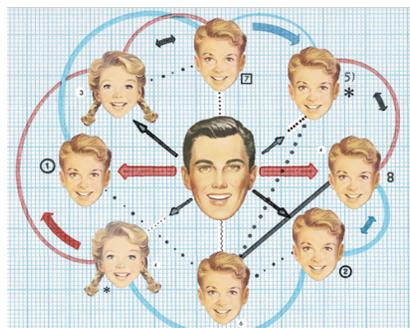


The Ambiguity of Open Gamete Donation



THE
DONOR SIBLING REGISTRY
EDUCATING, CONNECTING AND SUPPORTING DONOR FAMILIES



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DISCLOSURE & LEARNING OBJECTIVES



Disclosure: ACCME compliance requires all presenters to disclose commercial and financial relationships with commercial or financial interests and/or other relationships with manufacturers of pharmaceuticals, laboratory supplies, and/or medical devices at the beginning of every lecture/presentation. **I have nothing to disclose.**

The following information is based on:

- 21 years as Director of the Donor Sibling Registry, educating, connecting, supporting, and studying more than 80,000 parents, donors, and donor-conceived people in 135 countries.
- Evidence based on both anecdotal reporting and data from 26 published research studies in peer-reviewed academic journals on all stakeholders: sperm/egg/non-bio parents, offspring, sperm donors, egg donors, and the donor's parents.
- Raising a donor-conceived child (now 31) who was the first to find his biological father via a DNA test in 2005 and who currently has 21 half-siblings.

Because of ASRM time and space restrictions, the complete White Paper including all supporting documentation, corresponding testimonials, sperm banks' responses, and research data can be requested: wendy@donorsiblingregistry.com.

The Ambiguity of Open Gamete Donation



The concept of “open” or “open identity” or “identity-release” or “willing-to-be-known” donation is simple:

- A young man sells his sperm to a sperm bank as an “open” donor: he agrees to have contact with the children he helps to create when they turn 18;
- Parents wanting a child purchase that man’s sperm from the sperm bank. Note: vials of this non-anonymous sperm can be more expensive than anonymous-for-ever sperm;
- A child is conceived, parents are thrilled, the sperm bank makes money, and the donors think they'll stay anonymous for 18 years.
- The resulting child expects contact when they turn 18 (if desired).

While there have been many happy connections made between adult DCP and their biological fathers via the sperm banks, all too often donor-conceived people report that sperm banks:

- Don’t respond to their calls or requests;
- Claim that donors can’t be found;
- Or claim that the donor has refused contact (sometimes this is just not the truth).



“I was a donor at CCB who was open to contact and still every time a biological child of mine has reached out they have put up roadblocks.”

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Are the sperm banks too often failing to provide DCP with what both the donor and the parents agreed to, and what they, therefore, expected at age 18?

There is quite a bit of evidence and therefore good reason to question, doubt, and challenge the way that sperm banks present, promise, and follow through with their "open donor" policies.

Mandating 18 years of anonymity serves the financial best interests of the sperm banks and fertility clinics, but they've too often tried to scare parents and donors into believing that this mandate is in *their* best interests by telling them:

- *nonsense* about legal custody and financial battles (there have been none that include a sperm bank/egg clinic donor);
- *non-existent* donor rights and responsibilities; (a sperm bank/egg clinic donor has none);
- and *non-existent* anonymity "laws" and "FDA anonymity mandates" (there are none).

Maintaining donor anonymity for 18 years is not possible, and hasn't been for more than 16 years.

For many medical and psycho-social reasons, contact long before the age of 18 can be crucial and beneficial for all stakeholders.

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The interpretation of an open donor is left to each different facility, or to the whim of young men, many who donate while in college and who are not properly counseled or educated about the numbers or the needs of the children they're helping to create, the reasons that their biological children might desire contact, or about the likelihood that they won't be able to stay anonymous for 18 years*.

- **Some donors have tried to change from anonymous to open, but couldn't.**
- **Some donors who were sold as open just don't respond to contact requests, thinking that they can remain anonymous.**
- **Many donor-conceived people report that their "open" donor refuse contact.** One reason is that donors with 50, 100, or 200+ offspring can feel completely overwhelmed and not have the family support, emotional bandwidth, or capability to connect with that many kids, as many of them were promised and expected no more than 10 or 20 kids or families.

We have thousands of egg and sperm donors on the DSR who either chose anonymity or who weren't given a choice, and when given the opportunity, are very open to establishing relationships with their biological children who are both over and under the age of 18.

