

2015-2017 Huffington Post Contributions



Wendy Kramer, Co-Founder and Director of the Donor Sibling Registry

Wendy Kramer is Co-Founder and Director of the Donor Sibling Registry (DSR). The (DSR) was founded in 2000 by Wendy and her son Ryan to assist individuals conceived as a result of sperm, egg or embryo donation that are seeking to make mutually desired contact with others with whom they share genetic ties. With almost 60,000 members, the DSR has helped to connect 16,000 of those with their half siblings and/or their sperm or egg donors. (2018)

As a charity organization without outside support, Wendy, Ryan, and the DSR have pioneered a national discussion about the donor conception industry and families, with research, speaking engagements, media

appearances and interviews. Besides uniting relatives, the DSR informs, counsels and supports donors, offspring and parents. The DSR is also actively involved in research regarding gamete donation outcomes. Via outreach activities and through the media, the DSR educates medical professionals and the public about issues relevant to all families affected by donor conception.

Wendy has been a peer reviewer for the journals Human Reproduction and RBM Online. Wendy and her son Ryan have appeared on 60 Minutes, The Oprah Winfrey Show, Good Morning America, The Today Show, NBC.com, ABC News, CBS News, CNN, NPR, and many other news shows and documentaries. She was Associate Producer of the 2011 Emmy Nominated *Sperm Donor*, a Style Network TV show, and MTV's 2013 6-part docu-series *Generation Cryo*. Wendy is co-author of *Finding our Families: A First-of-its-kind Book for Donor Conceived People and Their Families* (Penguin). Publications include the NY Times, the LA Times, the London Times, the Chicago Tribune, O Magazine, MORE Magazine, and hundreds of other publications around the world.

Huffington Post closed down their contributor platform in 2018. Here are Wendy's Huffington Post contributions from 2015-2017 that address many important issues that affect donor families around the world.

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Donor Conception: Old vs. New Thinking

11/08/2017



Old thinking: *Infertility is something to be ashamed of.*

New thinking: Coming to terms with infertility is a process. With proper education and [counseling](#), healing can begin so that the shame of infertility isn't passed along to the child as the shame of being donor conceived.

Old thinking: *Keep the secret. Don't tell anyone that you used a donor, especially your child.*

New thinking: Secrecy implies shame. Openness and honesty are the best choices for all families and your child has the right to know about how they were conceived. Donor children do not love their non-bio mom or dad any less, so this is something that shouldn't be feared.

Old thinking: *Wait until the child is "old enough" to understand donor conception before telling them they are donor conceived.*

New thinking: [Research](#) shows that starting the conversation long before a child can fully understand is best. That way, the information is incorporated into a child's identity, and there is never any "telling" event.

Old thinking: *Wait until a child is "old enough" or until they ask before telling them about half siblings.*

New thinking: We don't wait to tell children about any other relatives, so why wait to tell them about half siblings? Why not give a child the opportunity to grow up knowing their half brothers and sisters? Why risk a child asking later on, "You mean I could have grown up knowing my half siblings? Why didn't you allow that?"

Old thinking: *If your donor conceived child finds out the truth, ask them to keep the secret.*

New thinking: It is not healthy or fair to ask your child to keep this information as a secret. Secrecy implies shame. Being donor conceived is a part of their identity and needs to be acknowledged and embraced. If the child is struggling with this new information, it's a parent's responsibility to walk with them and support them. Parents: you can apologize for keeping the secret. This is no longer about you.

Old thinking: *Donors can and should remain anonymous, for 18 years ("open" donors) or forever ("anonymous" donors):*

New thinking: DNA= Donors Not Anonymous. With DNA (and the Internet, social media, public records, etc.) donor anonymity ceases to exist. Many egg clinics/agencies are now writing the Donor Sibling Registry into their contracts so that contact between parents and donors is made right from pregnancy or birth. Why don't sperm banks do the same?

Old thinking: *Donor conceived people should be kept from their biological parents for at least 18 years, as with "open" or "willing-to-be-known" donors:*

New thinking: It can be extremely important for both medical and psychosocial reasons for donor offspring to connect with their biological parents, long before the age of 18. Parents: the choices that you make early on will affect your child for decades to come.

Old thinking: *If donors are anything but "anonymous" they will have rights and responsibilities for their donor offspring.*

New thinking: Donors who donate through clinics and sperm banks have no legal rights or responsibilities.

Old thinking: *Donors shouldn't tell their spouses or children that they were donors.*

New thinking: Donors should be telling anyone that they are in a serious relationship with that they have sold their eggs or sperm. Donor's children should be told that they (might) have (many) half siblings, as they too might want to connect. Again, secrecy implies shame. Own it and share it. Your family has the right to know.

Old thinking: *DNA doesn't make a family.*

New thinking: DNA is certainly not the only way to make a family, but it can and does define family. As with adoption, many donor-conceived people wish to connect with and learn about their ancestry, medical history, and first-degree genetic relatives. There is no need for a parent to minimize the importance of their child's "other" genetic relatives. For parents, it might be nothing more than a "donated cell", but to a donor child it can mean so much more.

"You can't really know who you are and where you're going unless you know where you come from." -Bruce Springsteen

Old thinking: Donors shouldn't have any obligation to update their medical records.

New thinking: Updating and sharing of medical information is crucial and can even save lives. Parents

should know about all medical issues reported by families and donors, both before and after pregnancy.

Old thinking: *There is no need for accurate record keeping on the children born from gamete donations.*

New thinking: There is a dire need for accurate record keeping so that groups of half siblings of 50, 100, or 200 stop happening. You can't notify families of reported medical issues if you don't know who they are.

Old thinking: *It is more important to put profit before ethics in the reproductive medicine industry.*

New thinking: The needs and rights of the child should be considered first and foremost.

Choosing a Sperm Bank...What to Know



An open letter to anyone choosing a sperm bank

08/24/2017

Hello Future Parents,

I am so glad that you're reading this, and that you are doing your due diligence. And I know, this can seem completely overwhelming- hang in there! Honestly, right now there is only one sperm bank that I can recommend, and that is The Sperm Bank of California (TSBC). Maybe it's because they are a non-profit, they do seem to try a bit harder to keep accurate records and to act in a more responsible and ethical manner. They are not perfect, but do seem to try harder to contact donors when a child turns 18, not just send a generic letter in the mail, as some banks, like California Cryobank have done. [Or not responding, or claiming that donors are not really "open" at all, as some banks do.](#) TSBC's "informed consent" form (on our [Which Sperm Bank](#) page) that you'd need to sign, implies that you or your child shouldn't contact donors or half siblings outside the scope of their mutual consent/age 18 recommendations, but this is unenforceable as [anyone can contact anyone, at any time](#) - and, your child is not signing or agreeing to anything.

We think that 18 is an arbitrary number, only in place to protect the sperm bank's liabilities. That's why any family can make contact at any time on the Donor Sibling Registry (DSR). (Children under 18 do need their parent's permission). There is no psycho-social research that recommends waiting until age 18, and a lot of research and that does show the benefits of connecting early on in a child's life. If a child could

have the opportunity to grow up knowing their first-degree genetic relatives, then why deliberately keep them from him/her?

Many egg clinics and agencies are now writing the DSR into their parent-donor contracts, so anonymous (if wished) contact is made on the DSR right from pregnancy/birth. Messages, photos and medical information can then be shared freely. Parents and donors are empowered to decide exactly what type of communication they are interested in, without the need of a middleman who knows nothing about them or their family, or the needs of their child. Not one sperm bank will do this. Ask your potential sperm bank "why not?"

Some sperm banks "claim" to limit numbers of children, but the truth is...you can't limit until you actually have accurate records, which none do, as reporting births is voluntary. Some sperm banks have estimated that only 20-40% of women actually report back their births back to the sperm banks. The DSR has many half sibling groups of more than 100. Xytex and Fairfax are the two sperm banks with the most number of very large half sibling groups.

Because of little regulation or oversight, besides the FDA mandated STD testing, and testing for a small handful of other diseases, each bank can say what ever they want, and then do what ever they want. So, some banks, test some donors, for some diseases. You can read all about the medical and genetic issues [here on the DSR's Medical Issues page.](#)

Sharing medical information with half sibling families and donors on the DSR is oftentimes the only way to know about this type of important medical information. Families should never rely on sperm banks to contact families when medical issues arise, as most often they are unaware, and even when they are made aware, we know that they frequently do not update the families.

I would definitely steer clear of the big banks such as California Cryobank, Xytex, Fairfax/CLI/Pacific Reproductive Services (PRS), NW Cryobank, the US "Scandinavian" sperm banks like Seattle/European Sperm Bank/Cryos, or New England Cryogenic (NECC). I used California Cryobank, and could never recommend them, as on many occasions I haven't

found them to be honest. See the [Johnson vs. California Cryobank](#) case (the sperm bank deleted Polycystic Kidney Disease from a donor's profile), this [O magazine Article](#), and my [Blog entry on the DSR](#). At least two sperm banks, Fairfax and NECC have not let their donors know their own donor numbers, trying to actually prohibit the sharing and updating of information by donors with families on the DSR.

Read these NY Times articles: [One Sperm Donor, 150 Offspring](#) and [In Choosing a Sperm Donor, A Roll of the Genetic Dice](#). Also, see [this \(one of many\) disturbing article about Xytex](#). Read this 2016 NY Times article: [Sperm Banks Accused of Losing Samples and Lying About Donors](#). And there's also [this one regarding an NECC lawsuit involving a child born with Cystic Fibrosis](#).

Read through the user comments about these and other banks on our [Which Sperm Bank](#) page. Ask your potential sperm bank the 30 questions we've provided on that page. For the most part, these sperm banks seem only responsive to people before they sell their product.

I hope that you'll be using an open donor- please read through the 25 published papers on our [Research](#) page and the advice that donor conceived people offer on the [DSR's Offspring page](#) to better understand why using an open donor is SO important. The DSR has spent many years researching, listening, and responding to the needs and issues of donor-conceived people, and we know that they do not recommend that prospective parents use anonymous donors. Remember though, that without offering early connections (like the egg clinics/agencies are doing) *all sperm donors are essentially anonymous, albeit some only for the first 18 years of a donor conceived person's life.*

Also, I would suggest that after making a short list of possible donors, that you check the DSR to see if any of the families who used those donors are already listed on our site. If so, you could reach out to them to see if there are any medical issues that you should know about. Also, you can see how many families are already posted for that donor. Sharing and updating medical information on the DSR with other families (and the donor) can be important and even life-saving. Wouldn't you want to know if the donor you're thinking of using already has 30, 50 or 200 kids out there and that too many of them had autism, ADHD, or a heart disease?

Please read ALL the articles in [my Huffington Post Blog](#), as they contain a lot of information you won't find anywhere else, for example: "[10 Things your Doctor or Sperm Bank Won't Tell You](#)". I highly recommend reading [Finding Our Families: A First-Of-Its Kind Book for Donor Conceived People and Their Families](#), as it's everything I wish I would have known when I was beginning my journey as a parent of a donor conceived child.

We just submitted (July 2017) an [FDA Citizen's Petition](#) with 173 powerful comments, stories and testimonials from parents, donors and donor conceived people that should be read by anyone wishing to learn more about the reproductive medicine industry.

Best wishes and good luck!

~Wendy

Sperm/Egg Donation: Genetics & Mental Illness

03/29/2017



These two recent comments [submitted to the the Donor Sibling Registry's FDA Citizen's Petition](#) highlight the need for more comprehensive medical testing of donors, including psychological evaluations, the intake of complete family medical histories, and continued updating and sharing of medical information reported by donors and families.

My Fairfax ID donor committed suicide in 2013. I learned of his death one week after the birth of my second child in 2016. That means I posthumously conceived one or both of my children with a Fairfax Cryobank donor. I did not consent to this, and I do not know if the donor would have consented to this. When we were making the critical decision on who would be biological father of our children, we specifically required two things: 1) the donor had to be an "ID option" donor so that our children would have the access to learn as much, or as little, about their biological father as they desire; and 2) the donor have no history of mental illness. In the two sentence informal letter I received in 2016, Fairfax advised me that the donor committed suicide in 2013. Fairfax said they last got a medical update on the donor in 2013 and no mental illness was reported or "noted by any staff member". As a result of Fairfax's lack of action, my children have not only lost their right to seek out their donor at age 18, but they also may or may not have inherited a predisposition to suicide. Fairfax still has this donor

listed on their website as "inactive" - with no indication whatsoever that he is dead. This is unconscionable. The FDA needs to step in and regulate this industry on a federal level.

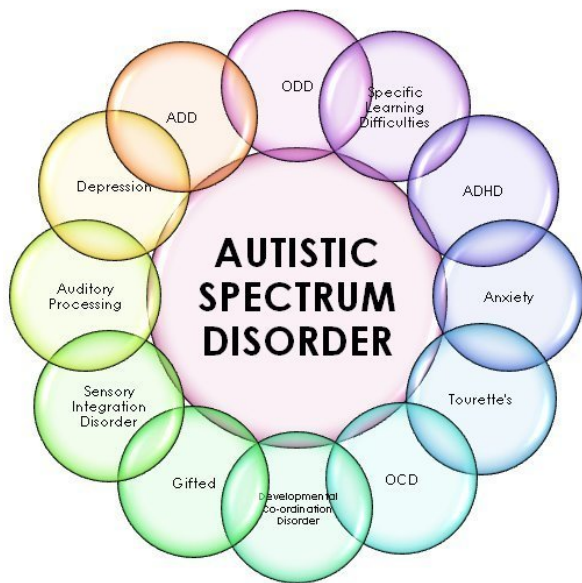
I am a donor offspring (1953). My bio father turned out to be my mother's very own physician. She was assured that it would be a resident from the hospital, but he confessed to her later, when she asked him about the color of my eyes. They looked like his. He died at the age of 41, very young. I was told about him when I was in my early teens, and she gave me a copy of his obituary and a photograph. My son was 16 when he ended his life. I have battled depression for years. I decided to research my paternal side and was shocked by my findings. Both of my paternal grandparents died in a psychiatric hospital in Iowa. I sent for copies of the medical records and found that my grandfather suffered with psychosis and my grandmother lived out her life in a catatonic state. My bio father had a son, who ended his life by an overdose, when he was in his early 30's. My bio father had one brother and three of his children ended their lives. One drove her car over a cliff and the other two overdosed on prescription medication. I found a history of depression, schizophrenia and bipolar disorder in the family. I went back further in the family tree, and there I found self inflicted gunshot wounds, overdoses, and one even took poison. My paternal grandfather was really unbalanced. He was a bigamist and married to four different women (no divorce) that he simply walked away from. He walked away from his first two children as well. That is not normal. I have many serious health problems as a result of that donor. Unfortunately, so do my children, and now my Four year old grandson is showing signs of a disorder.

