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.