WILLIAM HEISEL'S ANTIDOTE: INVESTIGATING UNTOLD HEALTH STORIES

Code Unknown: Trying to connect with sperm donor through online community

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PART SIX (Read parts one, two, three, four and five.)

Frustrated and frightened by her experience trying to find sperm donor who allowed her to conceive, Gloria Fraser was looking – as so many of us do – for answers online.

She had read so much that was scary about the condition her daughter, Miranda, had developed: long QT syndrome. It can lead to sudden arrhythmia death syndrome (SADS). A website she found had stories of families who had lost a parent, parent had lost a child, men and women who had suddenly lost a spouse. One day the person was perfectly healthy and the next day the person was dead. Gloria wanted to find the donor so she could warn him and the other children conceived through his donations that they may have a fatal flaw in their genes.

Then Gloria found the Donor Sibling Registry (DSR). The site was created by Wendy Kramer, a mom who had conceived with the help of an anonymous sperm donor, just like Miranda’s mom. Kramer wanted to create a supportive place for parents, children, and the donors themselves to share enough information about each other to make connections. In 2009, Kramer described for me how she started the DSR:

Because my son was curious about his donor, we put up one little posting in September 2000 on a Yahoo! group. By October 2003, we were so busy on the Yahoo! group that it was impossible to facilitate the matches so we created our own site. Now not a day goes by that somebody doesn't find a match with somebody else. As of today we have helped connect 6,173 people all over the world. Half brothers and sisters and donors to kids. We have 23,134 people who have registered with our site.

Gloria was excited by the possibilities of making the same kind of connection. To her, the DSR reminded her of the Delete Blood Cancer DKMS organization, which encourages bone marrow donation. Her oldest daughter had provided volunteer legal work for the group. Maybe Gloria’s sperm donor would be one of the 1,000 donors who have signed on to the registry? Maybe one of her half-siblings would be registered on the site as well?

“The DSR reminded me of that program, and the work done by the DKMS, because of their professionalism, empathy, realistic goals to save lives, people friendly attitude, and not being cost driven,” Gloria told me. “I was definitely intrigued by the success stories.”
The site’s success stories included this one:

When I got to the DSR, I was the first person to create a listing under my mom’s doctor’s name, from New York City. About eight months later, a woman emailed me to say that her mother had used the same doctor as mine, just two years later. We figured we could band together to find out as much as we could about how the doctor (now long deceased) had gone about finding donors. After a few months of research, we were able to piece together that the pool of donors he used was actually small. It honestly hadn’t occurred to us before that we could be siblings, but once we learned about the small donor pool, we figured why not give it a shot. So we found the most reliable and thorough testing facility, and did a half-sibling DNA test. Lo and behold, it came back with 99.7% certainty that we were sisters! So for all the older donor offspring out there who have only fragments of the story their conception, don’t give up hope.

So Gloria registered on the site and posted her profile and her experience conceiving through the help of the University of Florida and giving birth at Shands Hospital in Gainesville. And she regularly combed the site for that someone might be connected to her. Did someone else mention the same doctor her mother used? Was someone else born at the same hospital around the same time? Did another Florida child have long QT syndrome?

Gloria had a few moments of hope when people started to contact her, but when she wrote them back, nothing materialized. She felt like things weren’t moving quite fast enough. The variation of the syndrome that Miranda and her kids have – known as LQT-3 – can kill at any moment, usually when someone is asleep. Gloria thought she needed to find the donor before it was too late. As she explained to me:

When I first found out that Lauren and Miranda had long QT, I was just beside myself. There are people out there who need a chance, just like my kids need a chance and just like my grandkids need a chance. That’s why I’m looking for them.

The way anonymous sperm donation works, only the donor knows where he donated, and the donor potentially holds the key to warning all kinds of families that their children might have a fatal genetic disorder. There are barriers, of course, because donors don't have access to the records of the patients who ultimately received donations. But only the donor can say with any certainty whether they donated once in one place or 20 times in 20 different places. The chances of one of those children or the donor turning up in the Donor Sibling Registry are higher every day as more people join the site. (It is nearing 45,000 registrants this week.) But Miranda decided she needed to supercharge her search.

Gloria contacted Kramer and talked with her about options. Kramer told her about genetic testing, and that opened a new world of possibilities.

Next: How a mother rolled the genetic dice on multiple tables.

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