[Five Major Mental Illnesses Traced to Same Genetic Variations](#)

All medical updates should be available to all families who have purchased the gametes of any one donor, and all donors should be aware of children born with any health issues.

Both nature and nurture contribute to many psychological and mental disorders. But most donor conceived people know little to nothing about the family history, or the ongoing psychological health of their unknown genetic relatives. The self reported medical information that donors submit are only reflective of one day in the life of a healthy donor, what that donor wants the clinic to know, and certainly not what happens afterwards. Regular medical updates are necessary as many mental illnesses are adult onset, and sharing updated information among related families is imperative. Additionally, donors with mental illness/issues or groups of half siblings with mental illness/issues should deter sperm banks from continuing to sell that donor's gametes.

The Donor Sibling Registry has high numbers of large half sibling groups reporting children with these issues:



I have had a theory for a while that there is a higher incidence of Asperger's among donors. I have heard from quite a few donors with Asperger's and also from families who discover that their donor has Asperger's once they connect on the Donor Sibling Registry. These families oftentimes have half sibling groups that have children with ADHD, Asperger's, Tourette's, and with kids somewhere on the autism spectrum. 36% of our 1700 surveyed sperm donor recipients report

children with these issues, while some Autism studies report that 1 in 68 people have autism. Very interesting!

My theory about donors is that Asperger's may sometimes contribute to that "disconnect" needed to donate sperm: to not be concerned about having (many!) biological children out in the world that they'll never know. I know a lot of men who say they could never donate for this reason, so I do think there is some level of emotional disconnect needed. Again, this is my opinion/theory, and not backed up by any actual research.

From one donor:

"I'm a donor who probably has Asperger's, and I'm aware that one of my donor children exhibits many traits of Asperger's, but his mother hasn't formally diagnosed him. My son from my marriage also exhibits Asperger's and Tourette's symptoms.?"?

From a few parents:

"I have 3 children, all from the same donor. One is PDD (High Functioning), the other 2 are ADHD. In our siblings group there are is a pair of autistic twins and one other PDD child, and I think also at least 2 ADHDs."

"...we also have a high rate of autism diagnosed among the boys in the sibling group (we have 60 families)".? ?We have multiple offspring with tics (including several with Tourette's) and ADD/ADHD.?"??

"My daughter has pdd-nos, nonverbal learning disability, mood disorder-nos and adhd. Her doctor has raised the question if Asperger's. My donor's daughter with his wife has Aspergers & adhd. The donor had adhd & undiagnosed Aspergers.?" ?

"I had genetic testing on my 2 boys that were conceived from the same donor. They inherited a mutation. On a gene that is known to cause autism and Rhett syndrome. Both of my boys are autistic. One of their donor half siblings who is also autistic just received genetic results and she also inherited the same mutation in the same exact spot in the her genome as both my boys."

"I noticed on a Facebook site that 3 half-sibs all had autism ... I checked and that donor's profile did not include this update! The mothers reported it but the clinic decided not to 'update' the donor's profile

cause they said there was no proof that autism is genetic!”

“We used California Cryobank, and I actually called them after our daughter was diagnosed with autism and anxiety disorder, just to ask why they did not, and maybe they should, ask these types of questions on the donors health info. The geneticist told me that they wouldn’t take a specimen from an autistic person, that the staff “would have known by meeting him” if he had ASD. Ha! People with ASD go their whole lives without being diagnosed...you cannot tell by LOOKING at someone! I was surprised and disappointed at their lack of knowledge on it.”

[What You Need To Know About The Genetics of Mental Disorders](#)

If you have a story to tell, an expert opinion, or just want the FDA to hear your voice, please add a comment to our [FDA Citizen’s Petition](#): ***Because the FDA currently mandates only minimal medical testing of sperm and egg donors (no other regulation exists), we request that the commissioner of the FDA look into the state of affairs surrounding the sperm donation industry, and then develop the appropriate and much needed regulation/oversight.***

Half Siblings from Sperm and Egg Donation

03/13/2017



Three half sisters meet

Family can be formed and defined in so many different ways, but biology has always been the most common family bond. If biology didn't matter, we'd give birth to our babies, and then just pick any baby from the hospital nursery to take home. That doesn't happen! In most cases, parents want to take home and raise the child that they have a genetic connection with.

Having a biological connection to a child (to one parent) matters to parents who use sperm and egg donors*. So, if parents value this genetic connection on one side of our 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.

Donor offspring 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 anonymous 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.

Even children of donors can be curious about their half siblings.

We often talk about the importance of honesty in donor families, and honoring a child's curiosity about their first-degree genetic relatives. Do donors also owe their own children the truth about their donating? Do the donor's children have a right to know that they (may) have half siblings? DNA testing is already revealing these family connections, and it will only continue to become more common. My guess is that most donors do not inform their families, as some are ashamed, some don't consider donor children as true "family", some are afraid of 100 kids coming forward, and some have spouses very much against it. I should note that we do have a few thousand donors on the DSR who are open to contact (with some wonderful resulting stories), and we do hear about positive donor-offspring connections also made through DNA.

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.

Why not give children the opportunity to grow up knowing their half siblings?

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.

Some parents who have seen their children's half siblings posted on the Donor Sibling Registry (DSR) have said that they will wait to establish contact with the half siblings 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 Aunt Shirley, Cousin Frank, or Grandpa Larry to make the introduction. Our children grow up knowing their relatives, and then, when they are older, they choose who they wish to be in contact 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.

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.

[Connecting on the DSR may be the only way to share/update important medical information with other families.](#)

For most, 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 siblings (I'm close to three sisters and one brother). We get closer every year because we FaceTime, text, and get together in the summertime; ever since I was three. My sisters and I are now teaming up against our brother. And it's fun picking on him. 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.



Twins (on either end) meet half siblings for the first time

You're never too old to find half siblings.

When I signed up with the DSR a year ago, I did it more with the hopes of finding information about my donor, than with any thoughts of actually finding a sibling. After all, I'd be conceived in the late sixties,

well before the existence of sperm banks with registered donors. At that time everything was very secretive, with absolutely no information given to the parents. When I got to the DSR, I was the first person to create a listing under my mom's doctor's name, from New York City. About eight months later, a woman emailed me to say that her mother had used the same doctor as mine, just two years later. We figured we could band together to find out as much info as we could about how the doctor (now long deceased) had gone about finding donors. After a few months of research, we were able to piece together that the pool of donors he used was actually very small. It honestly hadn't occurred to us before that we could be siblings, but once we learned about the small donor pool, we figured why not give it a shot. So we found the most reliable and thorough testing facility, and did a half-sibling DNA test. Lo and behold, it came back with 99.7% certainty that we were sisters! So for all the older donor offspring out there who have only fragments of the story of their conception, don't give up hope.

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 more flat or sometimes even more of a struggle. Our families are made up from all races, religions/non-believers, academic backgrounds, gender identities, sexual orientations, abilities, socio-economic backgrounds, political perspectives, nationalities and varied personality types.

All families have issues. Not all people are like-minded, or have enough in common to wish for continued relationship, and sometimes people don't agree on the desired level or degree of contact. [When we look around our Thanksgiving table](#), do we want to hang out with everyone there? Sometimes not! Some family members are just not the kind of people you'd want to hang out with, and some may just be people with whom we don't have enough in common. Are these reasons to not seek out your (or your child's) unknown genetic relatives? We think not!

* People who sell their sperm and eggs are commonly known as "donors", although most don't actually donate anything.

Sperm & Egg Donation: Telling is the First Step

03/10/2017



In 2000 when my son and I started the Donor Sibling Registry (DSR) (initially as a Yahoo chat discussion group), the predominant conversation was about disclosure. Back then many, mostly straight, parents were invested in keeping the secret, and came from the point of view that as a parent, disclosure was their personal choice to make for their family. They did not like to hear about why not telling (lying) might be harmful to offspring and unhealthy for their family. They didn't want to hear that secrecy implied shame.

"Secrets are like landmines you know. They can go off at any time, but until they go off you're sort of treading around them."- Donor Conceived Person, Barry Stevens

Some felt attacked and offended when offspring or other parents gave reasons as to why lying to their child was not right. They stuck to their guns, even when they heard from offspring who reported feeling like their world had been turned upside down, when they discovered the truth later on in life. These parents insisted that they were not telling their children because it would "hurt the child" to know the truth. They didn't want to hear that non-disclosure was more about their own (or their partner's) shame and fear and not at all about what was in the best interests of the child.

Why should a parent's right to secrecy trump a child's right to the truth? Healthy relationships are built on foundations of trust and honesty. We expect honesty from our children, shouldn't they expect the same from us?



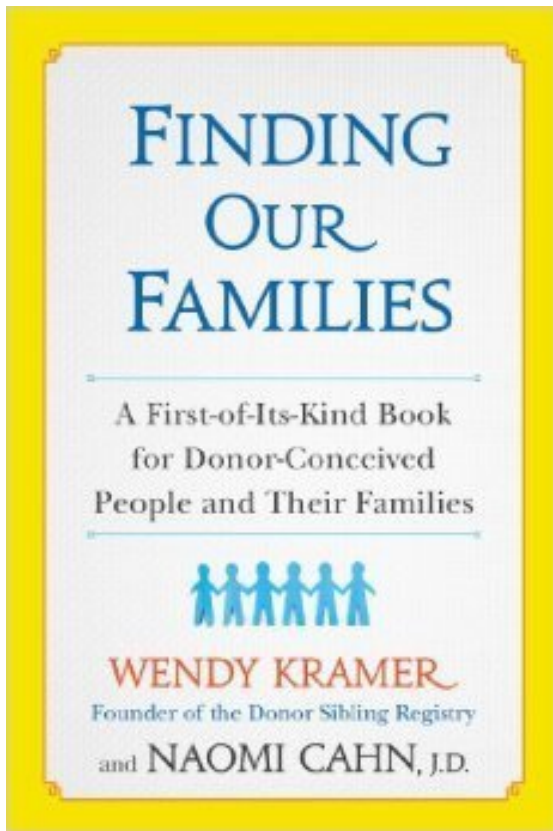
This conversation is not a new one. Honesty has long been an accepted practice within adoptive families, while at the same time, sperm banks and egg clinics were (hopefully no longer) advising parents to "keep the secret". There was never any psychological research to back this up, so we know that the advice had no psychological foundation and no merit. It only served to keep the industry's dirty secrets secret. It also served to protect the infertile non-bio mom or dad, and it perpetuated the shame of infertility. It created so many parents with shoulders heavy from carrying a deep dark secret for decades. This is why we strongly recommend infertility counseling (before pregnancy) for non-bio moms and dads. It's important that they work through their own grief about being infertile so as not to pass along that grief, in the form of shame, to their children.

Many of the parents who chose to "keep the secret" left our group. Some have joined the DSR in secret, connecting with other families only to tell them that they have no intention of telling their children. I can't help but wonder how these families have fared, if/when the secret came out, how the children reacted, and how long they all have before [DNA reveals the truth to everyone](#).

Telling is just the beginning though. Just because a child knows that they were conceived with the help of a donor, doesn't mean they will have peace with not

knowing about one half of their identity, medical background and close relatives. The conversations on the heels of disclosure are extremely important. They should acknowledge, honor, and validate any curiosity that donor offspring have about their unknown first degree genetic relatives. They should support any desire that a donor offspring has to search for, and to connect with these relatives. The conversations should be ongoing and affirming. **Telling is only the first step to creating healthy and happy donor families.**

If you need help in supporting your donor conceived child, including deciding when and how to tell your child, read through our DSR Counseling Page. For more in depth advice (from all of the stakeholders: offspring, parents and donors), read [Finding Our Families: A First-of-Its-Kind Book For Donor Conceived People and Their Families](#).



Some other issues addressed on our Counseling Page:

How to move forward in connecting with a donor or a half-sibling family (or many families).

Non-biological parents feeling uncomfortable about their children reaching out to biological relatives.

How to cope when you have a burning desire to know your genetic/ancestral history, both with and without parental support.



One Week Of News About the Sperm Donation Industry

02/10/2017

WISC TV: [Woman hopes for more regulation, protection for donor-conceived people](#)

"I'm not looking for a new Dad. I have a Dad," she said. "He's the best Dad I could ever ask for. I'm just looking for a part of myself and I'm sure there are lots of people out there doing the same." "I feel like everybody has a right to know where they come from," she said. "If he was sick, if he was carrying a genetic disease, I feel like I should know about that. Otherwise, it's like a crap shoot. What could I have that I'd pass on to my kids? I have no idea."

NBC Denver: Mother worries about sperm donor's medical history

A story about a mother who used sperm from California Cryobank.

The reality of conceiving with an anonymous donor hit her when she learned the boys were speech delayed. When they turned six, Jayden was diagnosed with cancer. "All of these doctors, including the pediatrician, would ask me about their genes, about their family history," she said. The information Lynnette did have was limited. A medical history questionnaire with was virtually blank. The donor claimed neither he, nor any of his close family, suffered anything on this long list of illnesses. Even to the question "any other condition not listed above" he said "no."

