

WILLIAM HEISEL'S ANTIDOTE: INVESTIGATING UNTOLD HEALTH STORIES

New Family Trees: Five Ways to Reform Fertility Medicine

Fertility medicine, genes, genetic mutations, sperm donors, egg donors, Donor Sibling Registry, Finding Our Families: A First-of-Its-Kind Book for Donor-Conceived People and Their Families, Tay-Sachs (Show more tags)

By **William Heisel**

September 16, 2013



I like to call it **Fertopolis**. If all the people born in the United States as the result of egg and sperm donation lived in one city, there would be more than 1 million strong. More people than all eight of the largest cities in the country, bigger than Seattle 17 times the size of my hometown of Great Falls, Montana.

And if they all lived in the same city, they probably would have a lot more clout. As it stands, they can't find out much of anything about at least one of their biological parents. Their family of illnesses and genetic disorders remains off limits. And the number of people who share a parent with them – even on

the same city block – remains a mystery.

Wendy Kramer, the founder of the **Donor Sibling Registry**, and **Naomi Cahn**, a George Washington University professor, want to change the rules that govern Fertopolis and give its citizens the same rights as all citizens. Their proposals will not be easily embraced. They are outlined in their new book: **Finding Our Families: A First-of-Its-Kind Book for Donor-Conceived People and Their Families**.

I have summarized the five I find the most intriguing below to start a conversation about the fertility industry and the families that have formed as a result.

Require mandatory third party counseling for all prospective donors and parents. This is a low-cost requirement that could pay significant dividends, albeit in a few cases. It may, for example, have helped in the case of **Krystie Karl-Steiger**, who was born with Tay-Sachs, a rare genetic disorder more common among people of Jewish, French Canadian, and Cajun descent. Had both the egg donor and the father of Krystie – sperm from whom was used to fertilize the egg – been adequately counseled, they may have pushed for more genetic testing and the mutation would have been found.

Mandate comprehensive medical and genetic testing for donors. This would be a more expensive requirement and would add a layer of red tape to what already can be a cumbersome process, but, again, as in the case of **Karl-Steiger**, it could prove worth it. When Kramer asked sperm donors if they would have consented to genetic testing, she found that 93% said “they would have been open to genetic testing if it had been offered to them.” The authors also quote **Kirk Maxey**, a physician and former sperm donor, who says that sperm and egg donors should be required to undergo full genomic sequencing and report every genetic variant known in the Johns Hopkins **Mendelian Inheritance in Man** database, which includes about 12,000 genetic traits. Would this grind all dona-

a halt? Maybe. Would some people see the possible genetic risks, match them against their own genetic risk take a gamble? Probably.

Require donors a.) to provide a full medical history at the time of donation and b.) to update their full medical history regularly. Kramer's survey of donors found that "98 percent of surveyed egg donors and 84 percent of surveyed sperm donors report never having been contacted by their clinics to update health information after donation."

Track all recipients, donors, and births and safeguard all records in a central data bank indefinitely, with information accessible only to involved families. The industry promised to do this nearly five years ago. In January 2008, I wrote a story quoting representatives from the Society for Assisted Reproductive Technology, a leading fertility industry organization, saying they would work to create a [system for recording the histories](#) of and surrogate mothers. "If you have a case of a donor who is a carrier for Tay-Sachs, there is no mechanism right now to let other parents and agencies know. We need to change that," said Dr. David Grainger, a Wichita specialist and a member of the reproductive technology society's executive council. I intend to follow up with Grainger and others to see what's been done since then.

Limit the number of births from the sperm or eggs of any given donor. Can't you see this one playing out like an episode of *The Good Wife*? A strident donor goes into court to fight for her right to generate as many offspring as the ovaries will allow? And she's represented in court by Michelle Duggar (star of [19 Kids and Counting](#)). Kramer and Cahn note that the U.S. fertility industry recommends that the number of offspring per donor be kept to 25 pregnancies from one donor within a given population of 800,000. There are two problems with that, they write. One is that in New York City, for example, "this would allow for almost 300 donor-conceived children to be born from the same donor, which is approximately one child per square mile." The other problem is that the limits are just suggestions. "Mandated limits would ensure that one donor does not spread diseases to dozens of offspring and would also protect children from the psychological consequences of learning that they are 150th in a 'herd' of children."

Have your own ideas for fixing the fertility industry? Send me a note at askantidote@gmail.com or write me on Twitter [@wheisel](#).

Image by Paul Inkles the UMF via [Flickr](#)