

**The Donor Sibling Registry (DSR) - A Global Registry for Donor Families**

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**Donor Sibling Registry**

In the late 19th century, donor conception was born into secrecy and shame. It is only now, more than a century later, that 3rd party reproduction has begun to shake off this sigma as policy changes around the world have begun to reflect new and more open attitudes. Even though, today’s US reproductive medicine industry is under no obligation to keep track of, report, or place limits on the number of births; track the health of donors; make information available to the children born from donor insemination; or facilitate mutual consent contact amongst families who have used the same donors and who then share a genetic connection.  Many sperm banks and clinics offer only “anonymous” donations and still advise parents to “never tell”. This poses many ethical, medical and psychological questions that are too often dismissed by many in the industry.

US sperm banks are run with very little oversight or regulation, and because they ship sperm to more than fifty countries around the world, *this is of global concern.* There are minimal US federal requirements for medical testing of donors. There is no regulation regarding record keeping or tracking the number of births per donor. There are only “recommended” guidelines put forth by professional organizations like the American Society of Reproductive Medicine (ASRM), but compliance is voluntary, so there is no active enforcement. The US Food & Drug Administration’s oversight has been directed at the prevention of infectious diseases including STD’s, with little attention paid to the potential transmission of genetic diseases.

The DSR is a non-profit, worldwide organization dedicated to educating, connecting and supporting donors, parents and offspring. Since 2000, the DSR has helped to connect more than 14,000 of their 54,000 members with half siblings and/or biological parents. The ability to help so many re-define “family” through reaching out to genetic relatives previously unknown has made available an incredible opportunity to learn about what these connections can mean, why they are desired, and what types of challenges can result from being born out of a highly unregulated industry.

Because there are no accurate records kept on the number of donor-conceived people born, no one knows how many offspring have been born around the world. As these children grow up, many ask the same questions: What is my genetic and ancestral background?  Do I have half brothers or sisters?  Where did my ancestors come from?  What attributes, talents, interests or parts of my character do I get from this unknown side of my family? What is my family’s medical background?  Does my missing family have a history of cancer or heart disease or Alzheimer’s?  Many former donors are also very curious about any offspring they might have, have medical information to share, and a desire to connect.

We believe that health and well being of the children being born is given top priority. Three key issues that deserve immediate attention are as follows: anonymity, medical and genetic issues, and tracking/limiting the number of births for any one given donor.

**Anonymity**

Is it fair to bring a child into the world who will have no access to knowing about one half of their genetics, medical history and ancestry?A growing number of countries have recognized that anonymity violates the human rights of the offspring, impairs the offspring’s ability to protect their health and the health of their children, hinders the process of identity formation and can cause grief and pain to offspring. We want to see counseling for donors and recipients done prior to donation or insemination by trained, experienced mental health professionals who operate independently of clinics, to ensure that they are not in a conflict of interest. All parties should be fully educated on the differences between “anonymous” vs. open, or willing-to-be known donors, including being fully aware of the potential curiosities of the children to be born.

**DNA= Donors Not Anonymous.** There should be no false promise of anonymity granted to a sperm donor, since it can no longer be guaranteed in this era when genetically identifying information is publicly available on a cheap and widespread basis.

Since 2005, DSR members have been known to identify their own or their children's donors by simply genetically testing themselves, or their children and matching with genetic family on publicly accessible DNA databases. As many thousands of people are now volunteering their genetic information for publicly accessible genealogy projects more and more sperm donors are becoming identifiable via this method. Sperm donors who have never submitted their own DNA are now frequently found. Additionally, Google and social media websites are allowing donors to be found by simple searches using some of the non-identifying information listed on a donor’s profile.

Consequently, if donors believe that they are anonymous, they are very likely to be shocked, surprised and possibly angry, when they find out that their assurance of anonymity was a false and misleading guarantee. It is simply not within the capacity of the sperm banks or courts to grant it to them.

The DSR strongly believes that anonymity can be harmful, posing a substantial risk to the physical and mental health and welfare of donor offspring.

An essential part of a person’s identity is their genetic inheritance. Most offspring born from sperm donation have a very strong need to know where they come from- their genetic, medical, and ancestral histories. Many also want to know the identity of their biological fathers. Not being able to know a genetic parent can impair a person’s ability to protect their own health and that of their children in an age when the impact of genetics is increasingly important. Not having access to their genetic, biological and ancestral background can hinder their process of identity formation.

