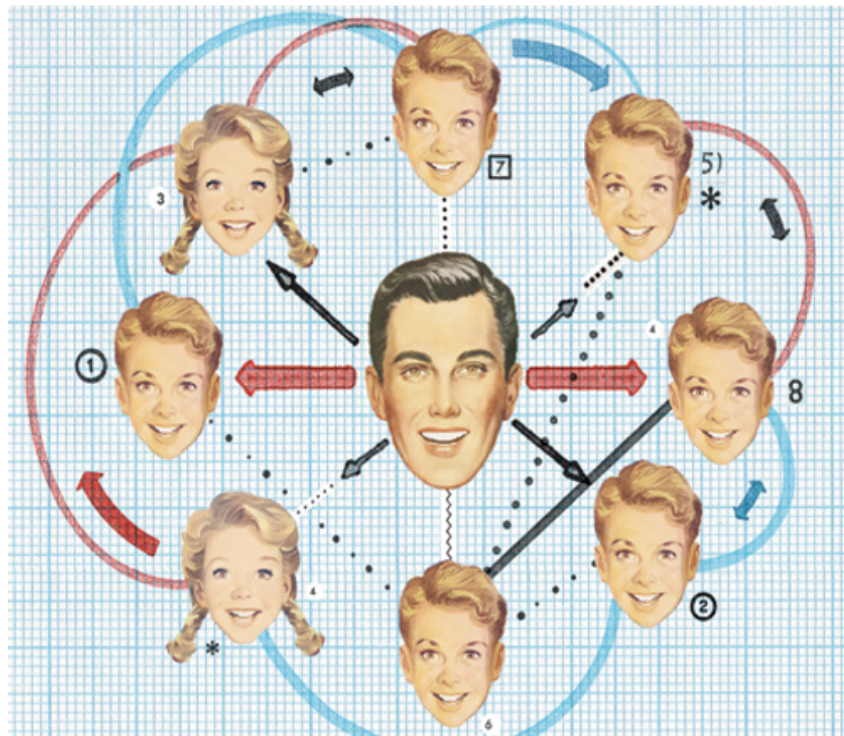


THE DONOR SIBLING REGISTRY

EDUCATING, CONNECTING AND SUPPORTING DONOR FAMILIES

The Ambiguity of Open Gamete Donation: A White Paper

By Wendy Kramer



There is overwhelming 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.



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. Vials of this anonymous-for-18-years sperm can be more expensive than anonymous-for-ever sperm.
- A child is conceived, parents are thrilled, the sperm bank makes money, and the donor expects to stay anonymous for 18 years.
- The resulting child expects contact with their biological parent when they turn 18 (if desired).

Many thousands of donor-conceived people (DCP) have grown up thinking that they’ll get to know their biological father when they’re 18. But, for many years we’ve been hearing from families who purchased non-anonymous sperm, only to find out later on that this is not the case.

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

- Don’t respond to calls or requests from DCP or never follow-up;
- Claim that donors can’t be found (sometimes this is just not the truth);
- Claim that the donor has refused contact (sometimes this is just not the truth);
- Claim that a donor is anonymous-forever, even though the donor signed up to be an open donor or had no choice and has since made it clear to the sperm bank that he is open to contact.
- Refuse to give donors their own donor number.

From A Fairfax Parent:

We recently identified our donor via DNA testing and a geneticist. I sent him a message yesterday and he said he had called the bank (Fairfax), 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.

From Two Fairfax Cryobank Donors:

I, too, donated more than 20 yrs ago at Fairfax. I've tried all methods of which I could think to get Fairfax to open my record to anyone seeking it. They denied me every time, and have continued to deny me. They wouldn't even tell me my own donor number. Fortunately, one biological son found me on the DSR.

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Fairfax listed me as anonymous even though I had signed several documents that allowed for my information to be given out.

From a Fairfax Parent:

I have the same situation - a donor who was a yes and then turned into a no. I was told that a donor has the right to change their mind about being contacted and that this is what happened in our situation.

