that the donor had over a dozen successful births with zero reports of any children affected by autism. It confirmed that it had refunded the payment made by a woman who had purchased the donor's sperm but had not yet used it; she heard about Rizzo's lawsuit and asked for her money back. But the company said the donor's sperm was not removed from its inventory because it did not have enough information to further investigate the autism link.

As of August, Repro Lab was still selling vials, priced at \$450-\$525, from the donor. A Repro Lab official said they received a report from an anonymous caller regarding an increased risk of autism, but the report was "unsubstantiated," as the donor "did not report any history of autism in his family."

"We would deny participation to a donor in our program if he or any first-degree relative had a history of autism," the company said.



Danielle Rizzo holds hands with her younger son. Rizzo's boys are part of an autism cluster involving at least a dozen children conceived with sperm from the same donor. (Taylor Glascock/For The Washington Post)

The scientist

Desperate for help, Rizzo Googled "world renowned geneticist" and "autism" and came up with the University of Toronto's Stephen Scherer's name on several research papers and a YouTube video.

“I have two boys ages 3 & 4 that have been diagnosed and live with autism,” she emailed. “I have connected with other moms from the same sperm donor. We have found that 7 or 8 children have been diagnosed with autism. . . . This was a shock and devastation to say the least.”

Scherer was so intrigued that he replied at 4:36 a.m. He had never heard of such a large cluster in one generation of a biological family. “It was the perfect kind of genetic experiment,” he said in a recent interview.

For more than 20 years, Scherer’s lab, based at the Hospital for Sick Children in Toronto, has been collecting, cataloguing and trying to find patterns in the DNA of families affected by autism. It has more than 20,000 samples. A similar project, called SPARK and funded by the Simons Foundation in New York, has amassed 85,000.

Scientists know of more than 100 genes that appear to be associated with autism. Some are inherited, while others occur as new mutations. (Other factors have been linked to autism, including an older father or complications during pregnancy. A proposed link to vaccines was based on fraudulent research and has been disproved.)

Most mutations associated with autism do not definitively cause the condition; they only increase someone’s risk. But, Scherer says, an intriguing subset of “high impact” genes — estimated to be involved in 5 to 20 percent of all autism cases — appears to directly result in autism.

“We call autism one thing, but it’s different in every person. In some it’s all about the genes. Some it’s a combination of genes and the environment. Some people, it’s unknown,” said Wendy Chung, a professor of pediatric medicine at Columbia University and principal investigator of SPARK.

When researchers tested Rizzo’s older son’s blood, Rizzo says they found two gene mutations linked to autism — MBD1 and SHANK1. Her younger son has the MBD1 variant. Rizzo said all seven of the half-siblings whose parents had them tested have at least one of these mutations.

Neither was inherited from Rizzo, according to the tests, she said. While the research is still preliminary and the donor could have numerous other biological children who are not on the autism spectrum, Scherer says, “our hypothesis is that it’s something in his DNA.”



Rizzo's sons cover their ears as a loud vehicle drives by. Noise sensitivity is a common challenge for people with autism spectrum disorders. (Taylor Glascock/For The Washington Post)

The children

Doctors diagnose autism based on behaviors — rigidity, repetitive habits, difficulty with seeing things from someone else's perspective.

Rizzo's sons can speak, and the older is starting to read and write. Doctors have told her they are somewhere in the middle of the autism spectrum.

Both are still in diapers, throw their hands over their ears when there is a loud sound, and have not made friends at school. The elder's huge blue eyes light up when he's spinning and flapping his arms. The younger gets very upset if someone stands close to him, and has trouble engaging in conversations about anything other than Super Mario Bros. The boys, who attend an intensive autism therapy program at school, have daily meltdowns.

As for the other children Rizzo discovered, one half brother around their age who lives on the East Coast is mainstreamed in school and a gentle and happy child, his mother said in an interview. But he is several years behind in school. Another half brother is very high functioning, his mother says, but is in full-time special education because of difficulties with speech and dyslexia.

Rizzo loves her children, and said she believes God gave them to her for a reason. She finds a lot of joy in simple moments such as taking them to water parks, sharing slushies and piling into one bed reading “Captain Underpants” and “Dog Man.” But she wishes things could be easier for them, and she worries for their future.

“If I knew then what I know now, I don’t know if I would have ever used a sperm bank,” she said.

On March 14, she agreed to end the lawsuit by accepting an offer of \$250,000 from the company.

After the lawyers took their share, her ex — who takes care of the children one day a week and every other weekend — was awarded half of the rest. Rizzo said she desperately needed the money to pay for behavioral and social-skills therapies not covered by public assistance, to create a trust for the boys’ long-term care, and so that the family could get their own apartment.

She hopes her case will push government regulators to impose greater oversight of the sperm bank industry. “I did not sue because my children are autistic. I was suing to right a wrong.”

In late June, Rizzo heard of another mom with a boy — 1 ½ years old — who had used the same sperm donor. After agonizing, Rizzo contacted the woman and told her she had some “heavy information” about the donor and his offspring. The woman declined to hear it.



Rizzo's sons were part of a legal case that has been settled. (Taylor Glascock/For The Washington Post)

Alice Crites contributed to this report.

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