Many countries have come to the conclusion that anonymity violates basic human rights, and have abolished donor anonymity: The UK, The Netherlands, Sweden, Germany, Norway, Finland, Switzerland, Austria, New Zealand, and in Australia the states of Victoria, New South Wales and Western Australia.

Perceived anonymity can also encourage deception by donors. Many DSR members connecting with or identifying anonymous donors are reporting factual inconsistencies with the information they received on the donor’s profile. Common inconsistencies are frequently found in regards to academics and medical issues. Donors seeking to be accepted into donor programs say whatever they feel is necessary to ensure that they are considered desirable candidates. Many have embellished or lied about their academic and medical backgrounds thinking that they will almost certainly never be caught out or have to face any accountability for their lies.

**Importance of connecting with genetic relatives**

In 2010, the DSR published the largest study to date of donor-conceived children in the journal Human Reproduction. 1 Its findings have illuminated a need to address the impacts of unregulated, anonymous donating on the children of donors and their social families.

82% of the 751 surveyed donor-conceived people indicated a desire to connect with their donors and more so with half siblings. Reasons were as innocent as wanting to see what the person looked like, and as important as obtaining relevant familial medical histories. Although the DSR has created an invaluable secondary avenue for connecting with siblings and donors, it is simply not enough. Sperm banks and clinics need to be adequately educating and counseling potential parents so that they can make informed decisions that can affect their child for many decades to come.

The secrecy surrounding donor conception impacts the physical and psychological health of the donor conceived. Heterosexual couples who use anonymous donors and are far more likely to wait until the child is older (if at all) to tell them about their conception. Many still estimate that 90% of heterosexual couples never tell their children the truth about their conception. When this information is withheld until later in life, responses can be emotionally charged. Offspring report feeling “angry, hurt, betrayed, frustrated, abandoned, and guilty.”

Reaching out to, and making connections with new family members can be a meaningful experience.

*“I am happy to report that I have found six siblings as a result of my posting in less than one week. We have exchanged pictures and information and plan to stay connected.”* – From a Donor Conceived Person

Many donors also share this curiosity and are very open to connecting with their genetic offspring.

*“I recently found the wonderful woman who chose me from a list 16 years ago. I was lucky beyond words to meet her and become acquainted with my daughter and their family and friends. It is pretty funny to find out some of our personal quirks and watch our families mix for the first time”* - From a Sperm Donor

*"During that soul searching before registering on the DSR, I came to some realizations about the donor system in general… I came to feel uncomfortable about the anonymity of it. It didn't seem fair to keep that information arbitrarily secret from a child who had no ability to consent… in addition to my initial longing to be found, I actually had a responsibility to be available to be found by those who might really feel a sense of loss at not knowing the other half of the story of their origins*.”- From a Sperm Donor

**Counseling**

All prospective parents must receive counseling and education on the importance of early disclosure and on the potential curiosities of the child they are about to create. Sometimes infertility can bring with it a social stigma and, in many cases, shame. Non-biological mothers (eggs) and fathers (sperm) often fear that their children will feel differently about them once they learn that there is no genetic connection between them. These parents need to sufficiently process through any grief of not being able to have a genetic connection with their child. Many parents do not adequately process through this sadness before their child is born, and then have difficulty not passing this along, in some way, to their children. When this grief is not verbalized, validated, and fully processed by both parents, every member of the family can suffer.

In lesbian families where donor sperm was used to conceive, the non-biological mother may also feel insecure about her lack of genetic connection to her child. While the facts surrounding the child’s conception are more likely to be shared in that family arrangement, the non-biological mother may feel resistant to searching for a donor who might threaten her role in the two-parent structure, or for half siblings who offer a genetic connection with her child that she doesn’t have.

Disclosure is a very important part of any pre-conception counseling, as research has shown that the earlier a child knows about the methodology of their conception, the better off they will be. After telling, some parents may feel the need to minimize the genetic connection between their child and the donor. If a child grows up in a family where half of their genetic, ancestral and medical backgrounds are minimized or negated, they can feel a lot of guilt if and when they do become curious. Parents need to be very careful not to put their own fears or bias onto children and allow them to process and define these connections for themselves as they mature. Parents use donor conception because having a genetic connection with their child is important to them, so acknowledging the importance of their child’s genetic connection to their “donor family” is then also important.

Facilities must also counsel and educate prospective donors. The counseling must cover the legal, ethical and mental health implications of donating. Donors must understand their legal and moral responsibilities to be honest as a donor. They need to understand that donating is a lot more than a one time financial transaction with a facility, as with DNA testing and social media, there is a good chance that they will be found someday. Donors must understand that their actions today may have an incalculable effect on their future, and the future of their parents, spouses and children.

