

DONOR SIBLING REGISTRY: Educating, Connecting and Supporting Donor Families

I believe that it is of paramount importance that this industry examine and address the issues of educating, connecting, and supporting donor families as well as the necessity of more accurate record keeping and accountability. Although no donor conceived people or donors were invited to speak here at this meeting, my hopes are that somehow I can speak for them, and bring up many issues facing donor families that have not been adequately addressed in the past. I also hope that I can give you a better understanding of what we do, and why we do it, so you can perhaps walk away with a broader, more altruistic idea of what's possible in moving this industry forward. I hope that this industry can be focused on more than just achieving successful pregnancies, protecting anonymity and making a dollar.

I am the mom of Ryan, 17-year-old donor conceived child. When he was 9, we inadvertently found out from our sperm bank that they knew of 9 children born from our donor. Knowing that he may never get to know his donor, the possibility of seeing the "invisible" side of himself in another, was an exciting possibility. We quickly realized, though, that there was no vehicle to make these types of connections. In September of 2000, we opened a Yahoo group to see if perhaps other families had children with some of the same curiosities and yearning that Ryan experienced. This small discussion group is what has now grown into the Donor Sibling Registry, a non profit organization, serving more than 20,000 donor conceived, parents, parents-to-be and donors around the world. In the past 12 months alone we had more than 6 million hits to our site. We currently show more than 4,800 matched people, with hundreds more kept private. Every single day there are people matching on the DSR. We have more than 700 former sperm and egg donors registered on our site. We have been able to serve donor conceived people with their innate urge, at a deep-seated emotional, spiritual & biological level, to know where they come from. All of this was accomplished by one mom with a full time job, and one kid, a full time student. We have been funded by no one except our members and a few small grants.

The DSR has served as an independent registry, not operated or controlled by any industry party. It is for that reason that we have achieved the goals and maintained the focus of protecting the rights of the very people whose lives are affected by donor conception. We are trusted. We have made it possible for families to track medical trends and problems within their donor groups for years. Because our records are compiled from the families themselves, records on our site can at times be more thorough than the records at the banks, which is why the banks have been known come to our site to update their own

records. Sperm banks have so far been unwilling to partner with us to align records, even though this would greatly benefit all parties. I wonder whose best interests will be served by this proposed registry. If serving the needs of donor families was foremost, I wouldn't be hearing, on a daily basis, the frustrations of so many families who feel that their needs have been ignored.

I. Educating: Recipients, Donors, Public, Industry

Recipients: Pre-Pregnancy.

- We believe that people have the right to hear others' experiences with sperm banks, know of prior births, and hear about health histories. We have compiled lists of user comments, stories, and experiences with many of the sperm banks to help parents choose the right sperm bank for them. Many people connect with DSR families when they are pregnant, while others come even before pregnancy.
- We believe that people deserve to make an educated choice in regards to choosing open or anonymous donors. We want people to understand what it may mean to their child to never have access to answers about their genetic parent. We ask them, "If you choose an anonymous donor, how will you explain when your child asks why, if you had other options, you selected someone that your child could never gain more information on or hope to meet some day?" We want people to ask themselves the question, "What is in the best interest of the child being born?"
- We educate families about disclosure and the importance of honesty. Because of the education offered on the DSR, we are happy to say that many families have decided to come forward with the truth and have told their children of the methodology used to conceive them. We believe that disclosure should be mandatory.
- We educate families on the importance of honoring a child's curiosity. I have heard from many parents of donor conceived children, particularly the non-bio parent (both straight and gay), that they view the donation as merely a "piece of genetic material" or a "donated cell." Although the parents may feel this way, their child may view this "donated cell" as one half of his/her genetic or ancestral identity. Children hearing this as they grow up may begin suppressing their feelings and experiencing guilt if and when they become curious about the unknown parts of themselves. These children may not feel the freedom to express their curiosities because either they fear disapproval from their parents or do not wish to hurt their non-biological parent.

