

15th Year Information Booklet



THE
DONOR SIBLING REGISTRY

EDUCATING, CONNECTING AND
SUPPORTING DONOR FAMILIES

Educate, Connect and Support

Educate: Prospective parents, parents, egg/sperm donors, offspring, the infertility industry, and the public:

- Our website, www.donorsiblingregistry.com
- Research/published papers
- Articles and commentaries
- Conferences
- Media stories, TV shows, documentaries, book
- Outreach programs

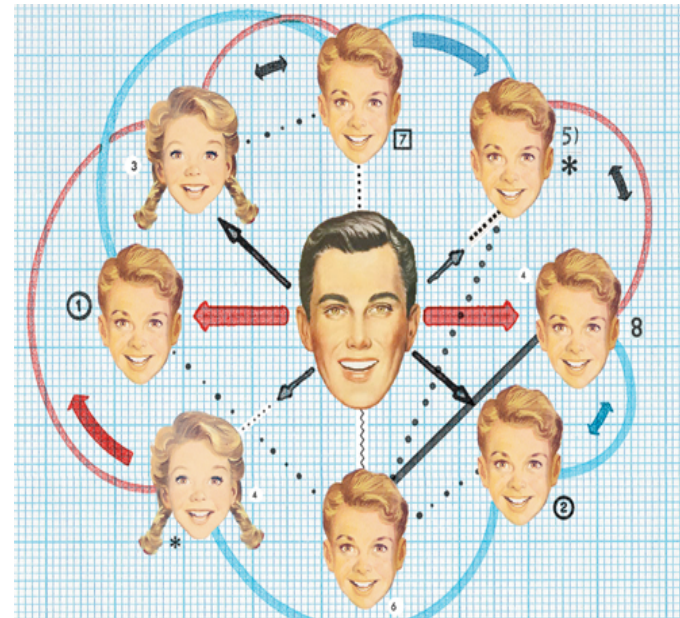
Connect and Support:

- Facilitate connections amongst donor families
- Licensed therapists available
- Group forum for discussion/support
- Families now have a community

**46,000 donors, parents and offspring from
40+ countries. 12,000+ people matched!**

Parent Membership:

50% Single Mothers by Choice | 33% LGBT | 18% Heterosexual Couples



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Counseling

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.



Anonymity: When will we ask publicly in the US, “what is in the best interest of the child to be born?”

The US must consider banning anonymous donations. HFEA numbers in the UK show donors increasing since banning anonymous donations in 2005.

All new donors registered

YEAR	SPERM DONORS	EGG DONORS	YEAR	SPERM DONORS	EGG DONORS
1992	375	451	2003	257	1,032
1993	426	528	2004	237	1,107
1994	417	732	2005	285	1,023
1995	414	749	2006	307	803
1996	419	806	2007	355	1,024
1997	343	910	2008	403	1,167
1998	256	943	2009	438	1,202
1999	302	1,120	2010	492	1,258
2000	323	1,241	2011	541	
2001	327	1,302	2012	631	
2002	288	1,174	2013	586	

2005
Identity
disclosure
went into
effect.

Other countries that have banned anonymous gamete donation: Norway, New Zealand, The Netherlands, Sweden, Austria, Switzerland, Finland, Victoria, Australia, and Western Australia. Germany and Ireland recently approved offspring's rights to know the identity of their donor. Anonymity carries potential medical risks to the children when they are ignorant of the evolving medical family history of their donors.



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Advice

If you chose (were given) an anonymous donor, do you now wish that you had used an open/identity release/willing to be known donor?

More than 60% ... of 1700 surveyed sperm donor recipients answered “yes”.

More than 49% ... of 108 surveyed egg donor parents answered “yes”.

More than 70% ... of surveyed donor offspring recommend that parents use an open or willing-to-be-known donor.



Redefining Family: How do we define family?

Terminology: More than half of 751 surveyed donor conceived people used the words “father or dad” to describe their donor.

22% ... of sperm donor recipients used those words when describing the donor.
Sometimes saying, "it was just a donated cell" or “just a piece of genetic material”.

83% ... of offspring who are not in contact with their donors, wish to be.