**Medical and Genetic Issues**

Quite often the DSR counsels recipients who have found out that their child has an inherited undisclosed disease, or that their recently traced donor did not disclose a hereditary disorder, or that the sperm bank did not disclose to them that offspring from the donor they used had reported a hereditary disorder.

Because US donors can father many offspring, a great number of people can be at risk from a single person’s genetic makeup. Information about a physiological or physiological predisposition can be a significant element in health care and particularly in preventative healthcare for donor offspring. In our published study on 751 donor offspring, 74% of the surveyed offspring who wish to make contact with their donors list learning more about their medical background as a main reason for the desired contact.

To complicate issues, research tell us that 27% of surveyed sperm donors donate to more than one facility.2 So the possibility of passing along disease to many children becomes more likely as the tracking of a donor’s medical history becomes much more difficult.

For an organization like the DSR who counsels many casualties of these sperm bank irregularities, there is immense frustration that even despite the enormously high price tag of donor gametes, clinics and banks are still attempting to cut costs and boost profits by omitting adequate medical and genetic testing screening.  In the US, FDA oversight has only been directed at the prevention of infectious diseases (STD’s) with little attention paid to the potential transmission of genetic diseases.

Current US screening requirements incude HIV, HTLV, Hepatitis B & C, Syphilis, Gonorrhea, Chlamydia and CMV. Some clinics and sperm banks test some donors for some of the following: Cystic Fibrosis, Sickle-Cell Disease, Tay Sachs, Canavan Disease, Gaucher’s Disease, Nieman Picks Disease and B-Thalassemia. There have been several cases of B-Thalassemia, Tay Sachs and Cystic Fibrosis reported to the DSR, so testing is not as thorough as it should be. The current screening model needs to be overhauled to include full genomic sequencing.

The DSR lists hundreds of medical issues reported by its members. In 2009 it was reported in BioNews.org3 that a severely handicapped and profoundly retarded baby girl was born who had inherited an unbalanced translocation from a New England Cryogenic Center sperm donor. In 2016 Canadian and US families sued Xytex Cryobank because they found out that the donor had lied about many things, including his medical history and had been diagnosed with Schizophrenia. 8

Here are a few samples from other families who have updated and shared medical information with on the DSR:

*“Our daughter is 6 years old and has been diagnosed with a hereditary bone disease called MHE. There is no history in our family…”* - Parent of Donor Conceived Child

*“My father and grandmother both died of multiple myeloma, a nasty cancer. Many members of my family suffer from depression. Allergies are an issue, as is arthritis.”* – Former Sperm Donor

*“This donor carried the Tay-Sachs gene. I know that one of the siblings died at 4 months of age. Children of this donor should have genetic counseling prior to conceiving to make sure* *they are not carries of this gene.” -* Parent of Donor Conceived Child

In 1995 a California Cryobank donor transmitted Autosomal Dominant Polycystic Kidney Disease (ADPKD) to a donor-conceived girl. According to the complaint in the Johnson vs. California Cryobank lawsuit, California Cryobank deleted this medical information fro the donor’s profile. As many as 1,600 sperm specimens were sold from this particular donor. Many offspring may still develop this adult onset disease, as well as pass the gene along to their own children. 5

Our research has shown that:

84% of sperm donors have never been contacted by their clinic(s) for medical updates. 6

96% of egg donors have never been contacted by their clinic(s) for medical updates. 7

23% of sperm donors felt that they had medical/genetic issues that would be important to share with families. 6

31% of egg donors felt they had medical/genetic issues that would be important to share with families. 7

94% of surveyed sperm donors would have accepted an offer for genetic testing, had it had been offered by their sperm banks. 6

Transparency is necessary when creating a life; it is much more complicated than donating blood. For a couple searching though donor catalogs, they will never know that their “perfect” donor might have already helped to create 35 children, with 12 of them already diagnosed with a genetic disorder.

Banks and clinics may not want to perform full genetic testing because by doing so they would end up excluding donors with serious genetic mutations and thereby reduce their numbers of donors and consequent profitability. But it is morally indefensible that they are currently selling non-genetically screened gametes, and thereby putting at risk the physical health of children and disturbing the well-being, physically, mentally and financially of recipients who rely upon them to screen the donors.

Accurate records should be kept on each donor, recipient and offspring.  All donors should be required to update their family medical history on an ongoing basis; otherwise medical information is merely a snapshot of a healthy young student at the time of donation. And all parties need to be aware on the importance of reporting and updating any new medical and genetic information with the sperm banks and clinics.  Facilities should not be allowed to refuse to record a matter just because they don’t judge it as hereditary.