NBC Atlanta: [Sperm For Sale, Fighting For Change](#)

A story about a mother who used Xytex Cryobank.

Max's biological father was convicted of burglary and diagnosed with bipolar schizophrenia, which has about a 10% chance of being inherited by his offspring. And it's believed he has many offspring. According to court records and emails, the donor has at least 36 children, scattered in 5 states and 3 countries.

That's why in January, Kramer filed a citizen's petition with the FDA begging for change. The FDA is taking comments from the public as it decides whether this is a serious enough issue with community or industry support to investigate. Several parents who have already commented say they too found "inconsistent information" in their donor profiles. One medical professional told the FDA "puppy breeding is more regulated." Out of interest, 11Alive checked the requirements for puppy breeders. Both must be licensed if they want to have a certain sales volume. Both are inspected with a focus on safety and cleanliness. The difference seems to come in the fact dog owners want to brag and are open about their puppy's lineage so claims of parentage are often better tracked. If you are told contractually you are buying a pure bred and later find out that's not the case, you have strong case in court.

WRDW12 News: [Both liquid nitrogen tanks were never permitted for use at Xytex, fire marshal says](#)

A police officer in Georgia died after inhaling a fatal amount of liquid nitrogen while trying to rescue a worker at Xytex Cryobank.

Investigators say one deputy has died after inhaling an unknown chemical substance at Xytex Corporation in Augusta. The State Fire Commissioner has issued cease and desist orders to company involved in deadly liquid nitrogen leak. The orders were issued to Xytex Corp Tuesday morning. The order states the Airgas Liquid Nitrogen tank was utilized without an installation permit inspection, according to Glenn Allen with the Office of Insurance and Safety Fire Commissioner. It turns out Xytex did not have a permit inspection to start using the Airgas tank. Now, the State Department of Insurance is citing them and the Nitrogen tank maker, Airgas. They are not allowed to use the tanks until they correct the system and the commissioner re-inspects it. Xytex and Airgas got two citations.

FDA Citizen's Petition: The Need For Sperm Bank Regulation

We just filed a "Citizen's Petition" to the FDA, and it's now available for people to add comments. [Please, add your comments](#), as the more we get, the better our chances of accomplishing something (anything...even a further conversation with the FDA would be considered success).

<https://www.regulations.gov/docket?D=FDA-2017-P-0052>

"Because the FDA currently mandates minimal medical testing of sperm and egg donors (no other regulation exists), we request that the commissioner of the FDA look into the state of affairs surrounding the sperm donation industry, and then develop the appropriate and much needed regulation/oversight."

From my FDA contact:

"Good Morning Wendy, I've attached your acknowledgement receipt for the petition. Its docket number is officially FDA-2017-P-0052. You may view or comment on the petition through www.regulations.gov here is the link to your petition: <https://www.regulations.gov/searchResults...> I have sent the petition to the FDA's Center for Biologics Evaluation and Research (CBER). Per regulation the center has 180 days to respond to you about this petition. That response may be a decision or an interim response. We won't likely receive an update before that time unless the center has questions for you. In that case, they will contact you directly."

A few initial public comments:

"Our cryobank has been unable or unwilling to locate our "identity release" donor for 6 months now, despite all requirements/paperwork being in order, and does not return phone calls or emails regarding the status of our request to contact the donor. However, with DNA testing we were able to locate the donor ourselves, only to learn that some of the original information we were provided by the cryobank was incorrect, including identity release status, ethnicity/religion, college information, SAT scores, and certain health information. This industry needs to be regulated so that donor information is factually correct and that the cryobanks are being forthright and honest in their dealings with clients."

"The United States is one of the only developed countries on earth that is lacking crucial regulation and oversight of the artificial reproduction industry. There is ample research supporting the negative effects that this lack of regulation continues to cause. The FDA has a responsibility to put common sense regulations in place to ensure the safe and ethical creation of human lives by donor conception."

"I strongly support additional review of the donor gamete industry. I believe the FDA should engage in further investigation of the business of egg, sperm, and embryo donation as a basis for developing further regulation and oversight. As an academic who has studied and written articles and books about the fertility industry, I strongly urge you to undertake additional review. Thank you.?"

"I reported to the sperm bank that my child was diagnosed with cancer (lymphoma/leukemia) the same week of his diagnosis and provided proof, so they could report it back to the donor and to the other families who had used the same donor. Almost two years later, none of the 11 families I am in contact with have been notified about my son's condition."

And I also submitted a comment:

Here is some recent input from families who used California Cryobank (from the Donor Sibling Registry Secret Facebook page, January 2017). This information illustrates the dishonest manner in which sperm banks (California Cryobank is not unique in this respect) disseminate information about limits on numbers of offspring for any one sperm donor:

"They told me in 2011 it was limited to 20 family units but they are now saying it has increased to between 25 and 30 family units."

"In 2011 CCB also told me that they limit families of open id donors to 20 and anonymous donors to 25."

"Back in 2004 I was told that each donor had 10 vials and that was it."

"When I used CCB in 1999 they told me limited to 30 families - as of right now there are 30 kids."

"In about 1990 they told me ten. I guess it just

depends on who answers the phone!"
"In 1991 they said 1 or 2 births was the limit."
"In 2005 we were told the limit per donor was ten families."
"In 2010, when we chose our CCB donor, we were told 10 families max."

Note: When a prospective donor called CCB last summer and asked this question: "What is the maximum number of children that you allow per donor? California Cryobank told the prospective donor, "12 to 15 family units."

Sperm and Egg Donation: 10 Things Your Doctor, Clinic, or Sperm Bank Won't Tell You

1. Most donors* and recipients are not properly **educated, counseled, or informed** beforehand about the needs and rights of the children they are helping to create. This includes the importance of connecting with families to share and update medical information, [and the innate desire of donor conceived people to know about their first-degree genetic relatives](#).
2. There is **no comprehensive medical and genetic testing** conducted by clinics and sperm banks. In the US the FDA only mandates for STD testing and for a handful of other diseases. Some facilities test some donors for some diseases. Testing for STD's does nothing to prevent transmission of genetic illness. Proper genetic testing of all donors is critical. [Hundreds of medical and genetic issues have been reported to the Donor Sibling Registry, many of them hereditary](#).
3. There is **little to no regulation or oversight of the US reproductive medicine industry**, which ships sperm to over 40 countries around the world (so this is a global issue). This industry is not required to maintain or update records regarding genetic disease transmitted to donor offspring. Information about inherited physiological and psychological predispositions are a significant element in obtaining appropriate medical care, particularly in preventative health care including screenings and preventative medicine. Examples: genetic predisposition for [heart disease](#), [mental illness](#), or [Cystic Fibrosis](#). A donor's medical profile is merely a self-reported family health history, along with a snap shot of one day in the life of a healthy young adult. [84% of surveyed sperm donors and 97% of surveyed egg donors were never contacted for medical updates](#).
4. **No accurate record keeping** exists about how many offspring are conceived for any one donor. Records, if any are kept, are incomplete regarding the number of offspring created from each donor, as all reporting is voluntary. There are many large cohorts of half-siblings, [some now as large as 200](#). If urgent medical issues arise, families can not then be notified. Many families who are on file with the sperm banks claim that they were never notified about medical and genetic illness reported to sperm banks by donors and by families who used the same donor: they learn about the genetic and medical issues by connecting with other families on the DSR.
5. Around three quarters of surveyed **donor offspring advise that prospective parents do not use "anonymous" donors**. Many countries have banned anonymous donation and we all need to ask the question "what is in the best interests of the child to be born?" "Anonymity" is never the answer. [Many heartfelt stories and testimonials by donor offspring have been reported to the DSR](#). Many parents use donor conception instead of adoption because a genetic connection is important to them, but then negate the importance of that very same genetic connection when it involves their child's relationship to the "donor", the other half of their child's genetic family, ancestry and medical history.
6. Many **donor conceived children long to connect with their half siblings and their donors** long before they are 18. 18 is an arbitrary number set by clinics and sperm banks to protect their own financial liability. This age limit is not backed up by any psychological research. Quite to the contrary, [research has shown](#) that many wish to connect, and have made successful connections, long before the age of 18. [Thousands have been doing so on the Donor Sibling Registry for more than 16 years](#). Many egg clinics (not one sperm bank) have been connecting donors and parents on the DSR

(anonymously) from pregnancy or birth for years. This allows parents and donors to share and update medical information right from the start, and it allows children to have access to their biological parents from the moment they start asking questions.

7. **DNA: Donors Not Anonymous.** Anonymity is a thing of the past and shouldn't be promised to any donor or to any prospective parent. Sperm banks and egg clinics need to stop the fallacy of selling "anonymous" donors. Donor conceived people have been locating their biological parents via DNA testing (along with Google and social media) since 2005, as reported in [New Scientist Magazine](#), so this is not news. Donors do not need to test their own DNA in order to be easily found by offspring and/or their parents, and there is no law prohibiting contact. Donors must be willing to be known by any offspring they help to create - and long before offspring turn 18.

8. Because of this end to guaranteed anonymity, **non-disclosure is no longer an option.** Many people who swabbed their cheeks to learn more about their ancestry and family tree have been shocked to find out that they are not genetically related to one of their parents, because their parents used a donor, and kept it a secret. Many have also been shocked to connect with half siblings. Finding out in this way that your parents have not been honest can wreak havoc on a donor offspring's sense of trust and stability in the family. If you are a parent who has yet to tell your donor conceived child that they were created with help of a donor, now would be the time to have that conversation, [and we can help with that](#). It's never too late to tell.

Family secrets can be toxic, and your donor conceived child has a right to know about the methodology of their conception, about their medical background, and about their ancestry. [If parents have not told, there is usually some grief associated with infertility that is unresolved, or there is an unfounded fear about a non-bio parent's relationship with the child being negatively affected by the truth coming out.](#)

Parents: This shouldn't be about your unresolved grief, your hesitations, or your fears. This should be about what's in the best interests of your child, and their right to the truth about themselves,

their medical background, their ancestry, and their genetic relatives. After telling (or after your children find out via DNA testing), please do not ask your children to keep the "secret". This may have been your secret, but it shouldn't be theirs. This type of response could cause unnecessary resentment, anger, and upset. Secrecy implies shame, and donor offspring have nothing to be ashamed of, most certainly not the methodology of their conception. Get yourself some counseling to help work through your unresolved grief, fear, or shame so that you don't pass it along to your children. You are, and always will be your child's mom or dad. You can work on becoming a more confident parent, secure in the knowledge that your child knowing the truth won't rattle the strong parental foundation that you have built.

9. **Telling is just the beginning.** Many parents think that just because they have told their child about his/her origins, that this will be enough. Many then minimize the importance of the "donor", thinking that because they don't feel DNA is important, then their child shouldn't either. Parents need to know that their child may view this invisible one half of their DNA to be a very important part of their identity and they may feel an urgency about gathering information and also connecting with their previously unknown genetic relatives. [DNA isn't the only way to make a family, but the importance of familial DNA connections can't be denied.](#) Honor your child's curiosity, and let them know that they have your full support as they venture out for more information. Don't behave in a way that forces your child to search for answers behind your back, as that can only create more resentment. They need you to be on their team.
10. **The choices you make early on about creating your family with a donor will affect your donor conceived child for many decades to come.** Try to think beyond your own needs, and educate yourself about [what we now know to be true for donor conceived people](#).

[The Donor Sibling Registry](#) (DSR) is a US based, global registry with a mission of connecting, educating, and supporting all those in the "donor family". The 501(c)3 non-profit organization facilitates mutual consent contact among donors, recipients and offspring, so that they can share important medical information,

and explore new relationships. Since it's inception in 2000, the **DSR has helped to connect almost 14,000 of its 52,500 members with their first-degree genetic relatives.**

*No one is "donating" anything, as all eggs and sperm are sold.

FINDING OUR PEOPLE: Wendy and Ryan Kramer's Story



[Finding Our People](#) Guest Blog by [Ellen S. Glazer](#)

As someone inveterately curious about people's lives, I hit "pay dirt" recently. Not only did I get to hear a family story in some detail, but it was not "just any" family story. My "pay dirt" took me to a series of interviews with Wendy Kramer. I had the incredible pleasure of hearing about her experiences as a mom helping her son, Ryan find his people. As the search unfolded, it was clear that these were Wendy's people as well. Here is a bit about why we had the interviews and how they worked.

First the **why**...For many years the DSR website has received and shared family stories of search, connection, kinship redefined. Countless stories have been offered, but one has remained largely in the background. I know that as a board member and reader of the book [Finding Our Families: A First-of-Its-Kind Book For Donor Conceived People and Their Families](#), I knew bits and pieces of Wendy and Ryan's story, but I had no sense of a time line, of how much—if at all—the website assisted Ryan in his personal search, about what—if any—relationships Ryan had with genetic siblings, his donor, extended family. There were pieces of information but I had lots of

questions. Admittedly, I'm a family story junkie, but in this instance, I was pretty sure I was not alone in my curiosity. From my perspective, this was a story worth telling and long overdue.

Now the **how**...This was the fun part! I don't watch TV, but have heard from so many others of the thrill of moving from episode to episode of an exciting and engaging series. Who among us has not known—or been—someone tethered to Mad Men or Orange is the New Black. Over the course of five or six weeks, I had my own thrill of going episode to episode: for me it was the Wendy and Ryan story.

