



When Anonymous Egg Donors Have Genetic Diseases

Jessica Wing Died of Cancer; Her Mom Wants to Warn the Family Who Conceived With Potentially 'Sick Eggs'

By **BARBARA PINTO**

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By all accounts, graduate student Jessica Grace Wing was the ideal egg donor. At 5 feet 11 inches, she was tall, slender and attractive. She modeled in her teenage years and would go on to graduate from Stanford University. This made her an ideal donor, "the kind of donor that would attract a great deal of money," her mother, Dr. Jennifer Schneider, said.

But seven years after she was paid to donate her eggs, Jessica was diagnosed with colon cancer, at the age of 29. She died two years later. Hers was a rare diagnosis for someone so young and something Jessica's biological children will never know, despite Jessica's mother's attempts to contact the broker who sold her daughter's eggs.

But when Schneider asked the egg donation broker to reveal the identities of the families who had received the eggs, the broker said she had destroyed her records. Jessica donated her eggs three times.

"At the time she died, I tried to get hold of the [in vitro fertilization] clinics. The egg broker and I couldn't get hold of anybody," Schneider said. "Nobody was interested in talking to me, and I understand why.

"The conflict of interest is the financial interest versus the welfare of the donor and of the children who are born," she said. "I think it's very hard for people to regulate themselves when there are billions and billions of dollars involved."

Colon cancer can be inherited. Because Wing was diagnosed at the age of 29, her biological children, Schneider said, should start getting colonoscopies at the age of 19. Schneider points out that very few families would think to have their children receive colonoscopies in their teens or 20s.

In addition to the families, Schneider also worries about the welfare of other women who are egg donors. She is concerned that the fertility drugs used to help her daughter produce eggs may have contributed to her cancer, and she wants studies done on other women who have also donated eggs and may have ended up with an early cancer diagnosis.

"My daughter Jessica was an egg donor when she was in college, and a few years later, she was dead of colon cancer," Schneider said. "It got me on this path of trying to find out if there's a connection between egg donation and colon cancer."

But while donors are screened carefully, there is little to follow up with later on. No one is keeping track

of these egg donations and no one is monitoring all of the donors' health histories.

Wing's case sheds light on the delicate questions surrounding sperm and egg donation. How much information should donors be required to reveal? Where does the donor's right to privacy end and the child's right to know begin?

"The forgotten people in this whole big business [are] the egg donor and the children," Schneider said.

Part of the problem, however, is that many people donate on the condition of anonymity.

Dr. David Adamson, president of the American Society of Reproductive Medicine, said, "One thing we know is that if we make it too intrusive people will not have access to these services because donors will not come forward."

William Jaeger, vice president of Fairfax Cryobank in Virginia, said his company offers an identification consent donor program that allows a child born of donor sperm to contact the donor once he or she reaches the age of 18. But the number of people using that option is still only about 20 percent, he said.

"This said to me that there isn't an overarching need for this service," he said. "There is a group who wants to know their donors but they're not disproportionately purchasing the ID consent program."

Wendy Kramer has done what the industry has yet to do, setting up a voluntary registry that has already connected thousands of sperm and egg donors and their children -- some who share valuable information.

It began with her son asking questions about his biological father that Kramer couldn't answer.

"I feel that my right to know who my donor is and my genetic origin is just as strong, if not stronger, than my donor's right to remain anonymous," her son Ryan Kramer said.

Nicole and Chris Witt initially didn't want to know much about the egg donor who allowed them to have Brianna, 5, and her brother Eric, 3.

After struggling with infertility for years, they were elated to finally start a family.

"The whole thing was anonymous, and that was how we wanted it at the time," Nicole said. "We didn't even want to see a picture."

Now, the Witts can see how the 15 pages of health information provided by their anonymous donor may not tell them everything they want to know.

But at this point, they believe their donor has done more than enough. "We love them to pieces," Chris said, referring to his children. "I can't imagine life without them."

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