Blended family: Egg donor and her 2 daughters meeting her 16 year old egg donor-daughter, with her parents on the Katie Couric Show 2014



Ryan Kramer and his three half-sisters



Half Siblings: Contact

90% ... of offspring with heterosexual (HET) parents and **84%** in lesbian, gay, bi-sexual and transgender (LGBT) families desire to connect with half siblings.

38% ... HET and **74%** of LGBT offspring expressed this interest by age 13.

Of those who had connected with half siblings:

32% ... describe the relationships like “brothers & sisters”

18% ... like “acquaintances”

12% ... like “good friends”

9% ... like “close relatives”

8% ... like “cousins”

“Our kids are two and half years old. They are only 3 weeks apart in age. They are so alike and they are so different. They spent 4 days together, fighting and playing and then fighting some more. Within our individual families they were only children. In our new family they are very much sister and brother. There aren't words to explain the sense of peace that has given us as parents. There's no yardstick that can measure how much this has enriched our lives.”



Parents: Tracking and Limits

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% maximum of ten families, per donor.

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



(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!)

"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



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Sperm Donors: Offspring Limits

35% of sperm donors were told there would be limits on the number of offspring produced. Anywhere between 3-25 children were promised.

Many sperm donors are surprised (shocked) to learn of many more on the DSR. The “bravest” donor registered on the DSR has 75 offspring, all under the age of 13.

You can not limit the number of births until there is mandatory tracking and record keeping by the clinics and sperm banks.



Sperm Donors: Contact

164 Surveyed Sperm donors:

72% ... currently married - 85% of spouses were open to contact.

57% ... with children, 71% of donor's children (old enough) wished to have contact with half siblings.

94% ... were open to contact with offspring. Of those, 94% were willing to answer questions, 90% willing to share medical info, 89% willing to share photos, 88% willing to exchange emails, 85% willing to meet, 78% willing to establish friendships, and 32% said they were willing to establish a parental relationship.

From a donor who connected with a 10 year old daughter 5 years ago: "Finding K was certainly a life-changing experience. Becoming a father overnight to a ten-year-old was frankly terrifying. Usually parents get a few years of trial and error before the kid remembers anything. Becoming Katie's father was a growing experience for me, and I credit her with teaching me how to be a father."

And from two other donors: "You are involved in the creation of real people, not an abstract concept. They will live and breathe and grow, and they will want to know about you. Be ready to have a big heart."

**"Read up on the current wisdom and knowledge that's developed over the years.
There's more to it than making a few bucks."**



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Egg and Sperm Donors: Health

74% ... of donor offspring who wish to make contact with their donors list learning more about their medical background as a reason for the desired contact.

84% ... of 164 surveyed sperm donors have never been contacted by their clinic(s) for medical updates.

97% ... of 155 surveyed egg donors have never been contacted by their clinic(s) for medical updates.

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

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

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

Sperm donor recipients say that health information was the most important factor when choosing a donor:

78% ... wish that all donors were psychologically tested.

67% ... believe that sperm banks should be legally required to comprehensively genetically test all donors.

84% ... said that they would be willing to pay more for sperm that had undergone comprehensive genetic testing.



Current Testing Requirments / Medical Issues Reported

Current US Screening:

Sexually Transmitted Diseases: HIV, HTLV, Hepatitis B & C, Syphilis, Gonorrhea, Chlamydia, CMV.

Genetic testing varies significantly at US clinics as adhering to ASRM recommendations is voluntary.

The less screening carried out, the fewer donors need be disqualified. Fewer tests also equals less cost.

Some clinics and sperm banks test some donors for some of the following: Cystic Fibrosis, Sickie-Cell Disease, Tay Sachs, Canavan Disease, Gauchers Disease, Nieman-Pick's Disease, B-Thalassemia

Medical Issues and the Donor Conceived Person:

Medical and genetic issues reported by sperm and egg donors for themselves or their immediate family include:

Albinism, Alcoholism, Asperger's, Autism, Bi-Polar Disorder, Brain Aneurysm, Breast Cancer, CF Carrier, Canavan Disease, Cavernous Angioma, Colon Cancer, Congenital Heart Disease, Hashimoto's Syndrome, Hemochromatosis, High Blood Pressure Leading to Stroke, Leukemia, Lung Cancer, Melanoma, Mitral Valve Prolapse, Multiple Myeloma, Multiple Sclerosis, Polycystic Kidney Disease, Prostate Cancer, Rheumatoid Arthritis, Spinal Muscular Atrophy, Type II Diabetes, Ulcerative Colitis

