



Commentary

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The Donor Sibling Registry: Connecting Donor-Conceived People with Their Half-Siblings and Donors



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Introduction

Infertility treatment has been reported since the 1800s, beginning with the use of fresh sperm administered in a doctors' office without the knowledge of the mother. In 1978, the first IVF baby was born and by the 1980s, the sperm selling industry flourished. Increasing numbers of couples struggling with infertility, and later, unmarried people, and LGBTQ couples turned to this industry to make their dreams of parenthood a reality. For many decades, the desires of donor-conceived people to know about their ancestry, medical backgrounds and close genetic relatives were ignored by the reproductive medicine industry [1].

The Donor Sibling Registry (DSR) was founded in 2000 to assist individuals conceived as a result of sperm, egg, or embryo donation who are seeking to make mutually desired contact with others with whom they share genetic ties. The DSR advocates for the right to honesty and transparency for donor-conceived people, promotes social acceptance and legal rights, and values the diversity of all families. The DSR's core value is honesty, with the conviction that people have the fundamental right to information about their biological origins, identities, and relatives [2].

Because the donor conception industry is largely a for-profit enterprise, after the gametes have been sold, most doctors, clinics, egg donation agencies, and cryobanks do not engage in discussions or activities that acknowledge the humanity and rights of the donor-conceived people. It is our mission to bring these concepts to the public arena for discussion, as has been done in many European countries, as well as in New Zealand and Australia. Since the beginnings of donor conception more than a hundred years ago, policies have been set to include the rights of the facilities to sell the gametes, the rights of parents to buy those gametes to build their family, and the rights of donors to sell their gametes and to remain anonymous. But this isn't an equitable situation as the rights of donor-conceived people have rarely been considered. We believe they should not only have a seat at the policy table but should also be listened to first and foremost [3].

The decisions that the parents and donors make early on affect donor-conceived people's lives for many decades to follow. Parents are sometimes not prepared for their children's curiosity and desire to know more about their genetic background. In order to move out of the secrecy and shame that has for so long shrouded donor conception, the DSR educates parents and the general public on the importance of honoring and supporting children's natural drive to know more about their identity [4]. The DSR has connected more than 25,000 donor-conceived people, parents and donors in 105 countries, many right from pregnancy/birth and early childhood. Every single vial of sperm sold in the US and Denmark is sold as anonymous, be it for 18 years or forever and it is now common for sperm donors to have 50, 100, or more than 200 donor offspring. Because the large US and Danish sperm banks ship to more than 50-60 countries, local laws (e.g., in the UK, Canada, and Australia) regarding anonymity or limits on offspring hold little meaning [5].

Family can be formed and defined in so many different ways, but biology has always been the most common family bond. Having one parent with a biological connection to their child is important to parents who choose sperm and egg donors instead of adoption. If parents value this genetic connection on one side of their child's family tree, shouldn't they also recognize and value its importance on the other side? All too often I hear parents negate or minimize the importance of their child connecting with their unknown biological parent, the donor, and their half-siblings, people conceived from the same donor. Some refer to the donor's contribution as merely "a piece of genetic material" or just a "donated cell". But to many donor-conceived people, it's so much more: it's one half of their identity, ancestry and medical backgrounds.

Donor-Conceived People Desire to Know about Their Genetic Relatives

"Genetic uncertainty has clouded my life since I was 12 years old, when I learned that my conception was facilitated by an anon-

ymous sperm donor. Though the shock dissolved in the following months, I'm reminded of this obscurity entwined in my DNA when I'm asked to fill out a medical history form at the doctor's office and have to indicate that, genetically speaking, half of my

family tree remains in shadow. I'm joining the Donor Sibling Registry in the hope of connecting with others who have had similar experiences, hearing stories, and maybe even finding a biological half-sibling or relative" (Figure 1).



Figure 1: I just found my half-sibling this year. I am 29 years old and wish that I could have known him my whole life.

For Thousands, Connecting with Half-Siblings on the DSR has Been an Overwhelmingly Positive Experience

"I just found my half-sibling this year. I am 29 years old and wish that I could have known him my whole life. It is really special, and I'm so thankful to have found him. We met a couple of months ago and it's like we have known each other all along."

"I think it's really cool that I have donor siblings (I'm close to three sisters and one brother). We get closer every year because we Face time, text, and get together in the summertime; ever since

I was three. We live thousands of miles apart, yet it feels like we all live together. We're talking about going to college in the same town."

"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" (Figure 2).



Figure 2: Some parents who have seen their children's half-siblings posted on the Donor Sibling Registry have said that they will wait to establish contact until their child is old enough to make that specific request.

Some parents who have seen their children's half-siblings posted on the Donor Sibling Registry have said that they will wait

to establish contact until their child is old enough to make that specific request. Generally, children don't decide when to meet

their relatives. (They also don't decide the timing of a lot of things.) We don't wait until they show interest or ask to meet their cousins, aunts, uncles or grandparents. Our children grow up knowing their close relatives, and then, when they are older, they choose who they wish to be in contact with and spend time with.

"Just imagine being 20 something and finding siblings on your own when DNA testing is even more wildly popular, or they find

you. You then develop some kind of relationship. You find that many of these siblings had parents who encouraged these relationships, even from babyhood. You see the pictures; you hear the stories. Disney, camping, birthdays... A couple of them will be roomies in college, maid of honor in a sibling wedding, etc. To me, this would be crushing. I would feel so cheated. Whether or not I had great neighbor pals, awesome cousins, or even siblings from the same home" (Figure 3).