From a California Cryobank Donor's Wife:

The only time we have ever heard from the Cryobank was in 2010 (he donated 2003-2005) to inform him that he would be "retired" because a child was born with a medical issue. At that time, they informed him that he would be receiving surveys, etc. to update his contact and medical information, which he never received. They have never reached out for updated contact information. He has reached out twice and been told he would receive surveys via email, which he has not. Is this typical?

My husband matched with a family via DNA and the mother told us that CCB told her that her donor "did not want communication". We were upset to hear the mother was told we did not want contact and that we had agreed to be contacted by the donor-conceived children.

From Three New England Cryogenic (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.....

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

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 never properly educated or counseled about the numbers or the needs of the children they helped 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.

- We know of donors who tried to change from anonymous to open, but couldn't.
- We know about donors who were sold as open but don't respond to contact requests.
- We also know about open donors who refuse contact. 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. Additionally, many sperm donors feel embarrassed or ashamed about their history of sperm donation and therefore feel very strongly about keeping it a secret.
- We have thousands of donors on the Donor Sibling Registry who either chose anonymity or who weren't given a choice. We've found that when donors are properly educated about the needs and desires of DCP and given the opportunity to connect, many are then very open to establishing relationships with their biological children who are both over and under the age of 18.

From a California Cryobank DCP:

...the donor refuses to meet, talk or provide any photos, even though he was a "yes" donor.

Since the beginnings of donor conception, 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 the donor-conceived people have not been considered when setting policy. We believe they should not only have a seat at the policy table but should also be listened to first and foremost.

Every single vial of sperm sold in the US and Denmark is sold as anonymous, be it for 18 years or forever. Because the large US and Danish sperm banks ship to more than 50-60 countries, local laws (eg., in the UK, Canada, and Australia) regarding anonymity or limits on offspring are meaningless.

The reproductive medicine industry needs to acknowledge that maintaining donor anonymity for 18 years is not possible, and hasn't been since 2005. If a person is thinking about selling their gametes, and wishes to remain anonymous for 18 years or longer, *they just shouldn't donate*.

Since 2000, the Donor Sibling Registry has been facilitating mutual consent contact between many thousands of donor-conceived people and their half siblings and/or their biological parents. For many medical and psycho-social reasons, contact long before the age of 18 can be both crucial and beneficial for all stakeholders: the parents, the donors, the donor's family, and most importantly, for the DCP.

So why continue to try and force families and donors to wait 18 years, or even refuse to connect donors with DCP after they're 18?

It's a financial thing:

1. Keeping and updating records costs money. Sperm banks do not have accurate records on how many children are born for any one donor.
2. Maintaining 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.

Mandating 18 years of anonymity serves the best interests of the sperm banks and fertility clinics. 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 custody battles** (there have been none that include a sperm bank or egg clinic donor), **non-existent donor legal rights and responsibilities**, and **non-existent anonymity "laws" and FDA "anonymity mandates"**.

The sperm banks don't want the donors to know that they have 50, 100, or even 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 from a single donor.

84% of 164 surveyed sperm donors were never contacted by the sperm bank for a medical update (most sperm banks promise families yearly updates) while 23% indicated that they or a family member did have a medical issue that would be important to share. Not updating or sharing medical information decreases the sperm bank's liability as medical issues can be ignored instead of shared. But, without medical updates, and if a donor-conceived person

doesn't know all of their half-siblings or their unknown biological parent, they could be missing out on sharing information about a physiological or psychological genetic issue that would warrant proper screenings, monitoring, or preventative medicine.

From A California Cryobank Donor:

For anybody that was looking for health updates or genealogy information for their children, I apologize for not posting to the registry sooner. 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 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 Fairfax Parents:

My son has 220 known 1/2 siblings...our donor donated for at least 6-7 years!! The sperm banks make their own guidelines....and self police. It is not a regulated industry!

We purchased from Fairfax in 2008 and they told us that there had been "2 live births" from the donor. Turns out Fairfax was aware of over 50 known at that time!! Fairfax lies!! But, it is our "normal" and a battle our kids may choose to fight when they become adults.

Fairfax lies a lot. They told me 10 families. My kids have almost 200 half siblings.

