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Opinion

The Need for Comprehensive Genetic Testing of Gamete Donors

Wendy Kramer*

Department of Research, Co-founder and director, Donor Sibling Registry, USA

***Corresponding Author:** Wendy Kramer, Department of Research, Co-founder and director, Donor Sibling Registry, USA.

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The Donor Sibling Registry (DSR) is a non-profit worldwide organization dedicated to educating, connecting and supporting those affected by gamete donation, including donors, recipients and offspring. At 48,200 members, including parents, donors and offspring, the DSR has connected 12,800 genetic first-degree relatives. Hundreds of donors enjoy contact with offspring and thousands of half-siblings have been able to connect with each other, some establishing close familial relationships.

In addition to connecting donor offspring with their first-degree genetic relatives, the DSR also shines light on serious genetic concerns about gamete donation. Frequently, the DSR counsels recipients whose children have inherited undisclosed genetic disorders, or who've discovered their donor was dishonest when self reporting their health history, or that the sperm bank didn't notify them about a reported illness or amended the medical profile. The number and severity of these health matters is discomfiting, as donors can father many offspring. There are many half sibling groups on the DSR numbering over 50, 75 and even more than 100. One DSR donor currently has more than 200 known offspring. Donors can therefore transmit disease to scores of children.

Currently, many sperm banks either refuse to update donor/offspring medical information, or even if they accept updates refuse to share the information, or make the process of reporting so complex or expensive that donors and recipients simply cannot comply or afford it. Recipients clearly need to be warned about hereditary disorders to prevent unnecessarily sick children being born.

Most sperm banks utilize basic screening of donors, obtaining a personal and family medical history in order to identify any recurring issues that may be genetic in origin. Some conduct basic testing, involving laboratory analysis, usually of a blood sample, to detect specific mutations (alterations) of specific genes. Some sperm banks test some donors for carrier status of the most common genetic conditions, such as cystic fibrosis (CF) and spinal muscular atrophy (SMA). Even so, reports of donor conceived children with Cystic Fibrosis have been made public.

Full sequencing of a gene, reading a gene from beginning to end and comparing the code to a database of known normal and abnormal mutations, takes longer, is more extensive, and is much more expensive. But a negative result would then reduce the likelihood of carrier status much more than targeted mutation analysis.

Some sperm banks test some donors for some diseases, and this isn't good enough. The large US and Danish sperm banks claim to ship sperm to clinics in more than 40 and 50 countries worldwide, so this has become an international problem. To protect donors, recipients, and offspring, the DSR is calling for the implementation of oversight and regulation by an independent authority, mandating compulsory whole genome sequencing (now less than $1,000 USD) by all sperm banks, especially those who ship sperm to countries around the world.

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