If a person is thinking about selling their gametes and they wish to remain anonymous for 18 years or longer, they *just shouldn't donate.

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Why continue to *try* and mandate 18 years of anonymity?

Why refuse to connect donors with DCP after they're 18?



1. Keeping and updating records costs **money**. Reporting births is voluntary, so sperm banks **do not have accurate records** of the children born from any one donor and they lose track of donors: *"If the sperm bank [CCB] 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??"*
 2. Keeping promises of updating and sharing medical information is **costly** and might result in lawsuits.
 3. Keeping promises of **limits** on numbers of offspring would be **costly** as selling less vials of a single donor would also affect their net profit.
- **Sperm banks don't want the donors to know that they have 50, 100, or more than 200 kids when they were promised no more than 10, 20, or 25 kids or families.** DCP in these large groups who desire contact with their biological father may never get it, just because a sperm bank was careless and there is now an unmanageable number of offspring.
 - **Liability: medical issues can be ignored instead of shared.** Too often it's reported that a donor, parent or child report a medical issue to the sperm bank, but find out later that the medical issue wasn't shared, as was promised. If a donor-conceived person doesn't have contact with their genetic relatives, they could be missing out on sharing and updating important medical information, as there could be a genetic issue that would warrant proper screenings, monitoring, or preventative medicine.
 - **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.



A Working Solution



Connect parents and donors right from pregnancy/birth.

More than 2-dozen egg clinics/agencies/attorneys write the DSR right into their parent-donor agreements:

- **CONTACT:** The issue of contact between the donor and the recipient is removed from the hands and focus of the agency/clinic.
- **CONSENT:** Since the DSR relies on mutual consent contact; the agency/clinic doesn't need to be worried about protecting anyone's privacy or incur the costs of tracking communication between donors, parents, and donor-conceived people.
- **CHOICE:** Each party can remain private if they choose, so the decision is ultimately in the hands of those involved. Each party can decide the depth and breadth of the information they're comfortable sharing.
- **CURRENT:** The sharing and updating of current medical information happens on the DSR, so the agency/clinic has less work since they have provided a tool for medical updates.
- **EMPOWER:** Parents and donors are empowered to set the parameters of their own relationships, without a middleman, and without waiting 18 years. **Donor-conceived people have the opportunity to establish relationships with their genetic mothers/fathers and half-siblings while they are developing, not having to wait until they are adults.**

Egg facilities report that once parents are properly educated and counseled, most choose this early contact option. Many donors realize that it's better to take charge of the contact instead of having their relatives potentially contacted via the DNA websites.

When will the sperm banks follow suit?

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Experiences of Donors, Parents, and Offspring



From Two Parents (different donors) who used PRS: *My son is 19 and last year contacted PRS to begin the process of contacting his “willing to be known” donor. PRS told my son his donor was anonymous and he couldn’t contact him. I had all my paperwork that clearly stated otherwise. Upon further investigation, PRS told us the donor had changed his status from “willing to be known” to “anonymous” one month after I conceived.*

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Through the DSR we have made contact with many families who used our donor. Our daughter will be 18 next year and was looking forward to getting more information about the donor at that time. We understand from one of the other families that the donor wishes to change his status to anonymous and has refused contact. We were also told that the sperm bank’s attorneys are preparing a letter to send to us. Needless to say, we’re terribly disappointed and haven’t figured out how to break it to our child.

From a PRS DCP: *I am joining to search for any siblings I have. My clinic, PRS, has been extremely unhelpful in my efforts to make contact with my donor, and have even sent hateful words to me via email when I have requested help.*

From a CCB DCP:

My moms used CCB as well and the narrative they/we were given was also that I could reach out when I was 18.. Well I did when I was about 21/22 and played phone tag with some sort of client relations person who never ended up getting back to me. ...didn't need her to anyway, because we found my donor.

From Three CCB Parents: *I will almost guarantee you that CCB never attempted to contact your donor. We've had several kids attempt contact through them and our donor reports that he never received any correspondence from them. And his contact info is all up to date.*

I did look at the CCB website last night [2019] to check. They still sell Anonymous, Open and ID Release. Having paid premium pricing for Open (willing to be known) I looked at their new conditions with the third category. I was horrified to discover that the first statement on Open Donors is that it specifically excludes learning the identity of the donor. Not what I had in mind at all. ID Release gives the donor’s identifying details to the 18+ on request. However, amongst other conditions, they now require the DC person to sign a non-disclosure agreement specifically forbidding them to tell their siblings. Otherwise they will refuse to deliver the ID the parents paid for. These conditions and unilateral changes probably would not stand up to challenge under contract law but have not been tested yet.