From a Xytex Parent:

I used Xytex and my daughter has 100+ siblings which is a disgrace. I'm planning to write (another) complaint letter to the Fertility Society of Australia with details about the sperm banks that Australian clinics are using, and how they can justify using these banks when scenarios like this are happening and staff are admitting there are actually no limits.

From a Fairfax Parent:

I have recently found out that the sperm bank I used may have misrepresented themselves to me, and told me the donor agreed to be identified . They are now telling me (8 yrs later) that the donor is a NO donor not an identity release donor. Has anyone ever run into this before?? Any ideas on how to handle this??

From a Donor:

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. I only know that because a family that came after that insisted on contact. She showed me all of the info she had gotten on me. Those updates were not included. Any of the updates I have done since have not been passed on to her either.

From a California Cryobank Parent:

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.

From A California Cryobank Donor:

As an ID Release Donor my adult offspring should be able to contact California Cryobank, 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 California Cryobank. 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.

From Several California Cryobank Parents:

.. 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??

My CCB donor was also a yes (open) donor and now is a no donor. I am happy to say that we have four beautiful matches on the DSR. 2 girls and 2 boys. I don't know what the future has in store for us but I am happy to have the siblings we have now.

I had something like that happen to my donor. Also, at CCB. It occurred after he was asked to reactivate for a couple. He obliged but then he changed to no. Ironically, that's when I discovered this registry and recently discovered that there are 3 half siblings. I've made limited contact with one parent of a sibling at Christmas time.

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I have the same issue with CCB. When we were first looking at donors, we decided that we would like to use someone who was, at least, open to the idea of possibly being identified when my son turns 18. All of the information that I originally downloaded/printed said the donor was willing to be id'd when the children are 18...NOW, when I look at the information - even though the donor is retired - it shows him as a NO!

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From A California Cryobank Donor:

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

From a California Cryobank 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 through Ancestry DNA..



From Two Parents (different donors) who used Pacific Reproductive Services (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 your website, 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.

A PRS Parent received this explanation from PRS:

About "Willing to be Known" Donors: Most of our donors are willing to be known to the children conceived as a result of artificial insemination with their donated semen when the child has reached the legal age of consent (18 years old in the state of California). The child must contact PRS to initiate the disclosure of the donor's identity. PRS will attempt to arrange a meeting between the donor and the child. If PRS is unable to arrange such a meeting, the donor's identifying information will be released to the child to enable the child to pursue this process on his/her own. The child will sign a contract specifically requesting that s/he respect the donor's privacy in pursuing a meeting (i.e., not discussing the purpose of the meeting with anyone except the donor himself). Once a meeting has occurred, the donor's obligation has been fulfilled. Pacific Reproductive Services cannot guarantee that the meeting between the donor and the child will occur. PRS must rely solely upon the donor's representation and signed contract that he is willing to be known.

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. I'm hoping this can be a different experience.

From a PRS Parent:

All us moms were given different numbers. They shipped his sperm to other places which he wasn't aware of either.

From a California Cryobank Donor:

I am a donor who, through the DSR, started meeting my bio offspring (23 of them so far) when they were as young as 3 years old and, in every case, it has been a mutually rewarding and wonderful experience for all involved.

From a European Sperm Bank (Seattle Sperm Bank) Parent:

My kids were found by my donor's family [via DNA] and they are messaging my kids to connect. I am trying to get a hold of the donor to make him aware of the situation and ask his permission. [Update]: I actually found our donor (amazing guy), he is fine with us, but I think if he understood there was 75-100, he'd flip out. We were also told 25 families was the limit.... but now they are saying 25 in the US. They said he was also sent to Canada and Australia. They said that was it, but we know of families all over Europe.

From the Director of European Sperm Bank (Seattle Sperm Bank):

After presenting research at the ESHRE meeting in Vienna in 2019, Seattle Sperm Bank director Greg poked his head into a conversation I was having in front of his booth to add, "*The FDA mandates anonymity!*" No, they do not. The FDA only mandates testing donors for communicable diseases and a small handful of other diseases. As a result, some sperm banks test some donors for diseases like Thalassemia and Tay Sachs. No one mandates anonymity except the sperm banks and egg clinics. This sperm bank director's misinformation about the FDA's rules might be the reason for such a low sperm donor presence on the DSR's Seattle Sperm Bank list.