Figure 3: We chose early contact with half-siblings because we felt if he wanted to end contact when he was old enough to choose, he could.

"We chose early contact with half-siblings because we felt if he wanted to end contact when he was old enough to choose, he could. But if we waited until he was older, and told him we knew his half-siblings all along, and he wished for that contact, there would be a lot of years and missed opportunities gone. We feel

being open, honest, and having connected early on may instill a sense of pride and ward off any shame that may come about if we were secretive about this part of his story and family. We also have a son who was adopted at birth so we are big on celebrating and embracing the ways in which our family came to be" (Figure 4).



Figure 4: The Donor Sibling Registry has thousands of donors who are open to contact and there are now many positive donor-offspring connections.

Thousands of Former Egg and Sperm Donors Have Connected on the DSR

The Donor Sibling Registry has thousands of donors who are open to contact and there are now many positive donor-offspring

connections. "My goal in joining this site is to present myself so that if my kids are out there and would like to meet me and or get to know me, I'm here for them. I welcome and cherish such a special opportunity. I would never want for any child or person for that matter to feel less whole due to not knowing something

that is such an instinctual curiosity. From all the information that I've read, early contact and/or at least the knowledge of who a bio father is looks to be very beneficial for the children. That being said, I'm open to early contact and relationship building. I'm here to help and only add to the child's life in a loving and non-intrusive manner. This is all still very new to me but I will always do my best to be a good example, a positive addition, responsive with awareness and care for any communications."

"After about 5 weeks of conversation, [my donor child] told me that he is going to call me Dad from now on and I am his father because the man who raised him until age 15 was never much of a father and I have been more of a father to him in 5 weeks than that man has been his whole life. Very powerful stuff. I tell them this and will continue to tell them all when we connect: 'I have no expectation of what you will call me and how you will identify me. You will struggle to find what to call me. You will have conflicting feelings regarding this and it is normal and ok. You may try out whatever you like for as long as you like and you may change it any time you wish as many times as you like. When you find what works for you, you will feel it.'

Even Children of Donors Can be Curious about Their Half-Siblings

We often talk about the importance of honesty in families that use donated eggs or sperm and honoring a child's curiosity about their first-degree genetic relatives. Donors also owe their own children the truth about their donating as they also have a right to know that they have half-siblings. DNA testing is already revealing these family connections, and it will only continue to become more common. Some donors have not informed their families, as some are ashamed, some don't consider donor children as true "family", some are afraid of 100 or 200 kids coming forward, and some have partners/spouses who are against it.

"I recently found out that my father donated to sperm banks many times years ago and I wondered if I have any more siblings out there."

Updating and Sharing Medical Information Can Save Lives

All too often, sperm banks and clinics do not update and share important medical information amongst families as keeping records, and updating and sharing this information is costly. Reporting births is voluntary, so sperm banks do not have accurate records of the children born from any one donor and they frequently lose track of donors. Connecting on the DSR has helped many families share and update urgent medical information.

"If California Cry bank can't find the donor 3 years down the road when my sons were speech delayed or 6 years down the road when my son had cancer, why do they claim they can find him after 18 years??"

The Research

84% of 164 surveyed sperm donors were never contacted by the sperm bank for a medical update (most sperm banks promise yearly updates) while 23% indicated that they or a family member had a medical issue that would be important to share. "As a donor I updated my medical records between donations. They did not pass those updates on to previous donations NOR donations that came after those updates."

In 2009 97.4% of 155 surveyed egg donors were never contacted by their clinic for a medical update while 34.2% said they had a medical issue that would be important to share. Thirteen years later, in 2021, these stats only changed slightly: 94.3% of 345 had never been contacted for a medical update while 25% had medical issues to share.

Connecting on the DSR May be the Only Way to Share/Update Important Medical Information with Other Families

"My son has Asperger's, as do 4 of the 8 children we have made contact with. Worse, our donor has a genetic defect that results in aortic aneurysms and dissection. Half of his 33 living children will inherit the same. My son did; he had open-heart surgery at 17. I know it is a crapshoot when you rely on a stranger's DNA, but there needs to be tighter regulation in the sperm banking industry."

"I am the parent of two children who were born with a sperm donor. They are both in their early 30s. In the past 6 weeks we have discovered that they were born with a bad gene and they have a rare heart disease. With this gene, a person just drops dead with no warning. In checking my grandchildren, two of them, under the age of 10, carry the gene. My oldest child and the youngest grandchild have had surgery. My younger child is going to have a baby in December and that grandchild will have a 50 percent chance of getting the disease. Still testing etc. to see what that treatment will be. I have had DNA testing done and I do not carry the gene. Doctors said it had to come from the donor."

And Finally, of Course, There are no Guarantees That all Family Connections Will be Entirely Positive

Some people are suspicious when they look at the success stories on the DSR and have asked, "How can these connections all be so positive?" While the great majority of new family connections on the DSR are indeed very positive, some might be flatter or sometimes even more of a struggle. Our families are made up of all races, religions/non-believers, academic backgrounds, gender identities, sexual orientations, abilities, socio-economic backgrounds, political perspectives, nationalities, and varied personality types. Not all donor family members are like-minded or have enough in common to wish for a continued relationship, and sometimes people don't agree on the desired level or degree of

contact. In traditional families, when we look around our holiday table, do we want to spend time with everyone there? Sometimes not. Some family members are just not the kind of people we would want to hang out with, and some may just be people with whom we don't have enough in common. But that doesn't remove the relatedness or desire to know about each other. Parents with donor children owe them the opportunity to explore their donor family relatives and relationships.

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