Recipients-Post-Pregnancy

- We offer assistance to families regarding how to tell the truth at different ages. We have a FAQ page with access to a licensed therapist. We have "How to Tell" booklets and other various books and educational materials that deal with issues such as what happens when a child (adult) finds out

about their method of conception inadvertently. We also deal with the issues of searching, finding and redefining this new “family” as well as what happens after connecting on the DSR.

- We tell people how important it is to report their birth to the sperm bank. We believe there should be mandatory reporting. We were told by one sperm bank that only two clinics the bank ships to regularly report live births back to them. There is a huge issue with the number of births exceeding 20, 50 or even 100 for any given donor. Numbers like these, which are not uncommon, have proven to be quite psychologically challenging for many families and donors.

Donors, Pre Donation

We don't usually get the opportunity to speak with donors pre-donation, but if we did we would ask them certain questions at the front door. Would they be willing to provide ongoing current medical information with respect to themselves as well as their immediate family? Do they understand that sperm donated this year may be sold for many years into the future? Are women considering donating their eggs aware of the significant medical risks that may be involved with this process? We would let sperm donors know that they could end up with more than 100 offspring, who could be born anytime between now and 18 (or more) years from now.

All donors planning on being anonymous need to understand that the likelihood of their remaining “anonymous” in the future is slim because of advances in DNA testing and internet search engines. We would tell them that the children born from their donations may be curious and may want to search out their genetic “roots.” There is no doubt many of their children will wonder about who they may look like, where they get their talents and personality traits from, and what genetic and ancestral family history is missing. We would let them know that their actions of today may have an incalculable effect on the future. We would tell donors that their donation is much more than just a transaction with a sperm bank.

Donors, Post Donation

- We let donors know that they can update their medical information as well as make themselves available for contact at the DSR. We help them understand what their genetic offspring might be looking for in this connection.
- We provide education on and provide access to a full service DNA testing company that we partner with.

Educating the Public

Media: We believe that a public conversation can affect social policy and legislation for the benefit of the donor conceived. The DSR has been either the focus of or included in hundreds of newspaper articles, magazine articles, and television stories over the past 6 years. We believe the sperm banking industry

had no incentive to examine or contemplate changing policy until there was constant media attention given to these issues.

Lawmakers: We have been reaching out to law makers to let them know that more comprehensive laws are needed to better define the fact that a sperm donor who donated through a sperm bank has no rights or responsibilities for the children that are created. Many do not come forward only because they are afraid of the legal and financial ramifications. We have also alerted lawmakers to the ramifications of an industry that is seriously lacking in oversight and regulation.

Academic Partnerships: Our current research partnership with Cambridge University in England will be the first large-scale study that looks at the experiences of donor offspring, parents, and donors. The information we collect from this questionnaire will provide us with new and valuable insights into the lives of donor families. To date, we have had more than 1200 participants take questionnaires and expect to publish several papers within the coming year.

Educating the Industry

- The DSR has sent out several mailings to reproductive endocrinologists' clinics, sperm banks, and infertility doctors over the years, asking for acknowledgement, partnership, and alignment. Only one sperm bank recently requested 500 DSR information sheets which will now be included in their new patient packets. In an ongoing survey we ask DSR members how they came to be aware of the DSR. Current numbers show that .3% come from infertility organizations such as Resolve, .5% are referred by an RE, nurse or doctor, and a mere 1.4% are referred by sperm banks. **In spite of this**, families are still finding the DSR. This is a testament to the commitment of these families to acknowledge the curiosities and desires of their children.
- There is a huge disconnect between the sperm donation industry and the families that they are helping to create. ASRM spokesperson Sean Tipton recently said, "I don't draw any conclusions from the Donor Sibling Registry. I don't know if there is any counterpart organization for happy children of sperm donors".* Equating this curiosity to unhappy people is, at best, ignorant. Negating the importance of searching for biological family also negates the importance of these connections. We hope that eventually the industry will come to realize that even happy, healthy well adjusted donor conceived people frequently want to know where they came from. By ignoring, negating, or minimizing this basic human need, **AS WELL AS THE NEED FOR ACCURATE RECORD KEEPING**, the ASRM and the infertility industry is denying a fundamental human right to the very people they help to create. I assure you, Mr. Tipton, the more than 4,800 people who have connected on the DSR feel very, very happy and experience increased richness in their lives.

