

DNA And The Exploding Myth Of Donor Anonymity

By Wendy Kramer

There's a strange but poignant story first reported in *New Scientist* (2005) that may be a significant bell weather of change to come. A 15-year-old donor conceived boy, eager to find out about his countries of origin and a little about his ancestry, swabbed his cheek and gathered some cells. He sent the specimen to a DNA data bank and within weeks found two matches – men who were strangers to each other but who bore the same last name. Turned out the three were related to a relative from over 400 years ago. Now armed with a possible surname, the home-base city of the sperm bank, and the birth date on the donor registration, the resourceful teen compiled a rough working profile. Within 10 days on the Internet, he found his genetic father. Will every kid who swabs his cheek find his donor? Probably not. But we can expect this to happen with greater frequency as the DNA data banks swell with increasing numbers of individual genetic samples. As a recent *NY Times* article by Amy Harmon notes, people "(p)rompted by the advent of inexpensive genetic testing" are now "tracing their family trees with a vengeance heretofore unknown." It is the hunger for the connection to and an understanding of this invisible part of themselves and others who share their DNA that propels donor offspring to search.

It's a fact of life I see daily on the Donor Sibling Registry, an online resource for individuals and families to make mutual consent contact between donor siblings as well as between willing donors and their genetic offspring. Easy DNA matching opens the door to increasingly successful amateur investigations. The consequences are disclosures that were never intended by the donors or, in many instances, those who parent the offspring. The dilemma faced by the self-styled DNA detectives is the one the 15-year-old confronted: whether or not to contact the donor and give him the opportunity to know him. Or not. This boy did wonder why it was always assumed that the rights of a donor to remain anonymous trumped a child's right to know his genetic heritage. After all, this child has not entered into or signed any anonymity agreements with anyone.

As DNA matching moves from CSI episodes into the kitchen, it forces a new look at the long-standing discussion of disclosure that rages among bioethicists, sperm banks, psychologists, the medical community, the donor conceived and their families.

Anonymity is rapidly becoming a chimera, a contract between adults that isn't binding on a child with burning curiosity and Internet access. Science has propelled the conversation about a child's right to know from the ethical and moral spheres into a more pragmatic domain. This is something kids can do and likely will do with or without the consent of any adult authority. This is why I can only say now, louder than ever, and as the mother of the donor conceived son who inspired the creation of the Donor Sibling Registry, it's of the utmost importance for a child to be told the truth about the methodology of their conception. Not just because morally and ethically I feel it's the only right thing to do. But also because parents may have no control over a child's pursuit of his or her history. DNA testing is just another impetus to open up early. The issues that we in the donor conception community are facing are becoming increasingly urgent. Given that an enormous percentage of these kids will be coming of age within the next 5-10 years, now is the time to address this issue.

This is a radically different landscape than the one my (then) husband and I traveled 17 years ago. When we were never counseled that even though we regarded the donation as a single cell, the child would rightfully regard it as one half his genetic identity.

This is why we were so excited when Dr. Susan Golombok at Cambridge University approached us at the Donor Sibling Registry to conduct the very first research on donor families that are searching and actually finding each other. With a carefully constructed online survey (www.donorsiblingregistry.com) for donors, parents and the donor conceived, we are hoping to assemble "data" on the importance of searching for and actually making these genetic connections by the end of this year. We look for this research to be a groundbreaking and pioneering investigation of what it means for people born of donor conception to search for (and to find) family members with whom they have had no previous contact.

We are hoping to better understand these relationships once the connections are made. With this information maybe we can move forward with a better understanding of the needs of the donor conceived. The industry has addressed and catered to its own needs, as well as those of the people who want to become parents and the donors. It is time for us in the US to ask the obvious question," What is in the best interests of the child being born?"

Wendy Kramer, along with her son Ryan, founded the Donor Sibling Registry, the only worldwide organization facilitating mutual consent contact between thousands of donor conceived and their half siblings and/or donors.