From the VP of Communications California Cryobank (CCB):

NBC News, 2019: Scott Brown said, "*Family is what we are in the business of, not genetic connection.*"

Several years ago I asked California Cryobank about their open donor policy, and was told that when a child of 18 requested contact, the donors were sent a letter only asking them to “update” their information, not mentioning anything about a child desiring contact. So, if a donor read the letter and thought “I have nothing to update” he’d likely just toss the letter. He would never know a child desired to meet him, and the child would think that the donor refused contact. So I asked CCB: “Your rep said that when there is a request, donors are sent a letter to ‘update’ their file. They are not actually notified that a child actually wants to meet them. Is this true? This could explain the low response rate, as the donors are not made aware that a child is actually wanting to meet them.”

The reply I received back from CCB:

Our system is set up to protect the interests of all parties. We contact the donors via mail and/or email. If he chooses to respond, we explain the situation and ask if he is interested in moving forward with the contact. To send a letter with information about an offspring out of the blue could be very jarring, irresponsible, and could ultimately illicit an even lower response rate from the donors who do not understand the specifics of the interaction. We don't phone them until they give us the ok, because if they have a wife or children who could answer the phone, it could put them in an awkward position.

From a Parent:

I have friends in Australia who followed all the rules and picked an identity release donor with less than 5 families in Australia. It was only after they conceived that they discovered he has donated all over the place and is hitting 1000 with nothing to stop him from continuing to sell his sperm.

From Two California Cryobank Parents:

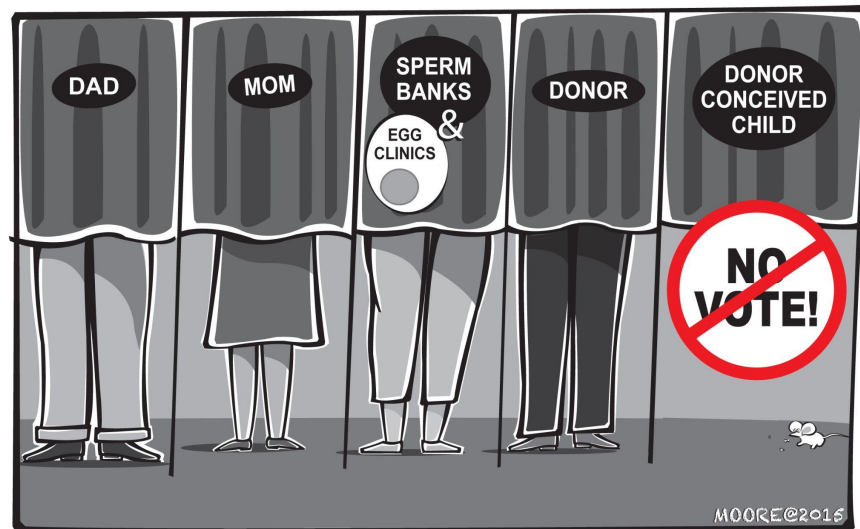
I did look at the CCB website last night [2019] to check. They still sell Anonymous, Open and ID Release. Having paid premium pricing for Open (willing to be known) I looked at their new conditions with the third category. I was horrified to discover that the first statement on Open Donors is that it 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.

From a DCP:

I don't think donor anonymity is an issue that is front of mind for the general public. It's individual fertility specialists and clinics seeking to retain control and living out their antediluvian paternalistic attitudes in practice that are the reasons behind the persistence of donor anonymity. They don't trust the lived experience of donors, donor conceived people or the parents of donor conceived people and believe that in call cases "doctor knows best". When you have a combination of capitalism and patriarchy you're going to have problems with getting progressive values into place.

The Voting Booth of Sperm & Egg Donor Anonymity



From a Donor:

My DC offspring may wait until they are 18 to contact me. In that time, they have lost out on meeting their biological great grandparents, and may miss out on their biological grandparents too. What if I wasn't still alive when they hit 18, and they could have known some family, but that time was lost too. These children have every right to track down and have the chance to know family before family may be gone. You can not undo time because you waited too late. Time is precious.