Some Privately Reported Health/Genetic Issues from Parents and Offspring: Acute Lymphoblastic Leukemia, ADD, ADHD, Albinism, Amniotic Band Syndrome, Asperger's, Asthma, Atrial Septal Defect, Auto Immune Thyroiditis, Bi-Polar Disease, Branched-chain Ketoaciduria, Complex Congenital Heart Defect, Congenital Heart Disease, Congenital Hypothyroidism, Cystic Fibrosis, Dwane Syndrome, Ebsteins Anolomy, Ectodermal Dysplasia, Heart Murmur, Hemoglobin D, Hemophagocytic Lymphohistiocytosis, Hole in Heart, Horseshoe Kidney, Hydrocephalus, Hypertrophic Cardiomyopathy, Hypophosphatasia, Hypospadias, Imperforated Anus, Juvenile Dermatomyositis, Juvenile Arthritis, Keratosis Pilaris, Kidney Disease, Lethal Dwarfing Syndrome, Marfan's Syndrome, Medium Chain Acyl CoA Dehydrogenase Deficiency (MCAD), Metabolic Genetic Disorder, Mitral Valve Stenosis, Multiple Hereditary Exostoses, PANDAS, PHACES Syndrome, Phenylketonuria (PKU), Polycystic Kidney Disease, Prader-Willi, Rasmussen's Encephalitis, Renal Disease, Retinoblastoma, Seizure Disorders, Severe Congenital Neutropenia, Spina Bifida, Spinal Muscular Atrophy, Tay Sachs, Tourette's, Tracheo-Esophageal Fistula, Truncus Arteriosis, Type I Diabetes, Van Der Woude Syndrome, Vesicoureteral Reflus, Von Willebrand Disease, Williams -Beuren Syndrome, Zellweger Syndrome



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How many donor offspring born per year? No Current Tracking

In 1988 the Office of Technology Assessment estimated that 30,000 children were born via donor insemination during the year 1986/1987 in the US.

A quarter of a century - and no further research - later, '30,000 annual births' is still trotted out in academia, lectures and the media. Sometimes the number is doubled, probably to allow for the passage of time, and occasionally a range of 30,000 - 60,000 is deployed. Using either of the whole figures is scientifically unjustifiable, and the range is just as flawed.

Experts should not be using such patently erroneous figures. Rather, they should be noting that there is no reliable method of assessing how many children are conceived via donor insemination each year. They should be pointing out that the USA has no accurate tracking or record keeping from which it is possible to make an educated assessment.

Instead of complacently relying on outdated best guesstimate figures from more than a generation ago, they should be demanding reliable, recent figures. They should be voicing outrage that neither the fertility industry nor any other entity is required to collect data or report statistics on the numbers of human beings conceived using donor sperm.

This is in stark contrast to the artificial insemination in cattle industry, which is much more tightly regulated and surveyed.



ASRM and SART Oppose Regulation

The ASRM and SART continue to fight the ideas of donor registries, accurately tracking offspring births, banning anonymous donations, and limiting the number of children born from any one donor.

February 20 , 2012, ASRM Office of Public Affairs

ASRM/SART sent a letter of opposition to members of the New York House and Senate health committees regarding problematic sperm donor legislation. AB 9039/SB 6272 would curtail the rights of patients who need a sperm donor to build their families.

The bills would limit to ten the number of offspring anyone donor can conceive and create a donor registry in the state. **ASRM argued there is no scientific evidence to support the cap at ten and referenced existing professional guidelines while maintaining a single state based registry would not only be ineffective, but also intrusive.**

The ASRM says it will strongly oppose any move to ban anonymous donations. "We think that people ought to be able to build their families the way they see fit," says Sean Tipton, a spokesperson for the ASRM. "And you don't change the rules in the middle of the game."