**Tracking and Limiting Numbers of Offspring**

Reporting live births must become mandatory. The sperm bank must track, and report to donors, prospective parents, as well as families already created, the number of births they have had reported to them, along with any health issues reported to them about offspring.

Assuming that accurate accounting and record keeping could be achieved, a limit needs to be set on how many children can be born from any one sperm donor. Although some countries, including Britain, France and Sweden, limit how many children a sperm donor can father, there is no such limit in the United States. Many people in these countries use US sperm, so the “limits”, are then meaningless.

There are “recommendations” from the ASRM that call for restricting conceptions by individual donors to 25 births per population of 800,000. (This would set limits at approximately 250 children for one donor in New York City alone.) And, this does not take into account the large numbers of donors that donate to more than one facility.

*Currently there are no limits because there are no accurate records as to how many children are actually born from any one sperm donor*. Sperm banks estimate that only between 20-40% of women actually report back their live births to the sperm banks, further complicating the tracking process.

Large half sibling groups create dilemmas for those who wish to connect, but who might now be intimidated or even traumatized by the daunting task of somehow reaching out to so many genetic relatives. Many donors had been promised that there would be no more than 10-20 offspring created from their donations, so are shocked when they come to the DSR and find dozens of offspring listed. While they are initially willing to make themselves available for contact, they have been known to later remove their postings, as the number of offspring becomes too overwhelming.

The NY Times reported in 2011 about a donor sibling group that was at 150. Currently, this group now hovers around 200: “*Now, there is growing concern among parents, donors and medical experts about potential negative consequences of having so many children fathered by the same donors, including the possibility that genes for rare diseases could be spread more widely through the population. Some experts are even calling attention to the increased odds of accidental incest between half sisters and half brothers, who often live close to one another. 9*

The fear of consanguinity is a valid one. Random meetings amongst half siblings are frequently reported - at a school function, a park, a party, or even on a vacation cruise. One donor offspring was camp counselor for her younger half brother, her donor’s son, and they didn’t know it until some time later.

**What is in the best interests of the child being born?**

This is the question we must all be asking as the reproductive medicine industry moves forward into a new era. Facilities need to pay attention to the voices of the donor conceived, the donors, and the parents, who have valid concerns, needs and desires that haven’t yet been properly addressed. Ethics should come before profit.

**1**[Offspring searching for their sperm donors: how family type shapes the process.](https://www.donorsiblingregistry.com/index.php/download_file/view/225/126/)  Human Reproduction. Sep;26 (9):2415-24. **Diane Beeson, Wendy Kramer, Patricia K. Jennings**

**2** [Sperm and egg donors' experiences of donating and of being contacted by their donor offspring](https://www.donorsiblingregistry.com/index.php/download_file/view/165/126/)**.**  Human Reproduction, Vol.26, No.3 pp. 638–645, 2011, (2011**).  Tabitha Freeman, Vasanti Jadva, Wendy Kramer and Susan Golombok**

3 BioNews Vol 535, November 16, 2009

4 BioNews Vol 532, November 2, 2009

**5** Fourth Amended Complaint for Fraud, Negligent Misrepresentation/Suppression,

Professional Negligence, Unfair Business Practices, at ¶¶ 63-64, 69, Johnson v. Cal. Cryobank,

Inc., No. SC043434 (Cal. Super. Ct. Apr. 2, 2003).

6 Several papers published in Human Reproduction, RBM Online and Advances in Reproductive Sciences: <https://www.donorsiblingregistry.com/library/dsr-research>

**7** [US oocyte donors: a retrospective study of medical and psychosocial issues](https://www.donorsiblingregistry.com/index.php/download_file/view/168/126/) **Wendy Kramer; Jennifer Schneider and Natalie Schultz**. (2009)  Human Reproduction; doi: 10.1093/humrep/dep309

# 8 April 2016 NY Times: *Sperm Donor’s Profile Hid Mental Illness and Crime, Lawsuits Say.* [*http://www.nytimes.com/2016/04/18/world/americas/sperm-donors-profile-hid-mental-illness-and-crime-lawsuits-say.html*](http://www.nytimes.com/2016/04/18/world/americas/sperm-donors-profile-hid-mental-illness-and-crime-lawsuits-say.html)

9 September 2011 NY Times: One Sperm Donor, 150 Offspring. <http://www.nytimes.com/2011/09/06/health/06donor.html>