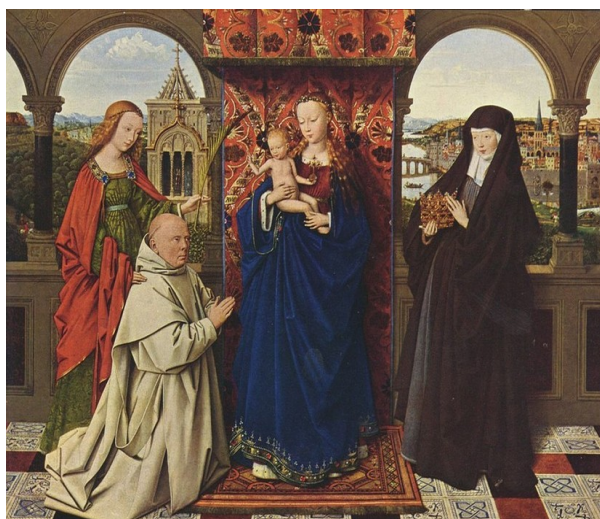
I suppose that Wendy and I could have covered the Kramer's story in one long, intense phone call but that wouldn't have worked for me. Instead I needed to take each episode in, write it up, marinate on what I'd learned and then move on. It was clear that each twist and turn in Ryan and Wendy's journey taught them new lessons about family and that these lessons were well worth passing on to others. I wanted to not only hear this fascinating story but to make sense of it. And so it was to this end that Wendy and I spoke once each week for about an hour over five week span. I remember looking forward to each call, eager to find out "what happened next" and how it was all unfolding.

Our conversations continued until the story was current and there was nothing more to tell—at least not yet. Hopefully Wendy will share new chapters in their story as they unfold and I will have the opportunity—I hope—to add them to the narrative you will see on the DSR website. For now, I hope that you will find [Finding Our People](#) ([the link to the pdf can be found here, on the DSR's Board Member Page](#)) as moving and compelling as I did. It more than satisfied this family story junkie.

-[Ellen Glazer](#), November 2016

(This story by Ellen Glazer can be found in its entirety at the bottom of this document).

The Ambiguity of "Open" Sperm Donation



JAN VAN EYCK: VIRGIN AND CHILD WITH SAINTS AND DONOR - EARLY 1440S

Yet again, the highly unregulated medical field of sperm donation is failing parents, donors, and the donor conceived. This time we're calling attention to their inability to manage or to offer any consistency with non-anonymous sperm donation practice and policy. The concept is simple: a "donor" (no one is donating anything, a man is paid for his sperm) makes non-anonymous sperm donations (he agrees to have contact with the children he helps to create when they turn 18), parents wanting a child purchase that donor's sperm (most vials of non-anonymous sperm are a lot more expensive than anonymous sperm), a child is conceived, and the sperm bank makes money.

We are now hearing from families who purchased non-anonymous sperm, only to find out later on that this is not the case. Sperm banks are failing to provide that which both the donor and the parents agreed to.

This issue highlights the need to legally ban donor "anonymity" so as not to leave the interpretation of a non-anonymous (often called an "open" or a "willing-to-be-known") donor, to each different sperm bank (or egg clinic), or to the whim of young donors, [many who donate while in college and who are never properly educated or counseled about the needs of the resulting children they are helping to create.](#)

We recently heard 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."

"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."

[Many more PRS testimonials here.](#)

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.'

Some donors who either chose anonymity, or who were never given a choice, become interested in connecting with the children they helped to create.

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."

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

[Many more Fairfax Cryobank testimonials here.](#)

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."

"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."

"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....."

[Many more NECC testimonials here.](#)

Families who used California Cryobank should know about their "open" donor policy: A couple of years ago I asked CCB about the 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 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."

[Many more California Cryobank testimonials here.](#)

The sperm banks handle "open" donations differently. Some, like California Cryobank, send the generic letter to donors asking them to "update their information", and if they don't hear back, that's considered a "no". Many sperm banks say that they will "try" to contact donors to see if they are still open to contact with offspring. Sometimes they can't find the donors, and

sometimes they never reply to an 18-year-old's request for contact.

I don't think the sperm bank's website or contract verbiage matters much at all. We know of donors who tried to change from anonymous to open, but couldn't. And we know about donors who are "open" but never respond to contact requests. We also know about "open" donors who outright refuse contact. And we know about donors who chose anonymity and who, when given the opportunity, are very open to establish relationships with their biological children.

From two formerly anonymous donors:

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

"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."

When choosing a sperm bank, it's important for prospective parents to research beyond the marketing materials on a sperm bank's website. The Donor Sibling Registry has a "[Which Sperm Bank](#)" page where user testimonials can be found.

My son Ryan was the first donor conceived person (that we know of) to locate his "anonymous" donor via

DNA testing in 2005. Many donors who chose anonymity are indeed open to contact when given the opportunity, and luckily, ours was. Ryan and his biological father (below) have enjoyed more than eleven years of getting to know one another and he has also been able to establish a wonderful relationship with his biological grandparents. None of that would have been possible if not for commercial DNA testing creating an avenue separate from the sperm bank's anonymity policies.



No Laws Prohibit Donor Recipients from Reaching Out to Donors

I recently heard from a woman so fearful about sperm bank repercussions that she wouldn't make a phone call to the Donor Sibling Registry (DSR) for fear of having the call somehow traced by her sperm bank, and she even opened up an anonymous email address just to ask me about signing up to the DSR and contacting her donor.

She included this sperm bank contract verbiage:

Purchaser agrees that Purchaser has no right to learn the identity of a donor and will not, directly or indirectly through a third party, make any attempt to contact a donor.

This appears to be no more than a fear tactic, as we know of no one ever sued by a sperm bank/clinic for reaching out to their donor (by a parent) or to their biological father/mother (by a donor conceived person) either via the DSR or through any other method. (We have 16 years of experience and more than 52,000 members on the DSR.)

Many egg and sperm donors and recipient parents have been told by their doctors, clinics, agencies and sperm banks that there are laws prohibiting donors and parents/offspring from connecting. Recently, a parent signed up to the Donor Sibling Registry who used Cryogenic Laboratories (Fairfax/GIVF/CLI, shipping to Canadian and worldwide clinics), saying, "if the laws change, this donor might be willing to meet his offspring." When I questioned her about it, she said that she was told by CLI that there were laws prohibiting contact between donors and families.

There have **never** been any laws that prohibit contact between genetic relatives formed via gamete donation. Any such agreement signed by recipients

and donors forbidding contact is therefore inoperative.



An attorney who is also a donor conceived person weighs in on the topic:

Family law trumps contract law: Family law always puts the best interest of the child before all. A parent can't sign a contract that restricts what is in the best interest of the child. No court would rule against this as it's unenforceable.

It would seem that the sperm banks and egg clinics who continue to spread this false information have done so only to protect their own liabilities. For example, if a sperm bank promises donors or families a limit of 10 or 20 children per donor, revelations that the actual number is in many cases considerably higher (in one known example, around 200) would shed light on the gross shortcomings of their record keeping. If medical issues are reported to an egg clinic or sperm bank and not shared among families, or if the sale of gametes from which serious medical issues are known continues to be sold and sick children are born, the subsequent facility liability could be severe.

As a donor I updated my medical records between donations. They did not pass those updates on to previous recipients NOR recipients 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.

There is also the risk that families might discover that donors were not necessarily honest with self-reported health and education information they reported on their donor profiles.

All of these scenarios are frequently encountered by families on the Donor Sibling Registry, underscoring the need for honesty, accurate record keeping, and accountability by sperm banks and egg clinics. These facilities need to stop falsely threatening families and donors who wish to reach out to one another. Mutual consent contact can be made between any of the parties, at any time. Connecting with first degree genetic relatives via the DSR, social media, Google or DNA testing is completely legal.

It's time for these egg and sperm selling facilities to stop working so hard to keep donors and recipients

from each other, and start supporting and promoting contracts that allow contact right from the start on the Donor Sibling Registry.

What Does A Relationship With The Donor Sibling Registry Do For Your Sperm Bank/Egg Clinic/Agency?

CONTACT: The issue of contact between the donor and the recipient family (and half-sibling families) is removed from the hands and focus of the facility. Messages, photos and medical information can be shared, all while remaining private.

CONSENT: Since the DSR relies on mutual consent; the facility doesn't need to be worried about protecting anyone's privacy.

CHOICE: Each party can remain anonymous if they choose, so the decision is ultimately in the hands of those involved. Each party can decide how much information they're comfortable sharing.

CURRENT MEDICAL: The sharing and updating of medical records happens on the DSR, so the facility has less work since they have provided a tool for medical updates.

“Donor Babies” are Sometimes Grandparents!

While hiking on a trail near my home in Colorado last month, I met up with a 57 year old man who recognized me from the Donor Sibling Registry and identified himself as a “donor baby”. This got me thinking about all the “donor babies” out there who are close to, or already at grandparent age.

The utilization of “donated” gametes has taken decades to be publicly talked about as an accepted methodology for achieving pregnancy. Today, the number of families using “donated” (no one is really donating anything, as all gametes are sold and then bought) sperm or eggs have skyrocketed. The Donor Sibling Registry (DSR) members: donors, parents and donor offspring, are now at more than 51,400. No one can know for sure what percentage of total worldwide offspring are members of the DSR, as [*no such records are kept*](#).

The majority of donor offspring posted on the DSR are under the age of 18. However, the DSR does include many donor conceived members born more than 50, 60 and even more than 70 years ago. The oldest donor conceived DSR member was born in 1943, back when the use of donor sperm was a secretive and often shameful procedure. Parents were advised to never tell anyone, not even their own child. It was common for parents to be told to go home and have sex so that they could always think that the husband just might be the biological father of the child. Family secrets do have a way of being dispelled though: deathbed confessions, found paperwork, chatty relatives, and now as commercial DNA testing becomes more popular, many are now shocked to discover the secret that their parents had kept for decades.

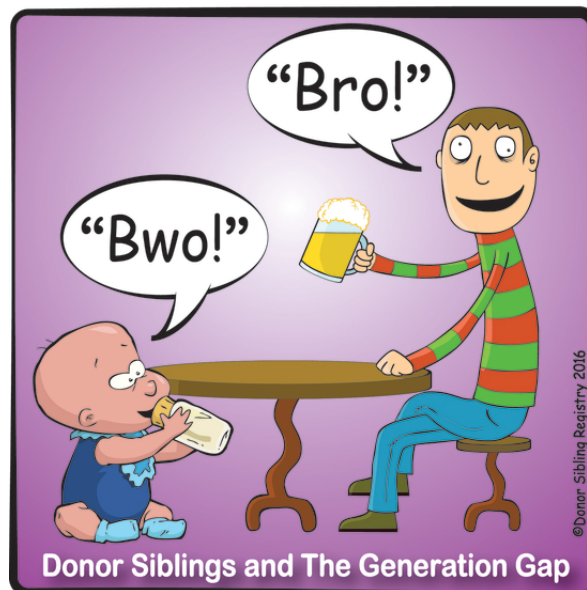
While we strongly recommend that everyone posts on the site, many DSR members never add their postings, so here are some very conservative numbers about older offspring ages:

- 3 offspring in their 70s
- 42 offspring in their 60s

- 72 offspring in their 50s
- 204 offspring in their 40s

The recommended secrecy was often rooted in the fact that it was not uncommon for doctors to inseminate patients with their own sperm, even into the 1980s. During this time, the patients were mostly women married to infertile husbands. These doctors were secretly (the couples were oftentimes told it was a “medical student in the other room”) inseminating their patients for decades. Sometimes it was a lab worker in the facility, and in one known case, it was the doctor’s weekend handyman who donated for three decades after having his own children in the decade before he even started donating.

Having a decades wide spread between half siblings is not uncommon. Donor conceived person [Barry Stevens](#), now in his 60’s, reports that he has located half siblings born between 1944-1972. Four decades of offspring, all sharing the same biological father: their mother’s doctor.



Donor conceived person Bill Cordray reports, “My father (my mother’s gynecologist) was born on the last

day of 1907. His oldest son was born in Feb. 1937. I am the oldest DI adult, born in July 1945 and my youngest new DI brother was born in May 1966.” He goes on to say that he knows of, “...two or three others who were born a year or so earlier than 1945.” Bill notes older donor conceived people that were known about back in the 1980’s, “According to what [author Annette Baran] told me, there was one DI adult in her small study who was 68 at the time she wrote Lethal Secrets in 1987.”

Many conferences that I see still address sperm donation, and even egg donation, (which has now been around for more than 30 years), as “new” reproductive technologies. So while many of the issues surrounding the ethics of the reproductive medicine industry are new to the public eye, [these methodologies have been around for a long time.](#) These are not “new” discussions to us, the stakeholders: parents, donors and offspring. As times goes on, we’ll certainly continue to hear more from the resulting children, as more of them become old enough to contribute valuable public input regarding the very industry that helped to create them.

And finally, it should be recognized that it’s not just the donor-conceived people who are becoming grandparents, it’s also the donors, many of who donated back when they were in college.



This donor had the opportunity to meet his first grandchild on the same day that he met his biological daughter for the very first time. Since then, he’s been able to welcome his second grandchild into the world, becoming an important figure in the lives of his child and grandchildren.

The more than 13,600 donor-offspring and half-sibling relationships formed on the DSR have become multilayered over time, and can span generations. This number will continue to grow and these relationships will continue to enrich the lives of both donors and the donor conceived, so long as transparency and disclosure continue on as a common goal. Ending the promise of anonymity to both donors and prospective parents would further “color in” the missing pieces of genetic histories, and bring emotional health and even physical peace of mind, wellness, and above all, happiness to the deserving donors and donor conceived people.

**Cartoon by Jen Moore*

A Multi-Billion \$\$ Unregulated Industry With No Oversight. What Could Possibly Go Wrong?



Many sperm and egg donors and recipients have been told by their doctors, fertility clinics, and sperm/egg banks that there are laws in effect prohibiting donors and parents/offspring from connecting. Recently, a parent who used Cryogenic Laboratories (CLI) (1) joined the Donor Sibling Registry. She said, “if the laws change, this donor might be willing to meet his offspring.” When I questioned her about it, she said that she was told by CLI that there are laws prohibiting contact between donors and families.

There have never existed any laws that prohibit contact between genetic relatives formed via gamete donation.