*"First you
have
a desire,
then
a need,
then
a right,
and then
finally,
a law."*

*- Governor
Jerry Brown*



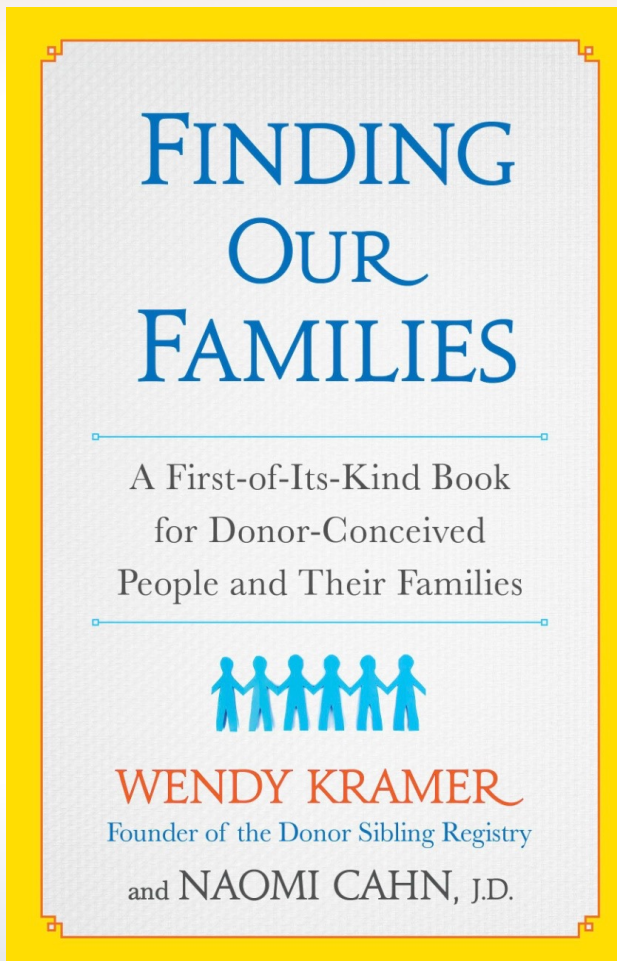
What we have learned

1. That there is inadequate record keeping currently maintained by the infertility industry. 20, 50 and more than 200 kids from one donor can be harmful to families- random meetings, medical issues, and for psycho-social reasons. Many of these children will have little chance of ever meeting their donor, just because of the size of their group.
2. Both recipients and donors are not adequately educated and counseled BEFORE donation and conception. This must be done to ultimately serve the best interests of the children being born.
3. The importance of parents-to-be having all pertinent information on prospective donors and the children they have already produced. Connecting can happen before insemination, during pregnancy, when children are young, or by adult donor conceived people. Many prospective parents are actually choosing their donors through the DSR- reaching out to the other families first to check on numbers of half-siblings, medical issues, to share photos and to establish relationships.
4. The importance of early disclosure and a child's right to know the truth.
5. The importance of honoring offspring curiosities and their right to search for, and to find their genetic relatives.
6. The importance of connecting: for donors, parents and the donor conceived. Also, for the extended families - wives, children and parents of donors.
7. The great majority of donor conceived people and their parents would recommend that parents use open donors. Anonymity should be banned everywhere.
8. That donors should not be promised anonymity- it's an outdated and unrealistic promise considering DNA testing and Google.
9. There is currently no comprehensive medical and genetic testing of donors. *Some* clinics, test *some* donors, for *some* diseases. FDA regulations cover STD's and a small handful of other diseases.
10. The importance of being able to update and share medical information amongst families. For all- parents-to be, parents, donors and offspring. Clinics outside the US need to let recipients know where the sperm originated from!
11. That some sperm banks refuse to give donors their donor numbers- this prohibits donors making mutual consent contact with recipient families and sharing medical information.
12. Long term health studies on egg donors are needed.
13. There is little regulation and no oversight. The infertility industry claims to "self-regulate" while halting all attempts to regulate.



Finding Our Families:

The first comprehensive book for children born through donor conception and their families.



If you are thinking about having a baby through donor conception, this book is for you. If you are a donor conceived person, this book is for you. If you are a parent raising a child who came to you through the help of an egg or sperm donor, this book is for you. If you are a medical or mental health professional, helping people build their families through donor conception, this book is for you...

-Ellen Sarasohn Glazer LICSW, Co-Author,
"Having Your Baby Through Egg Donation"

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