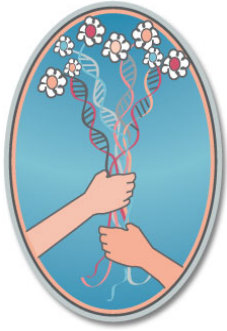




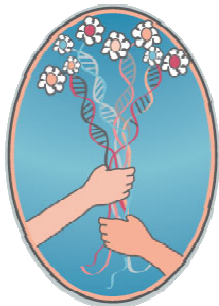
The Donor Sibling Registry

Educating, Connecting and
Supporting Donor Families



History of the DSR

- 1990: A soon to be curious donor child is born.
- 2000: The DSR is established as a Yahoo Group.
- 2002: Media attention begins. GMA, Oprah, Today Show, Primetime, 60 Minutes, NY Times, etc.
- 2003: www.donorsiblingregistry.com site is built.
- 2005: The DSR starts speaking publicly at meetings and conferences
- 2006: The DSR starts collaborating and presenting and publishing research. Cambridge University, Egg Donor Research, UCSF, CSHL and current DSR surveys
- 2010: Presently more than 26,000 members with more than 7,000 matched.



Educate, Connect, and Support

Educate: Prospective parents, parents, donors, offspring, the infertility industry, and the public through papers, conference talks, media stories and outreach programs.

Connect and Support: Facilitate connections amongst donor families. Helping to redefine “family”. Ethical, medical and legal implications. Licensed therapists available. Group forum for discussion/support.

Four Components:

1. Sperm Banks/Egg Clinics
2. Donors
3. Parents
4. Donor conceived people



What we have learned

- **The importance of connecting: for donors, parents and the donor conceived.**
- That there is inadequate record keeping currently maintained by the infertility industry.
- The importance of education and counseling to both parents and donors BEFORE donation and conception.
- The importance of adequate medical and genetic testing of donors.
- The importance of early disclosure and a child's right to know the truth.
- The importance of parents and the industry in honoring the children's curiosities and their right to search for and find genetic relatives. A survey of 750 offspring (52% not members of DSR). 70% of those with anonymous donors say they wished their parents would have used an open donor.
- The importance of being able to update and share medical information amongst families. For all- parents-to be, parents, donors and offspring.
- That 20, 50 and more than 100 kids from one donor can be harmful to families- random meeting, medical issues, psycho-social reasons.



Recommendations

- Require mandatory third party counseling for all prospective donors and parents. Disclosure. Anonymity.
- Track all recipients, donors and births and safeguard all records in a central data bank indefinitely. Information to be accessible by all involved families. Mandate reporting of all donor conceived live births
- Mandate genetic testing for donors and include genetic information in donor bank.
- Limit the number of births conceived with the sperm or eggs from any given donor.
- Require donors to regularly update their family medical history. Medical information to be included in donor data bank.
- Push the infertility industry to inquire into follow-up health histories of egg donors.
- Require legal and financial protection for anonymous donors so that they may feel safe to come forward to make contact and share and update medical information.
- End donor anonymity.