From a Parent:

By the time we found my son's donor we learned he died suddenly 2 years prior. We did find his sister though, and she is a loving aunt figure to the 26 siblings.

A 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 to be shared between donors and parents.
- **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. Donors realize that it's better to take charge of the contact instead of potentially having their relatives contacted on the DNA websites.

This is the future of gamete donation.

Some feedback from the egg donation industry:

“More and more of our recipient and donor pairs hope to sign up for the Donor Sibling Registry. We often have comments about how helpful you are as a facilitator.” - Andi, Oregon Reproductive Medicine

“Each year I see more intended parents who want to make sure their child one day “has the option” to meet their donor if they wish. As an agency, I am grateful that there is a program like The Donor Sibling Registry that can be an advocate for the child, donor, and intended parents who desire this type of relationship.” -Katy Encalade, Program Director, Egg Donor Solutions

“Just wanted to send a note to say how much our clinic appreciates this option for our patients. Currently, our office only offers anonymous embryo donation. However, some of our patients would like a more open arrangement. Your site allows patients who trust our office and want to stay with us, to have the best of both worlds. Now they have a place where they can go to control the amount of contact they have with their donor or recipient. It’s the perfect solution for them and we are grateful you offer this option!”- Christine The Fertility Center, MI

While exploring the idea of Egg Donation to build a family there are unknown scenarios that families may encounter. It is simple for both intended parents and egg donors to consider their feelings and needs now but may not fully understand what future questions there might be. The Donor Sibling Registry allows a safe and comfortable way to allow future communication when it becomes apparent it would be beneficial to a parent, the egg donor, or a resulting child. The Registry allows all parties to ask questions, exchange medical information, and possibly meet when the time is right for each. The Donor Sibling Registry allows all individuals to move at their pace, and the lifetime membership is a worthwhile investment. - Kallie Wilson, MSW, Care

When choosing a sperm bank, it’s important for prospective parents to research beyond the marketing materials on a sperm bank’s website. Because it’s important to hear about what happened 5,10, 20, or 40+ years later, the DSR has a **Which Sperm Bank** page where user testimonials (including many of the above) for most facilities can be found.



Research Data

All Published Research Studies are posted here: <https://donorsiblingregistry.com/dsr-research>

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”? 59% of DCP with LGBT parents answered yes.

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 (in 2009) 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.

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 another 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 only 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).

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

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

More than 49% of 108 surveyed Egg Donor Parents answered “yes” to, “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).

93% of 1700 sperm donor 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.

Contact and Donor’s Family Data From the Published 164 Sperm Donor Research:

Contact



“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.”

Knowing me does or could make offspring’s life easier:

No Contact	With Contact
62% Agreed	73% Agreed

Knowing me does or could offer my offspring more insight into the origins of genetic traits:

No Contact	With Contact
76% Agreed	93% Agreed

Knowing me does or could offer my offspring more insight into personality traits:

No Contact	With Contact
85% Agreed	91% Agreed



The Donor's Family



83% of those with contact say their partner is open to connecting with offspring.

- **164 Donors:** **71%** of donors were currently married or partnered, and of these **91%** had told their partner and **85%** of the partners were open to connecting with the offspring.
- **164 Donors:** **58%** of donors had children of their own, and of these **38%** know that their father has been a donor. A further **40%** are too young to tell, and of these **85%** will be told. **70%** of children who knew about sperm donations were interested in meeting half siblings.
- **114 Donors:** **94%** of those with and without contact say that their current partner knows they donated sperm. **75%** of those with no contact and **83%** of those with contact say their partner is open to connecting with offspring.



Donor Sibling Registry | Educating, Connecting and Supporting Donor Families

The highly unregulated* business of sperm donation is failing too many parents, donors***, and DCP with their inability to manage or to offer any consistency, accountability, or reliability with so-called “open” or “identity release” donation practice and policy. Unfortunately, with no regulating body and little to no oversight, this industry is not expected to change its policies and behavior any time soon.**

*The FDA only mandates the testing of donors for communicable diseases and a small handful of other diseases, although families on the DSR have reported kids with these specific diseases, e.g., Tay Sachs and Cystic Fibrosis. No entity regulates or monitors what happens after a donation is made.