The sperm banks and clinics who have spread this false information have done so only to protect their own liability. For example, if a sperm bank promises donors or families a limit of 10 or 20 children per donor, revelations that the actual number in many cases is considerably higher (for example, [50, 150, or 200 children](#)) would expose the gross shortcomings of their record keeping and their honesty. Donors should know that donating for 5 years, 2-3 times per week (which is not uncommon) could, in theory, result in

thousands of sellable vials of sperm because each donation can produce up to 24 sellable vials of sperm. Additionally, sperm banks have been known to sell a donor's sperm for more than two decades.

[Furthermore, if medical issues are reported and not shared among families, or if the sale of sperm with known genetic medical issues continues to be sold and children with genetic abnormalities are born, the subsequent sperm bank liability could be severe.](#)

[Families have also divulged that some donors were not necessarily honest with self-reported health and education information disclosed on their donor profiles.](#) These issues, (and others) are frequently encountered by families on the Donor Sibling Registry, underscoring the need for both accurate record gathering and record keeping by sperm and egg facilities.

Since sperm banks and egg clinics/banks “self regulate” it is quite obvious that some regulatory entity needs to step in and provide some proper oversight. Regulations are needed; laws are needed. This industry needs to be monitored and held accountable.

[While the FDA mandates testing of donors for STD's? and a handful of other diseases,](#) donors report to the Donor Sibling Registry that they were never given physical examinations, and all medical information is self reported - no medical records are transferred to the sperm banks.

[Sean Tipton of the American Society for Reproductive Medicine, the entity that issues unenforced guidelines for the industry, continually frames this discussion of regulation as one of “reproductive rights”.](#) He

frequently says that regulation would keep parents who desperately want children from having them. This is a scare tactic he uses to keep regulation out of the sperm and egg donor industry. It's this tactic, [along with lobbying and spending money](#), that has kept regulation out of the reproductive medicine industry. This is not about reproductive rights, this is about an unregulated industry that is fertile ground for unethical and irresponsible practices.

Laws or regulations are needed regarding:

1. Record-keeping on donors, parents, and offspring
2. Number of children? born to a donor
3. Limits on the number of vials sold for each donor
4. Searching for, and contacting biological relatives
5. Donors donating at more than one clinic

6. Comprehensive medical and genetic testing of donors, e.g. full genome sequencing ([now below \\$1500](#))
7. Creating a system where the sharing and updating of medical information among families who have used the same donor, and even the donor him/herself is available to all
8. [Informed consent in sperm and egg donation and sperm and egg purchase](#). Both the donor and the recipient should know that for more than 11 years DNA testing has made anonymity a thing of the past. Anonymity shouldn't be promised to anyone.

Proper education should be regulated and mandatory.

1. Parent company GIVF: Fairfax Cryobank/CLI: Ships to worldwide clinics including Canada.

A Brief History of Donor Conception

Early History

1322

Artificial insemination (referred to as AI until the 1980s) was first used successfully by the Arabs on mares.

1425-1474

Unofficial history claims that the first attempts to artificially inseminate a woman were done by Henry IV, nicknamed "The Impotent".

1784

The first artificial insemination in a dog was reported by the scientist Lazzaro Spallanzani (Italian physiologist, 1729-1799). This insemination resulted in the birth of three puppies 62 days later.

1799

This method of conception was first attempted on a human being in the year 1799 by the English physician Dr. John Hunter.

John Hunter (1728-93) was a brilliant Scottish surgeon known for pioneering research into venereal diseases, child development and the lymphatic system, among many other things. Although he liked to experiment on himself — particularly unfortunate in regards to his research into syphilis and gonorrhea — the official

surgeon of England's King George III was also known to instill within his patients an equal zeal for self-experimentation.

When a young married man, desperate to have a child with his wife, came to him in 1790 with a grim condition known as hypospadias, in which the urethra basically takes a wrong turn out the underside of the penis, Hunter developed a plan. He equipped his patient with a collection of large syringes and a prescription for frequent masturbation. He was to collect his semen and inject it into his wife's vagina. Tragically, the exact details of their bedroom antics are lost forever, but the fellow did reportedly follow doctor's orders over the course of two years. By most accounts, a single pregnancy resulted, and Dr. Hunter had proven the possibility of artificial insemination in humans. But it would be a while yet before any physician would formally take up the cause of assisted reproduction.

1866

The practice spread to the United States in 1866 when Dr. J. Marion Sims of North Carolina conducted a series of fifty-five inseminations with varying degrees of success.

1884

The earliest recorded AI in a medical institution took place at the Jefferson Medical College in Philadelphia by Dr. William Pancoast. It was so secret that even the woman being inseminated wasn't told that the sperm was from a donor, not her husband. A fascinating story worth telling here:

In 1884, Dr. William Pancoast of the Jefferson Medical College in Philadelphia went rogue and decided to have a little scientific fun with one of his patients, a Quaker woman who had long been unable to conceive. After many examinations, he decided that the fault in fact lay with her husband's low sperm count. The man, an elderly merchant many years older than his wife, was officially shooting blanks.

Rather than inform her and her husband of the sad state of affairs and move on from a point of full disclosure, Dr. Pancoast summoned the wife to one final "examination." As the woman lay unconscious and chloroformed on his table as six of Dr. Pancoast's students looked on, the good doctor injected into her cervix a large syringe full of semen - freshly donated by the student democratically deemed by the group to be the most handsome.



This unnamed woman delivered a healthy baby boy nine months later. Presumably, all were ecstatic. The only problem was that Dr. Pancoast never actually informed her about what he did to her on the table that fateful day. Whether it was to spare her the embarrassment of her husband's sterility, or whether it was simply to see if he could do it at all, Dr.

Pancoast's experiment remained a secret success for 25 years.

It was only after Dr. Pancoast died — a quarter-century after the successful insemination of his presumably pleased patient — that the truth became known. In 1909, one of the students present that day, the suggestively named and incredibly handsome Dr. Addison Davis Hard, fessed up and published a letter in the journal *Medical World* containing all the dirty details. It is interesting to note that Dr. Pancoast did actually inform the woman's husband of what he had done, and that they had decided together to spare her the truth. In addition, before the letter was published, Dr. Hard took it upon himself to tell the by-then all-grown-up baby boy as well. Hopefully, his mother was not a subscriber of *Medical World* in her old age.

1890-1910

AI gained acceptance and popularity in Europe and Russia. In 1897 Dr. Heape, an outstanding reproductive biologist from Cambridge, reported the use of AI in rabbits, dogs and horses. And in 1899 the first attempts to develop practical methods for artificial insemination were described by Ilya Ivanovich Ivanoff (Russia, 1870-1932). Although Ivanoff studied artificial insemination in domestic farm animals, dogs, rabbits and poultry, he was the first to develop methods as we know today in human medicine.

1894-1909

In 1909, Dr. Hamilton claims to have used artificial insemination for fifteen years, "without a single failure".

1924-1928

In 1924, Rohleder in a survey; of the world's literature was able to find only 123 cases reported, whilst in 1928 Engleman, in a further survey was only able to increase this figure to 185, of which sixty-five had been successful.

1937

Hihner, writing in 1937 claims to have begun extensive use of the practice in 1915.

1941

In the United States alone, AI resulted in ten thousand successful pregnancies. In England, the first publication of a modern account of what was then called 'Donor Insemination' (DI) was produced in the *British Medical Journal*. The doctor behind the

research, Mary Barton, was vilified in the press and condemned worldwide. Dr. Mary Barton stated that over a period of five years about 300 children had been conceived as a result of artificial insemination.

1941

In 1941 it was reported that 9,489 women had been successfully impregnated, and that 97 per cent of the pregnancies had terminated successfully. These figures were compiled from a questionnaire sent to 30,000 doctors, of whom 7,643 replied, and of these 4,049 reported that they had carried out successful impregnations.

1940s and 1950s

AI was carried out discreetly by private medical practitioners. It was decided that it was best to leave unregulated (and remains so today). Parents were told to never tell anyone, not even the child. (This practice of secrecy continues on for decades, and is still recommended by some “experts”, even today.)

1951

Further evidence as to the extent of the practice in the United States is the statement made by Ploscowe to the effect that by 1951 the number of children born as a result of artificial insemination had risen to 20,000.

1953

As a result of this research, the first successful human pregnancy with frozen spermatozoa was reported in 1953.

1955

A NY Post article in 1955 estimated the number of children conceived via AI to be 50,000, and growing by 6,000 per year.

1963

At the present time responsible estimates indicate the rate of one thousand to twelve hundred births per year, although higher estimates are offered.

More Recent History:

1970s

The sperm banking business becomes popular and commercialized.

1979

Of 711 physicians likely to perform artificial insemination by donor surveyed to determine their

current practices, 471 responded, of whom 379 reported that they performed this procedure. They accounted for approximately 3576 births by this means in 1977. In addition to treating infertility, 26 per cent of these physicians used the procedure to prevent transmission of a genetic disease, and 10 per cent used it for single women. Donors of semen were primarily from universities, were only superficially screened for genetic diseases, and were then matched phenotypically to the recipient’s husband. Most recipients were inseminated twice per cycle. Only 17 per cent of physicians used the same donor for a given recipient, and 32 per cent used multiple donors within a single cycle. Only 37 percent kept records on children, and only 30 per cent on donors. The identity of donors usually was carefully guarded to ensure privacy and to avoid legal complications.

1987

The Office of Technology Assessment made visits to 3 sperm banks and 10 in vitro fertilization clinics.

A total of 1,558 questionnaires were completed and returned by the sampled physicians (a response rate of 61 percent), which included 37 physicians in the cross-sectional sample and 385 fertility society physicians regularly doing artificial insemination, i.e., seeing four or more insemination patients per year. An amended survey form was also sent to 30 U.S. commercial sperm banks identified by the American Association of Tissue Banks (MTB) and the American Fertility Society (AFS), and 15 of those forms were returned. The survey estimates that 172,000 women underwent artificial insemination in 1986-87, at an average cost of \$953, resulting in 35,000 births from artificial insemination by husband (AIH), and 30,000 births from artificial insemination by donor (AID).

These incomplete numbers from 1986-1987 are still used today by the media and by industry experts. This has led many to the false conclusion that there is some entity requiring record keeping on the children born from egg and sperm donations. While SART insists that they have accurate numbers on the number of egg donor births, research finds that more than 40% of parents were never asked to report the birth of their child.

The often-cited figure of 30,000 births per year is based on an extrapolation from a very small number of voluntary survey responses. These figures are further confounded by a sharp decline of practitioners

at that time, due in part to increased quarantine requirements (including restrictions against fresh semen) resulting from the circa 1984 discovery that semen could transmit the HIV virus.

Prior to the AIDS crisis, donor insemination was likely much more prevalent in small clinics and doctor's offices in the absence of fresh semen restrictions. In the years following the OTA report, the prevalence of large sperm banks and increasing acceptance and popularity of the technology suggests figures have likely grown considerably. As a result, the OTA figures most certainly under-represent reality.

Other Key Dates:

1953: First successful pregnancy using frozen sperm.

1977: First successful in vitro fertilization (IVF) pregnancy achieved (although no birth resulted).

1978: First baby born from IVF (Louise Brown, in England).

1981: First IVF baby born in the United States (Elizabeth Jordan Carr).

1983: First successful egg donation at UCLA.

1984: First baby born from a frozen embryo (Zoe Leyland, in Australia).

1990: First child born following pre-implantation genetic diagnosis (PGD).

1992: First successful pregnancy using intra-cytoplasmic sperm injection (ICSI).

1996: A 63-year-old woman in California gives birth using a donated egg.

1997: First successful birth using frozen eggs.

1999: Natalie Brown, younger sister of Louise Brown, becomes the first IVF baby to naturally give birth to a child.

The Donor Sibling Registry Reaches 50,000 Members!

The Force with us! May 4, 2016!

Episode May 2016

**50,000
Members**

*It is a period of great growth
for The DSR, with more than 13,000 family
connections. The Donor Sibling Registry
continues to facilitate half-sibling and/or
donor-offspring matches.*

*Lives are enriched, families expand, and
important medical information is shared.*

**Founded in 2000; The Donor Sibling Registry:
Connecting, Educating, and Supporting
Donor Families for 16 Years!**

©The Donor Sibling Registry 2016

Sperm Donation Needs Federal Regulation

Access to critical information--and honesty of donors--must be a rule

Recent reports of parents [suing](#) a large U.S. sperm bank, Xytex, because their donor was found to have a case of unreported schizophrenia as well as an unreported criminal history that included jail time have raised a lot of questions: Do these families have the right to be upset with the donor? Should he have self-reported his updated medical information and criminal record with the sperm bank? Should the burden be placed on the sperm bank?

This case highlights the lack of regulation and oversight in the sperm-donor industry. These parents only learned of the donor's past by connecting with other families on the [Donor Sibling Registry](#), of which I am the director, and on Xytex's own website. How long will we continue to see the repercussions of an industry that exhibits a lack of accountability, ethics and responsibility that we would normally expect in any other medical arena?

All too frequently, the Donor Sibling Registry counsels children of sperm donors who inherit undisclosed genetic disorders, discover that their donor was dishonest about his medical history, or find that the sperm bank didn't notify them about reported illness or [amend their donor's medical profile](#). These types of situations have been reported for decades.

The number and severity of these incidences is discomfiting. Families clearly need to be warned about possible hereditary disorders.

Since donors can father [many offspring](#), donors can potentially transmit disease to scores of children.

Currently, many sperm banks either refuse to update donor/offspring medical information, or, even if they accept updates, are unable to share the information, as many do not have an accurate accounting of all children born from any one donor. Sometimes they can make the process of reporting so complex or expensive that donors and recipients simply cannot afford to comply.

According to Donor Sibling Registry research, [84%](#) of its sperm donors surveyed were never contacted for medical updates, and almost a quarter of them said they or close family members had health issues that would have been important for families to know about.

Too often the medical profile of a sperm donor is merely a snapshot of one day in the life of a healthy young man. It often doesn't reveal what will happen five or 10 years down the road to the donor or to members of his immediate family.

