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Donor 1047 leaves legacy – and mystery

Families connect to learn about siblings, father

JILL CALLISON  
[jcalliso@argusleader.com](mailto:jcalliso@argusleader.com)

BLOOMINGTON, Minn. - Their dad has straight brown hair, brown eyes and dimples in his cheeks.

A baseball fan who is loath to exercise, he has never lost at a game of Trivial Pursuit, describes himself as a "walking dictionary" and is adept in the kitchen. He likes to listen to talk radio and jazz music.

And his children - Zach and Zoë Forsberg of Luverne, Minn., Teddy Persson of Shetek, Wis., and Kelsey Spalding of Chaska, Minn., as well as at least 15 other youngsters - wouldn't recognize him if they met him on the street.

That's because the children were conceived through donor insemination. The sperm bank the families used, Cryogenic Laboratories Inc., in Roseville, Minn., lists the man only as Donor 1047.

In recent years, some of Donor 1047's children and their families have started to connect. But as they learn more about each other, they also have learned unsettling things about their common parent.

Zach has Asperger's disorder, and Zoë has autism. Their mother wonders about their donor father's health history, how many children he might have fathered in the area and how much care the sperm bank she used took in screening donors. But they, like others among the approximately 1 million families using donor insemination, have discovered it is tough to find answers.

Talking with others is a starting point. Keith and Sherry Forsberg and their two children, Kristie Spalding and her daughter, Kelsey, and Teddy Persson and his parents, Beth Ager and Mike Persson, have communicated by e-mail, phone and in person.

"A whole raft of topics has stemmed from our group: disclosure of origins, genetic diseases, the obligations of a sperm bank to notify families of potential problems, plus all the social and emotional issues one would expect from the use of donor gametes," Ager wrote about the experience.

Zach, Zoë and Teddy first met in 2004, and last month Kelsey and her mother traveled to a hotel in Bloomington to meet her three half-siblings.

"Not only did our kids find siblings who they can keep in touch with throughout their lives, but us parents have gained friendships with the parents of these other kids," Sherry Forsberg said. "We all have something in common, and it is great to compare notes on what is happening in the kids' lives."

## California bank accepts 2% to 3% of applicants

No sperm bank operates in South Dakota. But Dr. Keith Hansen, reproductive endocrinologist with Sioux Valley Clinic-ObGyn, Ltd. in Sioux Falls, said donor insemination is used frequently by his patients with male factor infertility caused by things such as radiation or chemotherapy to treat testicular cancer and genetic problems.

"It's a very good way of having children," Hansen said. "There are quite a few couples who go through donor sperm to have children."

Dr. John Brannian of Sioux Valley Clinic OBGyn estimated that of the 200 couples using intrauterine insemination last year, one-third relied on donor sperm.

Most people turn to the Internet to find a sperm bank. Hansen's staff doesn't recommend a particular bank, but they urge patients to make sure to use a reputable bank.

The founder of a California sperm bank, Dr. Cappy Rothman, said the industry is well-regulated, by individual states where firms are located and by federal agencies such as the Food and Drug Administration. In addition, The American Association of Tissue Banks (AATB) and the American Society of Reproductive Medicine have guidelines. The AATB accredits sperm banks. The Roseville firm is among the 11 on its list.

Of every 100 applicants to be sperm donors, California Cryobank Inc., Rothman's firm, accepts only two or three, and that is after months of testing. Screening is extensive, both for genetic problems and infectious diseases.

"By the time these guys are donating, and the sperm is released, we know these guys," Rothman said. "They've been here six times a week for six months. We have a good feeling about them, as much as you would about anybody."

But problems can surface.

In May, a sperm bank in Birmingham, Mich., revealed five children born of the same donor had a rare and potentially deadly genetic disorder.

Most banks generally screen only for more common illnesses such as cystic fibrosis - not for obscure diseases.

One of Donor 1047's children was born with a cleft palate, a genetic anomaly. Two others had congenital heart problems. After learning that, Forsberg scheduled an echocardiogram for Zach and received a sobering report.

"There's something they have to watch, and I have to take him back in November," she said.

Ager and Persson have been advised by CLI's parent company to have Teddy undergo an echocardiogram. They will discuss the sperm bank's recommendation with his pediatrician this fall. After learning two of his half-siblings have autism spectrum disorders, they are monitoring his behavior as well.

"We kind of wonder why the sperm bank didn't contact us, but I've come to find out that cleft palate and congenital heart problems are two of the most common problems, and, well, they could have come from anywhere," Ager said.

"There is a hereditary element, but it could have just as easily been from the mother. In a way, I don't see it as a really urgent necessity for them to contact us, but it would have been nice. I'm not too upset about it."

The women say they were told Donor 1047's sperm is no longer being used at CLI. The company did not respond to multiple calls seeking an interview.

In his profile, viewed by potential buyers, Donor 1047 indicated the medical conditions in his family are high blood pressure, stroke, heart attack, diabetes and allergies.

## **Registry a response to search barriers**

The Donor 1047 families are curious how many half-siblings their children have and where they live.

The Donor Sibling Registry, a Web site founded by Wendy Kramer of Nederland, Colo., to help donor-conceived children find biological half-siblings and the donors themselves, now has six children - four boys and two girls - listed under Donor 1047. Ager has been in touch with a Texas mother whose Donor 1047 child is two years older than Teddy.