**Eggs are mostly sold as only anonymous, although more than 2 dozen egg clinics and agencies now write the DSR into their parent-donor contracts, thereby facilitating connections from pregnancy/birth.

***This is a “donor misnomer”. No one is “donating” anything, as all US donors are paid, and list payment as the #1 reason for donating: Reproductive BioMedicine Online: [Semen donors who are open to contact with their offspring: issues and implications for them and their families](https://doi.org/10.1016/j.rbmo.2012.09.009), <https://doi.org/10.1016/j.rbmo.2012.09.009> (PDF) From a Donor-Conceived Person (DCP): “...this is an example of terminology that really needs to change, in the opinion of many DCP who live this reality every day. It’s a matter of fact that, [we] don’t have a “donor,” we have two biological parents just like everyone else. One DCP put it succinctly and eloquently: We’re not half human and half “donor.” We’re fully human. I hope recipient parents will support their children and their fellow DCP by helping to change the euphemisms intentionally created to distance ourselves from our full families.

Depth and Breadth: More Voices, Experiences, & Perspectives of All Stakeholders

Donor:

I was a donor in my early 20s when I needed some extra cash. I evaluated donating and decided to go forward, as it was helping people. I never gave it much more thought in the decades since until one of the children contacted me. She found me and two half siblings via a DNA test. I had gifted my elderly parents a DNA test last year, never thinking this would happen.

Donor's Child:

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.

DCP:

"I'm a 15 year old girl who is interested in meeting her donor in the future. I have a twin sister and neither she nor my parents are aware that I have found this information in some of the various manila folders in the file cabinets."

Donor:

I was an egg donor in Arizona between August 2002 through 2004, with multiple cycles. The matching agency was X and Y Consulting. Multiple attempts were made to notify X and Y Consulting that I developed a Life Threatening medical condition. They were unresponsive. Doctors in Chandler, Phoenix and Tucson were notified. Upon learning X and Y Consulting changed their name to World Egg Bank, they were notified of my medical condition. They did not make a positive identification or ask for a diagnosis. As of today, a known recipient family has not been notified of my medical condition via her doctor or matching agency. I notified her myself. I will be DNA testing.

Donor's Child:

I am the daughter of someone who was a donor and I had no idea. I did an ancestry DNA test and I found a close match, only to find that she is my half sister from when my dad donated back in the early 90's. She was elated to finally have found her biological father through me and I would love to know if there are any others out there! It was a shock at first but I've gotten to know and it so great to know that I had a half sister out there all along.

Donor's Child:

My Dad was a sperm donor for families that couldn't conceive. My siblings and I never knew. One of the "donor-conceived" children reached out to my parents, so my parents just shared that they had donated all those years ago.

DCP:

Feeling overwhelmed with curiosity and longing to find my biological father and half siblings. As many of us are, I am lost in a seemingly never ending search to do so.

DCP:

I am a girl searching for my egg donor. I won't bug you too much. I just want to know what you look like.

DCP:

I am the offspring of a sperm donor and a single mom. I want to start by saying this. I do not wish to violate my father's privacy if he does not want to contact me. If he is interested in a possible relationship, then so am I. In fact, I would welcome it. But, if he wishes to be left alone, I respect his choice. However, I would love to connect with any siblings I may have. My mother had no other children and I would love to meet any others my father may have helped produce. I hope to make contact with someone soon.

DCP:

I am 18 years old and I have been wondering about who my father is since I was about 12, but unfortunately my father wished to remain anonymous. When I was 15 my mother told me about the Donor Sibling Registry and I have been curious ever since about who I could be related to.

DCP and Parent:

As DCP, most of us yearn to be seen and loved and accepted by ALL our parents. I am also a parent of a DC child and I can attest that raising a child is a wonderful and unique experience.

But my daughter will, god willing, spend much more of her life as an adult than she will as a child. Who am I to say that, having loved her first, no one else can love her? I very much hope that she will be loved by many people including her own donor in due time.