II. Connecting: Understanding the psychological and medical importance of making these connections and Redefining Family.

- Donor offspring should be able to seek mutual consent contact with their half siblings and/or donors. Many people are thrilled by the idea of having extended families beyond one's immediate and known family circle. These connections have expanded and enriched thousands of families.
- It is important to know if donor conceived people from the same donor live in the same geographical area to prevent accidental incest. Many donor conceived people also want to know what medical conditions the donor and his family might have that developed after the day he filled out his profile. Many sperm banks refuse to give donors their donor numbers and clinics refuse to give donor conceived any information that would enable them to make these important connections. It is unconscionable to refuse these people the information that could help connect biological parent to child or half sibling to half sibling with mutual consent contact. We believe that, in going forward, we need to guarantee donor conceived people access to their genetic heritage and make this principle the cornerstone of a new industry code of ethics.

III. Supporting

Yahoo Message Groups.

We have thousands of donor conceived, parents-to-be, parents, and donors discussing issues, stories information ideas and advice on our Yahoo Groups. More than 15,000 messages have been posted.

Through direct correspondence and financial aid

- A large amount of correspondence relates to choosing sperm banks, deciding on open or anonymous donors, supporting the donor conceived's curiosities, and redefining this new family as connections are made.
- We provide support for donor conceived and their parents who cannot get information from clinics, doctors, and sperm banks on their donors.
- We provide support for donor conceived who can not afford to pay for the donor photos or additional donor information from the sperm bank.
- We provide support for donor families who do not have the funds to travel and meet each other.
- We provide support to donors who wish to make themselves available to the donor conceived. We also support their right to have their donor number. Many sperm banks will not give donors their numbers and some even prohibit donors from posting on the DSR.
- In going forward, we hope to also support egg donor children who were born through any unauthorized or undocumented arrangements so they too can hope to have access to their genetic roots.

Licensed Psychotherapist on the Site

For donor families, making these connections can be uncharted territory. We have a licensed psychotherapist on the site to help people with questions and issues like these:

- When is the best time to tell my child that she is donor-conceived? My child just found out he is donor-conceived, so how can I best support him? I want to tell my child that she is donor-conceived, but my husband/wife doesn't want me to- what should I do? We just made a match with a half sibling or donor- what do we do now?
- For the non-bio parent, we can help them become more secure and help them better understand why this connecting is important to their child.
- We help all parties cope with having many offspring posted.

Here in the US, we have served the needs of the industry, the donors, and the recipients without asking what might be in the best interests of the children being born. Other countries have indeed asked this question publicly. Many countries no longer permit anonymous donation. The move to end donor anonymity is still small in the US, but I believe that it will grow as this huge current generation of donor-insemination children reaches adulthood. This industry is about to be hit by a tidal wave of donor conceived people looking for answers and demanding accountability.

I believe that a national registry that is set up, run, and governed by the sperm banking industry is only a fearful reaction to the possibility of the FDA imposing its own regulations and will only serve to protect this industry's own best interests. Some sperm banks estimate that only between 20-40% of women actually report their live births, meaning that these records and this proposed "Registry" will be incomplete and therefore be of minimal significance much less result in change to the current system until there is mandatory reporting. Records need to be kept on each donor and each child born. Unless using open donors also become mandatory, we will continue to hear the frustrations of families that cannot get medical updates on their donors. Unless reporting is mandatory and limits are set, we'll continue to have 50, 100 or more children listed for donors on the DSR. We'll continue to hear from people who find out that what their donor wrote on the donor profile is not necessarily the truth. We'll continue to hear from donors that donated at up to 16 different facilities. Unless education starts at the front door, we will continue to have both parents and donors regretting their uninformed choices. If the records are over-seen by the same entities that do so now, we will have the same record keeping and the same level of accountability just with a new name and an appearance of regulation. For a registry to be effective, it should not only be overseen and governed by the industry it is set up to monitor.