The Food and Drug Administration requires sperm banks to test for STDs and a small handful of other diseases. Most sperm banks also obtain a self-reported personal and family medical history in order to identify any recurring issues that may be genetic in origin. And some conduct basic testing to detect specific mutations of specific genes and check for carrier status of the most common genetic conditions, such as cystic fibrosis and spinal muscular atrophy.

But without full genome sequencing, it is impossible to know about the thousands of other genetic conditions that have been discovered so far. And since many diseases, like schizophrenia, often do not affect people until they are adults, without a clear channel for

communicating and updating medical information among families and donors, we will continue to hear about stories like this one.

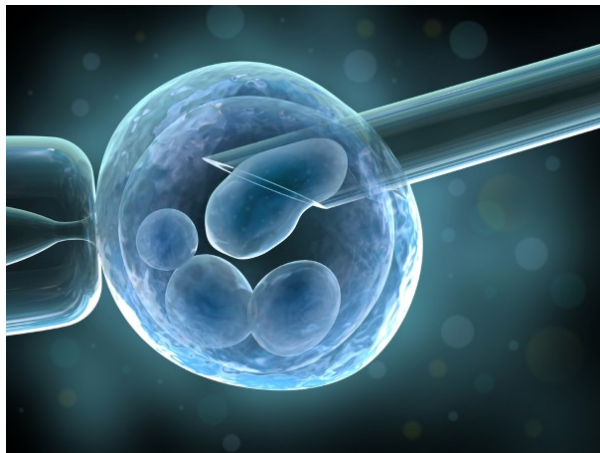
This is an international issue. The large U.S. and Danish sperm banks claim to ship sperm to clinics in more than [40 and 50 countries worldwide](#). To protect donors, recipients and offspring, we must implement oversight and regulation by an independent authority.

Its first orders of business should be to require accurate record keeping, limits on the number of children born for any one donor, and compulsory genetic and psychological testing of all donors.

This commentary was published in TIME Magazine 4/25/16

<http://time.com/4299641/sperm-donation-needs-federal-regulation/>

Egg Donation: Reporting Discrepancies & Medical Issues



We can see huge discrepancies regarding statistics that the reproductive medicine industry reports for the health of egg donors following donations. This information is regularly given to donors before they donate to reassure them that the process is safe.

For example UCSF Medical Center offers this information to potential egg donors:

[There is a small risk of ovarian hyperstimulation syndrome \(OHSS\) developing during an egg donation cycle.](#)

Another website, Angel Egg Donation reports:

[In findings reported to the ASRM, OHSS is associated with approximately 1% of Assisted Reproduction cycles.](#)

However, our research paints a different picture. [In our first published study of 155 egg donors](#), we found that 30.3% reported Ovarian Hyper Stimulation Syndrome (OHSS).

[In our second survey of 176 egg donors in 2014](#), we found that 32.4% of egg donor reported complications such as OHSS and infection.

Well, here is one possible explanation for the discrepancy in tracking complications with egg donors. This is from a recent email I received from a former egg donor on the Donor Sibling Registry:

I woke up during one retrieval. What I recall is that the doctor was roughly, rapidly, and aggressively plucking

my eggs. I could see the image of my grossly inflated ovary on the screen. I protested in some way-called out in pain or said "hey!" His reaction was angry-I felt hostility directed at me; it's possible that the nurse was actually the intended recipient of this anger. Perhaps she hadn't knocked me out sufficiently.

I subsequently had symptoms of OHSS ("warnings" or information about this had been extremely light and dismissive). My calls to the clinic went unanswered. I drove down there instead. They quickly got me out of the waiting room full of hopeful parents, looked at each other, and told me, "well, go to the ER then. I don't know what you want us to do." Keep in mind that they knew ahead of this cycle that I would no longer be donating. There was never any follow up from the clinic.

Interestingly, the records I recently requested and received (after intervention from my doctor) don't include anything about that cycle other than a few blood tests, whereas the records for the previous donations include detailed sonogram monitoring of the progress of the eggs, information about the meds (names and dosages), and the date and time of the trigger.

[A Canadian journalist](#) discovers other reasons that OHSS in egg donors may not be reported accurately (relevant to US donors as well) :

There are many reasons why CARTR (Canadian Assisted Reproductive Technologies Registry, which is maintained privately by the medical directors of in vitro fertilization clinics) data on donor-adverse events may not be complete. For one thing, it's not common practice for fertility doctors to formally follow up with donors after a procedure, unless the women are specifically at risk of OHSS. Several physicians told me that they simply invite donors to get in touch if there's a problem. Some women do so, but others may have already left town, or they're told by brokers not to contact doctors directly. Health concerns can also turn up weeks, months or even years after the donation. By that point, it's not clear if they're related, so some donors don't mention these issues to their fertility

doctors. Without deliberate follow-up, doctors may not be aware of what goes wrong after the fact.

Sean Tipton, the ASRM's [lobbyist](#) responds to the calls for long term health studies on egg donors in a TIME Magazine article: [The long-term health effects of egg donation have never actually been studied, in large part because the high cost of studies doesn't "seem justified in terms of what the possible risks \[of the procedure\] might be," according to Sean Tipton, spokesman for the American Society for Reproductive Medicine \(ASRM\).](#)

Additionally, when egg donors suffer medical/genetic issues after donating that recipient families should know about, they oftentimes have trouble getting this urgent medical information through the clinics and onto the families that deserve to be in the know.

We've recently heard from several more former egg donors with medical/genetic issues that they felt important for recipient families to know about:

I donated my eggs four different times at Genetics & IVF Institute in Fairfax, VA in the 90s/early 00s. Since then I discovered I carry a gene which means I'm at a much higher risk for getting several types of cancer. Since then I've tried to contact Genetics & IVF Institute so that they can relay this information to my offspring (they have a 50/50 chance of inheriting it) but they were not interested and it was obvious that they were not going to inform the families despite the fact early screening could potentially save these children's lives.

I've recently turned 42 years old and I was just told this week that I most likely have Ovarian cancer (this will be confirmed through pathology after surgery) and that I will need my ovary removed asap. I don't know if this is because of donating my eggs when I was younger or because of my family history. It's very upsetting either way.

They didn't update my medical information when I notified them. I have contact with 1/5 of my recipients. She was my 3rd donation. I notified them

prior to that donation of several issues. She did not receive those updates until we gained direct contact, and I updated them for her. It makes me sick to think this happens to more than just our case, and with conditions worse than what was found in our family.

I notified GIVF in 2005 (7 yrs after donation) that I had been diagnosed with a genetic condition. Someone there promised that they would pass along the information to any recipients. Last year, through DSR, a recipient and I made contact. No, they had not been notified. I imagine this happens a lot.

If you used the Cooper Center for IVF between 1997-1999, or know anyone else that did, please see the postings for this clinic on the DSR. Contact Wendy if you need more information. I have been a member of the registry since 2004. I donated eggs in 97, 98, and 99. I am concerned about the children that may have resulted from those cycles. I have been diagnosed with Autosomal dominant Polycystic kidney disease (ADPKD). I have 4 children, 2 have the disease. One does not and the youngest has not yet been tested. He is 15 and conceived from the cycle in 99. I kept 3 eggs and donated 20. I contacted the clinic immediately after I found out. They completely accepted the information but did not give me any real indication that they would relay the information. I lost my mom in 2005 to aneurysm as a result of the disease. My niece had aneurysm surgery 4 years ago. She was the youngest diagnosed with serious complications. My sisters are both in renal failure waiting for transplants.

The Society for Reproductive Technology (SART) claims that [they do have accurate records of babies born through egg donation. In our research](#), we found that 42% of parents of egg donor children were never asked to report the birth of their child. So how is it then possible to have accurate records? And why do both [SART and ASRM continue to block all calls for accurate record keeping?](#)

THINKING ABOUT SELLING YOUR SPERM OR EGGS?



Selling your sperm or eggs means much more than paying for a spring break vacation.

This kind of irresponsible advertising (from a NY sperm bank), only goes to show the lack of proper education given to prospective donors about decisions made now for a quick buck, that can affect them (and their families) for the rest of their lives.

If you are considering selling your sperm or eggs, are you thinking about your medical history, past, present and future?

Would you be willing to provide ongoing current medical information with respect to yourself and your immediate family? As a “donor”, it is important to consider the ongoing ramifications for any children conceived who share your DNA. If you sell your sperm this year, the sperm may be sold for many years into the future and potential mothers may keep that sperm for many years after purchase, attempting to provide their children with full biological siblings. Several families on the Donor Sibling Registry (DSR) report that they know of half siblings more than 20 years apart in age. Egg donors who donate to the new egg banks are now facing similar situations.

Should you or a member of your immediate biological family develop a health or medical issue following your initial completion of the donor interview, it would be essential that you provide this information to the sperm bank or egg clinic/agency/bank and post the information (anonymously if you'd like) on the DSR website, <http://www.donorsiblingregistry.com/>, which enables donors, recipients, and offspring to make mutual consent contact, to meet each other, and also to share and update medical/genetic information.

[Published research](#) has revealed that 97% of egg donors and 84% of sperm donors have never been contacted to update their medical records, while 31% of egg donors and 23% of sperm donors report that they, or immediate family members did have medical/genetic issues that would be important to share with families.

It's not just your looks, intellect or athletic abilities that might get passed along. Susceptibility to disease is also often inherited. For many years after your original donation, children who share your DNA may develop medical and health concerns that can only be properly addressed with your updated information.

Conversely, it might be crucial for you to know about any medical issues reported by families, as you may someday have children of your own. It is also important to note that the accuracy of the medical and health history you provide to the sperm bank or egg clinic/agency/bank is crucial to the potential parents reviewing that information. Certain conditions carry genetic components that are not readily tested for, and your accurate information is vital for proper screenings, testing, and preventative care.

If you have children of your own, or plan to....

Have you considered the possibility that in this small world your children may encounter biological half-siblings?

[At the present time, sperm banks and clinics do not keep, nor are they required to keep, any record of live births resulting from any specific donor.](#) What this means for the children born with your DNA is that they may be many in numbers. Currently, the largest group of half-siblings on the DSR is around 200. The children you have now, or may have in the future, may

meet your biological children born from your donations. Random meetings among half-siblings are regularly reported on the DSR. Honesty is essential. Before you donate, consider your willingness to be forthright with your children.

Are you planning on donating anonymously?

If you are planning on being an “anonymous donor” it is important to understand that because of advances in DNA testing and Internet search engines, the likelihood of your remaining “anonymous” in the future is growing smaller. Have you considered what your reaction will be if you are “found” by your biological children in the future? The children born from your donations may be curious and will want to search out their ancestry, medical backgrounds and their genetic roots. As noted above, many donors have more than 20, 50 and even more than 200 biological children.

Have you considered the possibility that you will be contacted in the future, even if your donation is anonymous? How would you respond if, one day in the future, you were asked to meet with your genetic offspring and his or her parents? You will need to think about the fact that this could be potentially disruptive to any family that you may have formed in the traditional manner.

With this in mind, would you consider registering on the DSR so that urgent information can be passed back and forth right from the start??

Please consider...

Please consider how you might feel about your donation in the future. It is likely that more than one child will come to exist as a result of your donations. These children are genetically yours; in fact, they may one day have children of their own who will be your genetic grandchildren!

Take a moment to imagine how donor offspring might feel. Many will wonder about where they got some of their physical characteristics. Or wonder about where they get their talents and personality traits from. Many are extremely curious about genetic family history and ancestry. And many feel a deep longing to connect with and to know their unknown genetic parent.

Imagine your reaction if your genetic offspring found you and expressed a strong desire to connect, or if they needed a lifesaving bone marrow transplant. Please consider these issues carefully as you make your decision on whether or not to become a donor. Your actions today may have an incalculable effect on the future.

Your donation is much more than a transaction with a sperm bank or egg bank/clinic/agency.

Donor Conceived People Searching – One Central Registry

Donor Sibling Registry “Copycat” Sites – Why Dilute the Search?

Over the past decade or so, there have been a few Donor Sibling Registry (DSR) “copycat” sites. ([I've addressed these copycat sites in 2008 and 2013 DSR blogposts](#)). These sites sometimes claim to offer the same capabilities that the DSR offers. They come and they go, and eventually, they all fizzle out. Recently, I have seen some new ones cropping up.

Some have stolen DSR website content such as our facility list, and the most recent one has lifted our User Policy (and other verbiage from around the DSR website). We worked for years to build our facility list, which includes hundreds of facilities, and have spent many hours over the past dozen years fine tuning our User Policy. Stealing our [copyrighted content](#) is an indicator that these new groups, in addition to claiming to replicate our [mission](#), and our [Success Stories](#), just don't have the vision, or the ability to put in the necessary work to make a unique, innovative organization of their own.

These new “registries” simply dilute what has been a single focused searching capability. I've heard from many adopted people, that they wish they had a “DSR” type of database, one central place to search. In

the same vein, people searching for genetic family at the commercial DNA sites have been frustrated, as there are 3 or 4 large DNA companies that don't share databases. The more donor “registries” the less likely people are to find one another.

Bill Cordray, for decades one of the most outspoken donor conceived people in the US, weighs in:

I think it is a bad idea to undermine the reputation of Wendy's work by setting up a competitive registry. Although it's a free Internet and you can do what you want, it will just weaken the value of DSR if several similar registries are set up and you'd have to go to all of them to do any cross-checking. As far as the fee goes, it is more than reasonable.

These new sites boast that they are free. Well, it's easy to be free while you have a few dozen members, or even a few hundred. *We were also free for the first five years of operation (2000-2005)*, as I ran and built the site with my own money and a few small donations. When we hit more than **7,000** members, it became clear that I would need help from members to continue expanding our charity organization, as we received no outside funding, and have an extremely complicated set of databases. It was only then that we

turned to our members for membership fee assistance to help us keep the DSR up, running and growing.

The DSR website is still completely free for browsing, and the [\\$75/year or \\$175/permanent membership fees](#) are only for people wanting to post their information or make contact. With almost 49,000 total members (donor conceived children and adults, parents, egg and sperm donors, and “others”), and almost 13,000 people matched- your odds are pretty good for matching on the DSR. If you were searching for first degree genetic relatives, your odds are much better at a website with 49,000 members than one with a few hundred.