Donor:

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

Donor:

I adore my kids (donor offspring) much more than I thought I would. More than I've loved anyone, really. I, too, wonder whether there is a chemical component. Though not required, several of them appear to love me back. I feel very fortunate.

Parent:

We know our donor thanks to DSR. I consider him a friend. He was willing to be known in the early 90's, and I didn't want an unidentified donor, but I had no choice then. And neither did he.

*It ate at me after my son was born. It bothered the donor and his mom during that time, not knowing who might be out there. Our donor used 2 different cryobanks. He contacted one to be known and **they said they had no records of him**. He feels badly that someone might need to find him and will be blocked. He has been excited about his 5 found offspring. Never pushy. But there in whatever way feels right for the offspring.*

DCP:

My donor told me through his sister that he was willing to provide medical history but “nothing else.” Everyone grows up asking “Who am I and what am I made of?” It’s troubling to find a big piece of the answer and be treated with indifference or like my existence is an inconvenience or intrusion. The anonymity arrangement between him, the clinic and my parents means almost nothing to me as a donor conceived person. He and my parents were practically children when they made their arrangement with the clinic and I’ve never been a party to it.

Donor:

I'm a donor who has had the great fortune of meeting four of my offspring so far (and three of their parents). All contact has been wonderful and awe-inspiring. The first couple of kids I met directly through DSR -- the others through various online channels. There are more kids out there still, some of whom I've heard about, and others who are still a mystery. I welcome all of them into my life and my heart.

Parent:

The fact that the industry is set up this way should be a warning to all recipients that regardless of what we do, and despite their minor child showing no interest in knowing their genetic identity, ancestral history, and biological relatives, we have all played a part in setting them up in feeling a sense of loss at some point in their lives. Telling the truth about being donor conceived, growing up knowing they were very much wanted, and love is not enough. Many DCP share stories of never having any interest in knowing bio relatives, until one day they do. Despite all of the love between them and their parents, the pain of loss remains. While we can't protect our children from all sense of loss and pain in their lives, it shouldn't be okay that recipients sit back and allow the industry to continue to profit by separating DCP from their biological families.

Donor's Mother:

I found out my grown son was a sperm donor through Ancestry DNA Testing and was completely shocked! We are now grandparents to a beautiful little girl whose mother got her tested when she was just two. My son has given me permission to use this site in order to find more of my grandchildren who I haven't met yet but love deeply.

Sperm Donor:

I tested and registered on AncestryDNA with my first name, last name, AND donor ID number, to confirm that I was a donor and I specified on my public tree that I invite contact.

Two Egg Donors:

I added myself to 23andMe because I too am a known egg donor from years ago and wanted to make myself available for contact. I've waited years and I had a parent/child match last month! I sent a brief message stating I've waited/hoped to be contacted.

I was an egg donor many years ago and registered on ancestry so that any offspring would have that info available if they ever sought it out. I would not be surprised if you received a really positive response.

Parent:

My daughter expressed interest in knowing who hers was when she was 14, I didn't even do dna, just a quick google search of the profile info and I came back with who he was. Since it was her journey to take I showed her the info and asked her what she wanted to do. She wanted to make contact so she wrote him a letter and we mailed it off- 4 months later we were driving across the US and met him and his wife for dinner.

Parent:

Through DNA testing we discovered the donor I requested was NOT the donor I received. Through further testing we found 3 half siblings and the donor because he had given his info to one of the donor conceived half sibs. We reached out just to confirm medical history. He was very welcoming. Two years later my daughter got a letter from him telling her how glad he was that she had reached out and how much pleasure knowing her has given him.

Parent:

I reached out to the second cousins of my daughters. One from each side of the donor family. They both were very helpful in providing info on their family side. One cousin knew who the donor was from the info I provided. He reached out to the donor & the donor's brother eventually reached out to me. After a year still have not heard from the donor, but have been in contact with his brother, received info and pictures too. Sometimes other family members are happy to provide info, while the donor processes being identified.



**THE
DONOR SIBLING REGISTRY**
EDUCATING, CONNECTING AND SUPPORTING DONOR FAMILIES