When Kramer's only child, Ryan, was 8 or 9, she found out accidentally, through the California sperm bank she had used, that he had "quite a few" brothers and sisters. He wanted to find them to learn more about himself, Kramer said.

"But the sperm bank was no help, and the doctor was no help, and with no agency to help, I realized there was nowhere to go for people who have mutual consent," she said.

That's when she founded the registry, which now has more than 6,600 members and has matched more than 2,500 people.

The most recent registry listed under Donor 1047 came just days ago when the mother of a 9-year-old boy in Washington state contacted the registry, seeking sibling and health information. The mother of a seventh child - a girl - withdrew her name after her husband objected, Forsberg said.

Forsberg suspects, based on geographic restrictions listed in a 2002 profile of Donor 1047, that his offspring were born in the Twin Cities, Milwaukee, Green Bay, Duluth, Fargo, Grand Forks, Ames, Iowa, and other cities in Minnesota, Wisconsin and Michigan. But the Washington state boy, conceived in Arizona, isn't included on the list of geographical restrictions for Donor 1047.

Kramer has been told by the sperm bank she used that only 40 percent of women report their live births.

While donor insemination has been around for decades, Rothman said its use has increased in recent years. That means more donor-conceived adolescents and young adults will seek answers.

If, that is, they know how they were conceived. Kramer estimates that only 10 to 20 percent of all D.I. children know the truth.

Most parents don't tell their children the facts behind their conception, Kramer said.

"It comes down to some kind of fear or some kind of shame," she said. "Either shame about the father's infertility or fear that it will somehow break up the family."

## **Donor's traits prompt questions for families**

Ager and her husband used donor insemination because Persson had had a vasectomy years before. In the six years before Teddy was born, Ager went through multiple miscarriages before doctors found she had a divided uterus. Surgery corrected the problem, and Teddy was conceived.

Spalding turned to donor insemination because her then-husband had fertility problems. Forsberg had been diagnosed with a condition that affected her menstrual cycle and fertility, and her husband, Keith, had a low sperm count. But the Forsbergs had another issue to confront. Keith has schizophrenia, which has a genetic component.

"When the doctor mentioned we could do artificial insemination by donor, we both said, 'OK, fine,' " Forsberg said.

Forsberg allowed staff at the clinic to pick out the donor, and 1047 was chosen through Cryogenic Laboratories of Roseville, now owned by the Genetics & IVF Institute in Fairfax, Va.

The single sheet of paper that Forsberg has from that time describes only the basics about Donor

1047: eye and hair color, 5-foot-10, 150 pounds, German/Norwegian ancestry, and a bachelor's degree in chemistry. Handwritten notes on the side written by an unknown clinic employee don't even list 1047 as one of the first three choices but do note "6 months free storage" of the sperm vials with long-term storage for \$120 a year. A later donor profile carried more detailed information, such as 1047's prowess at Trivial Pursuit.

Two months after beginning the procedure, Forsberg was pregnant. And nine months after Zach's birth Aug. 3, 1991, she ordered the same sperm for a second pregnancy. Zoë was born April 14, 1993.

But while the Forsbergs chose donor insemination in part to spare their children the possible struggles with mental illness that Keith faces, both Zach and Zoë have disorders that fall into the autism spectrum.

Autism is a disorder that affects ability to form normal social relationships and communicate. People with Asperger's have deficiencies in social skills, often have obsessive routines and might be preoccupied with certain interests.

According to the Autism Society of America, it is unknown whether autism is a hereditary disease or an acquired illness. It affects 1 in 175 children ages 4-17. Some of Donor 1047's more extensive profile - being a "walking dictionary" and excelling at Trivial Pursuit - could indicate some Asperger's traits, Forsberg says.

"He graduated in the top 2 percent of his class, and I don't know if he's in the autism spectrum or he's just smart," Forsberg said.

"(But) I wouldn't change my kids for anything in the world. And I always look at it this way: It could be worse."

## **Brothers, sisters meet, instant bonds forged**

Zach, Zoë and Teddy first met at the Mall of America in 2004. They had a second meeting last year in Rochester, Minn. In November, the Forsbergs traveled to Wisconsin to celebrate Teddy's third birthday. The meeting in Bloomington, where Zach, Zoë and Teddy met Kelsey, was the fourth gathering.

Spalding, Kelsey's mom, called the weekend a great success.

"I think it was Sherry that said it was kind of like finding pieces to a puzzle and putting them together," she said. "I think (that) weekend, we added a few of those missing pieces."

For Zach and Teddy, who has named a teddy bear after Kelsey, it also was a time to let a remarkable bond strengthen. From their first meeting, despite an 11-year age difference, the two boys displayed a connection. Ager noted that a 20-month-old wouldn't understand the concept of a brother. Zach even wrote about it in a school assignment.

"At the news I would be departing, Teddy began to cry, this being the first occasion he had ever done anything like that because someone was saying goodbye to him. ... After quelling his tears by assuring him that he'd see me again some day, we left. As our vehicle rolled us along the roads, the snow chasing us but never catching up, I took the time to marvel at the occurrence, and that his care for me extended to such a level.

"I'm still marveling today."

Reach Jill Callison at 331-2307.

Published: September 10, 2006 2:55AM

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