This new “the more the merrier” fallacy is misleading, and ultimately will result in keeping donor relatives from finding each other with the speed and ease that many others have experienced before them. Creating more “registries” is only a disservice to donor families around the world. If the focus is taken off of the DSR, it makes it harder for people to know where to post themselves so that they have the best chances for being found.

The copycat sites serve to dilute the search, as if you post on a copycat site, you may never know that your matches have been sitting on the DSR all along. After our [national media story on CBS](#) a few weeks ago, and a subsequent [article in Teen Vogue](#), families were reporting to me that the newest copycat site was taking credit for matches already made on the DSR,

(sperm banks have done this too), and speaking out publicly against me and DSR.

So....copycats, if you want to truly make a difference, don't replicate what's already been done and don't bad mouth our 15 years of successfully connecting, [educating](#) and supporting donor families, the public, and the [reproductive medicine industry](#). *Think for yourselves about new ways to encourage and affect a more ethical and responsible reproductive industry.*

Misha Angrist, PhD, MFA. (Senior Fellow, Duke Initiative for Science & Society, Associate Professor of the Practice, Social Science Research Institute and Visiting Associate Professor of the Practice, Sanford School of Public Policy, who has invited the DSR into his Master class to help educate students, had this to say:

I am happy for there to be a single DSR--a nonprofit with unimpeachable motives. For years Wendy Kramer has worked tirelessly to help donor-conceived people find each other and their biological family members. She has spent much of her own money and now relies on membership fees to keep the DSR afloat. She has earned the respect of thousands of families by connecting and supporting them and by standing up to the sperm banks. I worry that copycat sites have the potential to undermine her efforts and lead donor families down the garden path.

An Open Invitation to All Sperm Banks



I'd like to set a challenge to all sperm banks in the US.

I invite you to follow in the steps of many egg clinics and agencies, and offer your donors and parents the option of writing the Donor Sibling Registry into your sperm banking agreements - establishing anonymous (if desired) contact on the Donor Sibling Registry, right from the start.

The Donor Sibling Registry (DSR), is a non-profit organization that assists individuals who were conceived as a result of sperm, egg or embryo donation, and are seeking to make mutually desired contact with others with whom they share genetic ties. We facilitate contact amongst half siblings (and their parents), and also connect donors and families who wish to be in touch-- oftentimes long before the children turn 18.

Since 2000, we have helped to connect more than 12,700 people on the website, and now have a total of 48,400 members, including more than 2,400 donors. [One DSR sperm donor was featured this week on the CBS Sunday Morning News show](#) meeting several of his donor offspring.

Another donor describes his heartfelt reasoning for desiring contact:

"My decision to be a donor was inspired by the blessed gift of my children. They and their half-siblings (I only know of a son and daughter) have the right to know each other. With humility, I can say that I've never had misgivings about being a donor and continue to desire contact without any presumptions. I sent an inquiry and personal letter to [my sperm bank], and, having since discovered the DSR, will trust the universe in this quest. As a parent of children who are the light of my life, I already feel an affinity with the parents of these children conceived in trust and love."

We're reaching out to people who facilitate the creation of happy families. We'd like to partner with you. Here's why:

- As we move toward increased openness as a society, there's a particularly strong need to stay at the forefront of the trend within the donor industry.
- 2012 published research ([Reproductive BioMedicine Online](#)) on 164 sperm donors showed that, while 84% of sperm donors have never been contacted by their sperm banks for medical updates, 23% of the donors felt they, or close family members, had medical/genetic issues that would be important to share with families. 94% were open to contact with offspring.
- Registering on the DSR is the only way for parents and donors to stay anonymous (if desired) while still establishing relationships and sharing medical info.
- It can be of equal medical importance to donors that their offspring provide updated medical information, especially as the donors build their own families.
- We now know that there is desire for earlier contact between donors and recipient families. Many appreciate the ability to establish contact and foster relationships as a child is growing up. Many think that 18 is an arbitrary age that does not meet the needs of donor offspring.
- Families often wish they could ask their donors simple questions, such as, "My son would like to know if you ever played a musical instrument?" or, "Is there any diabetes in your family?" or, "My 10 year old daughter would like to send you a father's day message, is that ok?"
- The DSR can help by providing a valuable service to your parents and donors, and to your company - at no cost to you. (It's a win-win-win!)

In 2015, another published study of sperm donors in *Facts, Views & Vision in OB/GYN (the Scientific Journal of the Flemish Society of Obstetrics, Gynaecology & Reproductive Health)*, called "[Sperm Donors Describe the Experience of Contact with their Donor-Conceived Offspring](#)" revealed that most of the surveyed donors had become curious about, and had made contact with, their offspring. Almost half of the respondents

now considering their donor-conceived offspring to be “like a family member”. At the same time, donors were respectful of the integrity of the family in which their offspring were raised.

What Does A Relationship With The DSR Do For Your Sperm Bank?

- **CONTACT:** The issue of contact between the donor and the recipient is removed from the hands and focus of the sperm bank.
- **CONSENT:** Since the DSR relies on mutual consent; the sperm bank doesn't need to be worried about protecting anyone's privacy.
- **CHOICE:** Each party can remain anonymous if they choose, so the decision is ultimately in the hands of those involved. Each party can decide how much information they're comfortable sharing.
- **CURRENT:** The sharing and updating of medical records 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. Offspring have the opportunity to establish relationships with their genetic fathers while they are developing, not having to wait until they are adults.

We invite you to set precedent within the sperm banking industry. Become a leader in fully educating and supporting families and donors. If we ask, “what is in the best interests of the child being born?” the answer is never “to use anonymous donors”. Anonymity is antiquated. It is a concept of the past in the adoption community, and becoming so in sperm and egg donation as well.

The desire to connect is here now, and we can move the sperm banking industry forward in an open and supportive way, acknowledging the rights and needs of donor conceived people to know about their biological parents, the rights of donors to know about children that they help to create, and the rights of parents to better serve the needs of their donor conceived children.

We look forward to working with you! [We have sample contract verbiage and frequently asked questions](#) on the DSR website to help you incorporate the DSR into your donor and parent agreements.

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 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 Coordinator, Egg Donor Solutions

DNA = Donors Not Anonymous



I can't help but wonder when the sperm banks and egg clinics will start acknowledging that there is no such thing as guaranteed donor anonymity. I addressed this issue in my [recent Huffington Post Blog](#), and it [has been written about many times over the past ten years](#), starting with a [New Scientist article from 2005](#) about a boy locating his donor after submitting his DNA to a commercial DNA website.

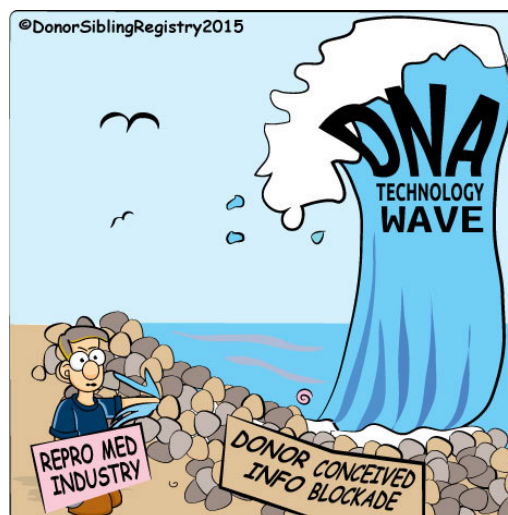
A quick review of some of the largest sperm banks and egg clinics finds that not one of them mention in their donor recruitment materials the ease with which, and the growing frequency of donor-conceived people identifying their donors via DNA testing. This is now a regular occurrence.

Many egg clinics not only offer anonymous donors, but actually require anonymity for all involved. Because egg donor children are now getting to the age where they are starting to get their own DNA tested, promised egg donor anonymity is also being shown to be a myth. New family finder type programs make connecting via y-DNA (surname connections) no longer the only way to find genetic relatives with DNA.

The DSR recommends DNA testing for its members, but also many people come to the DSR because they only just found out through DNA testing that they were conceived using donor sperm or eggs. After

confronting their parents about the news, they learn about which clinic or facility their parents used, and sign up on the DSR to connect with half siblings and/or their biological parent.

Last month I had a egg donor mom contact me saying that her 19 year old son had told her that he'd recently sent in a swab to have his DNA tested with 23andme, and was waiting for the results. It was clear that this boy had suspicions about his biological parentage. She was so frozen with fear that even with the impending DNA results on the way, she couldn't muster the courage to tell him the truth about the use of an egg donor.



I see no educational materials on the sperm bank websites, for both donors and potential parents) addressing the importance of donor-conceived children knowing about their genetic, ancestral and medical histories. Not one website pointed to the Donor Sibling Registry as a place to make mutual consent contact (unlike many egg clinics that now write the DSR into initial donor-recipient contracts so contact is established right from the get-go).

Both sperm and egg donors should know that they can share and update medical information, photos, and messages with families on the DSR at any time. This can be done without sharing identifying information, so if donors are not ready to establish relationships,

they still have a vehicle with which to share information. And it goes both ways, as medical information about the children they have helped to create could be beneficial to them too, if they have, or are planning to have children in their own family.

This [egg clinic](#) not only promises anonymity on their website, but also explains why anonymity is used by most of their families. Not only is there a lack of education, they are misleading parents to think that choosing anonymous egg donor will keep an unwanted party from intruding on their lives. This misleading and incomplete information is given to parents as they make decisions that will affect their child for decades to come.

An anonymous donor is not known by you, the recipient. With anonymous egg donation, the egg donor's true identity (name and address) is kept confidential in order to ensure privacy and anonymity. Similarly, your identity will not be disclosed to the donor.

The majority of egg donations are anonymous donations. Many intended parents feel better knowing that their egg donor will not be involved during pregnancy, and as they raise their child.

One of the largest US sperm banks has this on their FAQ page for donors:

Is the program confidential?

Your anonymity is very important to us. All donor information is completely confidential. Online applications are submitted directly to your local facility, and we do not share your information with outside parties. Donor files are numerically coded to assure confidentiality. Access to files is restricted. Your identity will not be revealed to any recipient, nor shall the identity of any recipient be disclosed to you.

Another sperm bank's [website](#) says:

Donor Confidentiality

[Sperm Bank] takes great care to protect your privacy. Our donor and patient agreements clearly protect and release donors from any obligations and rights to any child that results from the donor's participation in our donor program. No identifying information is released to patients or offspring without your express consent and participation in the Identity Disclosure program.

And finally, from [the sperm bank](#) claiming to be the "largest international sperm bank":

*The identity of Anonymous sperm donors always remains confidential**

.....heterosexual couples seem to prefer Anonymous sperm donors in order to protect the man's integrity as the father and thus their own family identity..

Sperm banks and egg clinics need to both address the issue of DNA testing, and how this affects the perceived and promised anonymity of sperm donors. Parents and donors need to be adequately educated and given accurate information. And of course, ultimately, all anonymous programs need to be abolished.

Additionally, I didn't see any information included on the sperm bank and egg clinic websites for donor offspring. Incredible that they have absolutely no acknowledgement or support for the very people they are helping to create.

*Full disclosure: As I was trying to explain (in person) how my son located his donor via DNA testing, this particular sperm bank's director responded by telling me that none of his donors would ever swab their cheeks for DNA testing and therefore would never be found. He could not understand (and therefore can not properly educate his donors) about the fact that a donor does not have to submit his own DNA in order to be found. He also told me that because of the DSR, his clinic was now offering "invisible" donors.

Illustrations by Jen Moore

NBC Story: 48 Donor Siblings and the ASRM

[How One Girl's Search Brought Her 48 Half Brothers and Sisters](#)

In NBC's 11/6/15 story about donor siblings that connected on the Donor Sibling Registry, we again hear from the spokespeople at the American Society of Reproductive Medicine (ASRM), and how utterly disconnected they are from the realities of donor family issues. Maybe that's because the ASRM is made up of the very people that they are supposedly making recommendations for. So it's a case of the fox watching the hen house. Without any outside regulation or oversight, it's a case of "self-regulation" by a multi-billion dollar industry. (Where else have we seen the repercussions from a set up like that?!)

Judith Daar, the chair of ASRM's ethics committee and a professor of law at Whittier Law School, questions whether it would be appropriate to put limits on sperm donors.

But the ASRM's Sean Tipton doesn't foresee the federal government establishing a sperm donor registry.

"They don't want to spend the money, they don't want the hassle," says Tipton. "Before you are going to regulate people's reproductive choices, you have to have a really good reason. I don't think you want to jump in on a legal solution where it's not certain what the long-term consequences would be." "Could a similar regulation be enforced in a natural situation? Would we tell people who want very large families to restrict the number of offspring?" said Daar. "I think we would not favor the law limiting the individual's ability to procreate naturally."

Right, Sean, but in a "natural situation" there isn't the possibility of creating 200+ children from one unknown person. And as far as having a "really good reason" for limits and accurate record keeping, take a look at the [Donor Sibling Registry Medical page](#), you'll see a lot of "good reasons" why this industry needs some sort of regulation, including comprehensive medical and genetic testing, updating and sharing of medical information, accurate record keeping on the children born from any one donor, and limits of the number of children born from one donor. The long-term consequences of establishing a more responsible

industry would only help donors, donor conceived people, and their families.

Instead of pointing people to situations that are unrelated to us, the donors, offspring and parents who have used donor sperm and eggs, why not be brave enough to address the actual issue -- that there is no oversight and regulation in a high profit industry that has acted irresponsibly and without ethics. Mr. Tipton has addressed the issue of regulation by saying, "[...we know any regulation of that is likely to impede access and increase the cost.](#)" This is not about regulating "people's reproductive choices", or a matter of money, as no one is challenging a person's right to reproduce.

