WILLIAM HEISEL'S ANTIDOTE: INVESTIGATING UNTOLD HEALTH STORIES

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

By William Heisel

December 19, 2014

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 looking – as so many of us do – for answers online.

She had read so much that was scary about the conditior daughter, Miranda, had developed: long QT syndrome. It to sudden arrhythmia death syndrome (SADS). A website found had stories of families who had lost a parent, paren 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 f donor so she could warn him and the other children conceived through his donations that they may have a fa in their genes.

Then Gloria found the Donor Sibling Registry (DSR). The site was created by Wendy Kramer, a mom who ha 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 o 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 f 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 ou site.

Gloria was excited by the possibilities of making the same kind of connection. To her, the DSR reminded her Delete Blood Cancer DKMS organization, which encourages bone marrow donation. Her oldest daughter ha provided volunteer legal work for the group. Maybe Gloria's sperm donor would be one of the 1,000 donors w 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 w 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, fr New York City. About eight months later, a woman emailed me to say that her mother had used th 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 fe 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 abou the small donor pool, we figured why not give it a shot. So we found the most reliable and thoroug testing facility, and did a half-sibling DNA test. Lo and behold, it came back with 99.7% certainty th we were sisters! So for all the older donor offspring out there who have only fragments of the stor 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 fo that someone might be connected to her. Did someone else mention the same doctor her mother used? Wa someone else born at the same hospital around the same time? Did another Florida child have long QT sync

Gloria had a few moments of hope when people started to contact her, but when she wrote them back, nothi materialized. She felt like things weren't moving quite fast enough. The variation of the syndrome that Miran her kids have – known as LQT-3 – can kill at any moment, usually when someone is asleep. Gloria thought s 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 potenti 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 different places. The chances of one of those children or the donor turning up in the Donor Sibling Registry a higher every day as more people join the site. (It is nearing 45,000 registrants this week.) But Miranda decid needed to supercharge her search.

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

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

Photo by Jean-Pierre Dalbéra via Flickr.

long QT, electrophysiology, sudden arrhythmia death syndrome, rare genetic disorders, sperm donors, Miranda Dyer, Delete B Cancer DKMS, Donor Sibling Registry, Wendy Kramer, SADS (Show more tags)