My oldest daughter reached out to CCB last spring when she turned 18, requesting contact with the donor. After a few days, Latrice Allen emailed my daughter and told her that they “know his whereabouts” and will reach out to him, but not to expect contact because he has the right to say No. She said they would attempt to contact him 3 times. My daughter never heard back.

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Experiences of Donors, Parents, and Offspring (Continued)



From Two CCB Donors:

As an ID Release Donor my adult offspring should be able to contact the Cryobank, and say "Hey, # XYZW was my donor. Please give me his contact information." Every time I have moved or changed phone numbers or email addresses I have dutifully updated CCB. So I asked one of my 20 year old kids (who I met through the DSR 7 years ago) to test the sperm bank. He called them, and was transferred to voicemail. I figured nobody would call him back, but lo and behold they did call him today. They asked him a bunch of questions to prove his and his mother's identity, then told him I was an anonymous donor (Lie) and they didn't have my contact information (Lie) but they would try to get in touch with me.

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I naively assumed that CCB would have requested updates or actually informed me of any offspring that tried to reach me after turning 18. My experience with CCB is very similar to what is reported by others on your website. I remember being explicit that I wanted to be available if any offspring wanted to contact me. Yet they had me listed as anonymous. And I also remember them assuring me that only 5-10 families would be sold to.

From Three NECC Parents:

I chose a "yes" donor/donor release option, have paperwork saying the info will be released to my daughter once she's of age, yet the owner of the bank is not honoring the agreement, and wouldn't even return a phone call for months, then after one okay/civil conversation, in which she agreed to call me back with no information...completely disappeared and never called back.

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We have been trying to work with NECC to contact our identity release donor for months now and are not having any luck hearing back from them as to the status of our request except that they have the paperwork needed to move forward. Phone calls and emails are not returned.

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I am going through this with NECC now! It is dragging out to months and I can't get any info from them as to what is taking so long. They acted like this was the first request for donor contact they had gotten.....

From A FF Parent:

We recently identified our donor via DNA testing. I sent him a message yesterday and he said he had called the bank and asked to change his status to known, and they would not do it. He said at the time of donation (20 yrs ago) they did not give him the option to be known but he told them he was ok with contact. My point is, they DENIED him and the families this option. He said he anxiously awaited the day he would be found. It angers me that the bank took it upon themselves to deny his request.

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Data from Published Studies



73% of Donor-Conceived People (DCP) with heterosexual parents answered “yes” to “if your donor is anonymous, do you wish that your parents would have used a known or willing-to-be-known donor

74% of 485 DCP who wish to make contact with their donors list learning more about their medical backgrounds as a reason for the desired contact.

85% of 164 sperm donors and 97% of 155 egg donors have never been contacted by their clinic/sperm bank for a medical update, while 23% of the sperm donors and 31% of the egg donors felt that they, or a close family member, had medical/genetic issues that would be important to share with families. NOTE: Our 2021 surveys of 345 egg donors showed that 94.3% were never contacted for a medical update while 25% indicated that they did have a medical issue that would be important to share with families.

97% of 164 sperm donors said that they “thought about the offspring that they helped to create. 94% said that they were “open to connecting” with the offspring.

In a study of 114 sperm donors, 94% of donors with no contact and 98% with contact say “that they thought about their offspring”. 83% with no contact and 89% with contact say that “they wondered if offspring thought about them.”

70.3% of 485 surveyed DCP have tried to locate/find their donor.

24.1% of them utilized DNA testing, 31.6% used the DSR, 17.6% used a record search, 21.2% tried contacting the sperm bank.

84% of DCP who had contact with their donor agreed, “I think a lot about the characteristics that I might share with my donor”. 60.7% agreed, “I understand myself better because I have thought about who I am in relation to my parents and donor”.

More than half of 751 surveyed DCP used the words “father or dad” to describe their donor, while 22% of sperm donor recipients used those words when describing the donor.

61% of 1700 recipients who used an anonymous donor wish they had used an open donor. (NOTE: the majority of these parents still had very young children).

More than 49% of 108 surveyed Egg Donor Parents answered “yes”: “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? (NOTE: the majority of these parents still had very young children).

62% of 1700 recipients had no pre-insemination counseling.

80% of 164 surveyed donors said they were not counseled or educated about offspring curiosity.

93% of 1700 recipients would not have used a sperm donor who had produced an offspring with Autism.

75% of 1700 recipients wish that sperm donors were psychologically tested.

45% of 1700 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 108 egg donor parents were never asked to report their births.