



# For the Infertile Couple: Ethical Practice in Donor Conception: 5 Things You Need to Know

**Wendy Kramer (USA) Donor Sibling Registry**  
Educating, Connecting, and Supporting Donor Families

Founded in 2000  
50,000 Global Members  
More than 13,000 Matched

## #1 Donors and recipients are not properly educated or counseled beforehand.



**62%**

... of sperm donor recipients had no pre-insemination counseling.

**49%**

... saying, "it never occurred to me".



**72%**

... of husbands/partners never received counseling.

**80%**

... of sperm donors say they were not counseled on offspring's curiosities.

**66%**

% ... of egg donors felt that they were not properly educated and counseled on offspring's curiosities.

## #2 There is no comprehensive medical and genetic testing conducted by clinics and sperm banks.

**Proper medical and genetic testing of all donors is critical.**

### Current Required US Testing:

- In the US the FDA only mandates for Sexually Transmitted Diseases: HIV-1/2, HTLV-1/2, hepatitis B, hepatitis C, syphilis, and CMV.
- Testing for STD's does nothing to prevent transmission of genetic illness.
- Genetic testing varies significantly at US facilities as adhering to ASRM "recommendations" is voluntary.

### Recommended testing for ALL donors:

- Whole Genome Sequencing (WGS): Now below \$800\*
- WGS provides the most comprehensive map of an organism's genetic make-up. The information amassed through WGS holds an unprecedented level of breadth and detail which can be pivotal to our understanding of many key life processes, including the manifestation of major pathological conditions that continue to negatively impact human health.
- More thorough physical examinations, including organ function, a face-to-face medical history intake, and a full psychological screening.

\*<https://www.scienceexchange.com/labs/applied-biological-materials>

## #3 There is little to no regulation or oversight of the US reproductive medicine industry, which ships sperm to over 40 countries around the world.

This industry is not required to maintain, update or share information and records regarding genetic disease transmitted to donor offspring.

Information about inherited physiological and psychological predispositions are a significant element in obtaining appropriate medical care, particularly in preventative health care including screenings, diet, and other lifestyle choices. Examples: genetic predisposition for heart disease, alcoholism, and many types of cancer.

## #4 No accurate record keeping exists about how many offspring are conceived for any one donor.

**45%** ... of sperm donor recipients had no request by the sperm bank or clinic to report the birth of their child(ren).

**31%** ... of those say that the sperm bank is unaware of the birth of their child.

**42%** ... of egg donor parents were never asked to report their births.

**Limits:**  
**43%** ... wanted to see a maximum of ten offspring, 32% a maximum of ten families, per donor.

**78%** ... think that sperm donors should be restricted from donating at multiple banks.



*"I was pretty overwhelmed when I was pregnant and found your site. There were 50 kids listed for my donor. It is probably getting closer to 200 now."*  
– DSR Mom, April 2012

(This photo is not of the half sibling group of 200. It does show 200 people, so that we can see what 200 half siblings might look like as a group.)

Between 22-27% of surveyed sperm donors, in 2 separate studies, say that they donated to more than one sperm bank. One donor claims to have donated to 17 different facilities.

## #5 Almost 3/4 of surveyed donor offspring advise that prospective parents do not use anonymous donors.

*"Parents should understand that not everyone wants a relationship with their biological parents, but that information about one's origins is essential to identity."*

*"I think it would be good for those considering donors to be able to talk to children who were conceived via sperm/egg donation and get their opinion on it. They may say they love their parents but they all admit when they meet their biological parents, they feel complete."*

*"The matter of using a donor for conception goes much deeper than a matter of conceiving and genetics. People carry a great deal of meaning from their origins, family, and genetics, even though it may not seem logical to you when you want a child so badly."*

Many countries have banned anonymous donation, and we all need to ask "what is in the best interests of the child to be born?"

For many, it's much more than just a "donated cell". A donor conceived girl turns 18 and makes profound statement with a new tattoo.



### The Donor Sibling Registry

The Donor Sibling Registry (DSR) is a US based, global registry where those conceived with donor gametes can establish mutual consent contact with their half siblings and/or their biological parents to create relationships and to share and update important medical information.

Since its inception in 2000, the DSR has helped more than 13,000 of its 50,000 worldwide members to connect with their own, or their children's, first-degree genetic relatives.

### Connecting and Supporting:

- Facilitating connections amongst genetic relatives
- Counseling, group discussion forum

### Educating:

- Egg/sperm donors, recipients, offspring, infertility industry, academics, doctors, legal professionals, reproductive professionals, bio-ethicists, and the general public
- Researching donor families: recipients, offspring, egg and sperm donors, non-bio parents, parents of donors
- Conferences, media stories, book, and outreach programs
- Ethical, medical and legal implications

[www.donorsiblingregistry.com](http://www.donorsiblingregistry.com)  
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