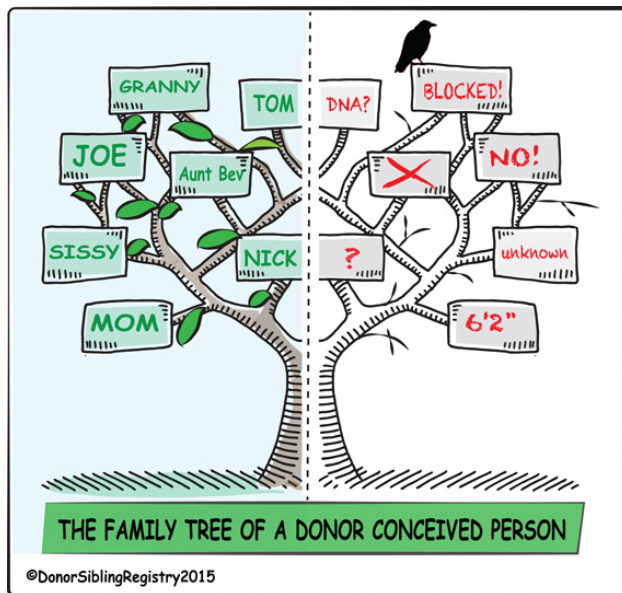
This is a different conversation; about the rights of the children this industry is helping to create. They should be able to know that there are limits on amount of half siblings they can have, as well as have access to medical information and to their own first-degree genetic relatives.

Mr. Tipton tells us that the industry doesn't want the "hassle" of creating a registry for accurate record keeping. I feel that regulation and oversight of the infertility industry is a necessity, and would only improve this broken system, and help thousands of families who have used donor eggs and sperm to create their families.

A picture of 200 random people. This picture illustrates the largest number of half siblings reported to the DSR.



Biology and Birth Certificates: Our Right to Accuracy



Most U.S. citizens raised by their biological parents never question whether the information on their birth certificates is accurate. With the evolution of adoption and alternate means of conceiving a child, “accurate” is an increasingly subjective term. Is the purpose of a birth certificate to portray a biological account of a person's birth parents, or is it an account of one's “legal” parents -- the ones responsible for raising them?

The U.S. Bureau of the Census created Birth Certificates in the beginning of the 20th Century as a means of tracking the effects of disease and urban environments on mortality rates. The task of issuing birth certificates was transferred to the Bureau of Vital Statistics, a division of the Department of Health and Human Services, in 1946 where it was decentralized into our familiar state systems of today.

As the document evolved over the last century, so has its purpose. It has become an important (if not our sole) means of identification when we obtain anything from a driver's license to a passport. It has also become an indispensable tool for genealogical researchers.

So how do we decide who should be listed in the categories of “Mother” and “Father” on a birth certificate?

For donor-conceived and adopted people, there is oftentimes a clear distinction between one's genetic parents, those with whom you share DNA, and one's legal parents, the ones who have rights and responsibilities attached to their parenthood, and most-times, the ones who are raising them.

However, ever-increasing numbers of individuals in both situations are clamoring for reform, namely their right to have a birth certificate that portrays accurate biological background as well as their legal parentage.

Our birth certificate practices concerning non-biological parents began with adoption. In the mid-20th Century, there was rising concern that adopted children's birth certificates read “illegitimate.” In response, states began to issue adoptees amended birth certificates, listing the adoptive parents as if they were the genetic parents, thus hiding the shame of the child's illegitimacy and the adoptive parents' infertility. The originals containing the biological parents' names were sealed and not available to anyone (including the adoptee) except by court order. The new birth certificates showed no indication that they had been amended, which gave adoptive parents an easy way to not tell their children of their adoption.

Despite the fact that “legitimate/illegitimate” language was replaced with the mother's marital status in 1979, the practice of amending birth certificates to reflect legal parentage persists to this day. In most states, adoptees original birth certificates remain sealed.

No federal birth certificate revision has been issued to address donor conception scenarios. Therefore, married couples in all states who use donor sperm are automatically granted the right to list the husband as the father and women who use donor eggs to become pregnant are listed as mothers on birth certificates. No official asks them if they used any donated gametes to conceive, or for any information about the donor who is genetically related to the child. In addition, in some states, the biological parent and the gay co-parent can both be listed on the birth certificate.

So many believe that they share the same ancestry and medical background as both parents listed on

their birth certificate, when instead, they were adopted or an egg or sperm donor has been used, and the child shares their DNA with an unknown person(s).

There is a whole host of concerns raised by adoptees and the donor-conceived, including the right to identity, ongoing medical history, biological heritage, and the right to know their genetic parents. How do we deal with an adopted or donor-conceived person's right to an accurate birth certificate? Looking ahead, do we keep the same birth certificate structure, or is some sort of adjustment needed?

Our federal government has been agonizingly slow to address these issues, if it acknowledges them at all. There is a long history of deferring what it considers "family law" to the states, including how parentage is listed on birth certificates and whether or not adoptees can obtain their original birth certificates.

This has caused many to attempt to circumvent their state system by hiring private detectives, posting their information on the Internet, or using commercial DNA testing companies. 23andme, Ancestry.com and Family Tree DNA now have hundreds of thousands of submissions and are helping connect thousands of family tree branches to one another. In addition, almost 12,500 donor-conceived people have connected with their genetic relatives on Donor Sibling Registry (DSR). Unfortunately, none of these methodologies guarantee the finding one's biological parents.

The birth certificate problem exists in other countries as well. As adoptees and donor conceived people across the world find their genetic relatives and parents, some have taken the task of proper documentation into their own hands.

Earlier this year, a donor-conceived woman in the UK successfully had her birth certificate amended to remove her legal father, and have the place for "father" blank, as she has an unknown biological father (sperm donor).

Currently, a man in Australia is petitioning the courts to do the same, removing his (now deceased) father from his birth certificate, saying, "I'm doing this because I want an accurate and factual record of my conception, of birth." He goes on to say, "It's not just for my kids but also my descendants in that if anybody in the future was to conduct genealogy research on our family, I don't want them to go down the wrong

path and if they have an inaccurate birth record, they will basically believe a lie."

Adoptees are expressing the same concerns about descendants being able to connect the dots when researching their ancestry. Because two birth certificates exist in adoption, there's no guarantee that the factual one would be released & therefore "searchable" by descendants. This has led many adoptees in the U.S. legally change their names to reflect biological relationships.

Ignorance of biological ancestry has had devastating consequences for some. In the U.K. in 2008, twins that were separated and adopted at birth unknowingly married each other. This year, a Brazilian couple found out after they were married that the same biological mother had abandoned them as infants. Random meetings amongst half siblings are not uncommon, as many have reported in the news, and on the DSR. One mom realized that a distant relative, one whom she and her children had spent time with at family gatherings, had donated sperm and was in fact the biological parent of her children.

Although cryobanks claim to limit the number of births to one donor, this clearly isn't the case. We have seen as many as 200 half siblings from the same donor connect on the DSR, and there are many more groups of 30, 50, 75 and more... and these are only those families that have registered on the website. Clearly, this poses a public health crisis, in the case of shared genetic illness, or if the offspring are in a concentrated geographic area and/or do not know they are donor-conceived.

The U.S. does not require cryobanks to keep accurate records on sperm donor families, nor are they forced to limit the numbers of children born to any single donor. If a donor reports a serious illness, there is no way for the sperm banks to notify all involved families. Diseases such as NF1, Lynch Syndrome, Cystic Fibrosis, and HCM, a sometimes-fatal genetic heart condition, have all been reported on the DSR, and have been written about in the media. Hundreds of other medical conditions have also been reported and shared amongst DSR families and the sharing of this type of information has saved lives. The problem is that the DSR is a voluntary website, and in most cases, all families will not be listed and contactable.

The US Surgeon General reports on their [website](#) that, "A recent survey found that 96% of Americans believe

that knowing their family history is important.” To help Americans focus on the importance of knowing family health history, The US Surgeon General along with the Department of Health and Human Services created the “Family Health History Initiative.” The website notes that, “Tracing the illnesses suffered by your parents, grandparents, and other blood relatives can help your doctor predict the disorders to which you may be at risk and take action to keep you and your family healthy.” It certainly begs the question why the Department of Health would, by its refusal to address this birth certificate crisis, prevent millions of donor-conceived and adopted people from having access to this information.

The United Nations felt the need to address identity in Articles 7 and 8 in its [Convention on the Rights of the Child](#):

“The child shall be registered immediately after birth and shall have the right from birth to a name, the right to acquire a nationality...” (CRC Article 7) and “States Parties undertake to respect the right of the child to preserve his or her identity, including nationality, name and family relations...” (CRC Article 8).[3]The U.S. has yet to ratify this treaty.

Donor conceived adults in the [International Donor Offspring Alliance](#) list these as their “Summary of Aims”:

We assert that people have a moral right to know the truth about their personal history. Where the state has custody of relevant information it has a duty not to collude in deceiving or depriving individuals of such information.

Adoptee rights organizations have been fighting for the right to identity, including the unsealing of original birth certificates, for decades. American Adoption Congress states on its website:

The [American Adoption Congress](#) believes that growth, responsibility, and respect for self and others develop best in lives that are rooted in truth. The AAC is therefore committed to achieving changes in attitudes, policies, and legislation that will guarantee access to identifying information for all adoptees and their birth and adoptive families.

It follows that:

- The truth about an adopted or donor-conceived person's genetic and social parentage should be recorded on their relevant public documentation.
- In the normal course of events of life it should be impossible for a person to fail to find out that they are adopted or donor-conceived.
- The principal legal instrumentality of this should be the person's birth certificate.

Since 1902, the U.S. has made twelve Standard Birth Certificate revisions. Legitimate concerns raised by the adoption and donor communities suggest a thirteenth federal revision should be made to accurately portray biological identity on birth certificates and ensure that procedures are uniform in every state.

Most in the adoptee rights community feel that issuing two birth certificates to adoptees is a leftover relic from an era of shame and secrecy and should be abolished altogether. We believe it is important to issue one certificate only so information cannot be hidden from the individual by parents or the government.

It is no question the best interests of the child should be paramount. With this in mind, for both adoptee and donor situations, we would recommend a U.S. Standard Birth Certificate revision expanding the “two parent only” format to include categories for Legal Parents, Genetic Parents, and Surrogates. In the case of adoptees, we would like to see the child's birth name recorded along with his or her legal/adoptive name.

If the birth certificate is amended in any way (such as adding legal parents when an adoption is finalized) it should be unlawful to omit any original information, including biological relations, from the new copy. We would also seek to abolish anonymous donor conception, or at the very least, list the clinic and the donor ID on birth certificates.

We understand and acknowledge that this recommended system is not perfect. Whether a child is adopted, donor-conceived, or not, parents can always lie on a birth certificate. As donor conception is more easily hidden than an adoption, we advocate the establishment of a national registry where clinics and hospitals would be required to record donors and their children.

This has already taken place in several countries, most recently in September 2014 in Ireland, which is in the process of abolishing anonymous gamete donation and creating a national birth register for donors and their offspring. [The Children's Rights Alliance was quoted in the Irish Examiner](#) saying, "We know the pain caused to the many adopted people who can't establish the identity of their parents. This bill will ensure that donor-conceived children will not share the same pain."

There has been much debate in the donor and adoption communities on the "true" purpose of a birth certificate. Certainly, its original and enduring purpose is to keep accurate records for the good of

public health. For the individual, a birth certificate has become an indispensable proof of identity and ancestry. It should be of utmost concern to our Department of Health that birth certificates are serving neither purpose for the adopted and donor-conceived.

The time for birth certificate reform is now. Unfortunately for many, it should have happened decades ago.

Cartoon by Jen Moore.

Co-Written with Kristi Lado, Board Member Pennsylvania Adoptee Rights (PAR), Contributor to Adoption Therapy: Perspectives from Clients and Clinicians on Processing and Healing Post-Adoption Issues by Laura Dennis.

Donor Families Connecting: Love or Fear?

I think that many of the choices we're faced with in life offer us opportunities to choose between love and fear. After running the Donor Sibling Registry for 15 years, and facilitating tens of thousands of half sibling and/or donor connections, I see these choices very clearly. We've been able to watch so many first-degree genetic relatives, who are essentially strangers to each other, decide whether to connect, and then maneuver through defining this newfound family.

Brittan and her parents along with egg donor JoLana and her two daughters, with Katie Couric



Getting to spend time with Brittan and her parents Janet and Jim before, and after the Katie show was inspiring. Because Jim has a genetic connection to his daughter, I was more focused on Janet, Brittan's mom, as many non-genetic parents in donor families seem to struggle much more with the idea of their children connecting with donor relatives. When we watched Janet, we saw a confident and strong parent. Did she have fears and hesitations? Yes, most certainly. Did she realize that the benefits for her child would largely outweigh any concerns she might have had? It sure appears so.

We watched Janet be empowered as a parent, and witnessed her confidence, love, and support. She had

the grace to not only meet, but to completely embrace her egg donor JoLana (on national television no less!) We felt her sense of gratitude, and wonder, as she looked into the eyes and held the hand of the woman who made it possible for her to have her beautiful daughter. There was not a dry eye in the house.

While some donor offspring and their parents are overjoyed to connect with their half sibling and/or donor families, some parents seem to struggle much more with the idea of their children connecting with donor relatives. Decisions about donor conception, including the ones about connecting to unknown relatives, can be complicated, but I suggest we can simplify these decisions down to just two choices, love or fear.

Fears might include complicating your life, or opening your family up to a situation that might be out of your control. The truth is that as your child grows up and heads into the world, these concerns, as well as a plethora of others, are realized regularly, in our everyday lives of raising children. So we can keep our kids safe, at all cost, or give them opportunities to expand themselves in the world, and learn about their own power, strength, and their ability to open themselves up to love.



Certainly, when faced with opening our lives to unknown genetic relatives, parents might feel fear, confusion or worry. We can make choices solely based on these feelings. We can let our feelings of insecurity as parents hold us back. What if my child doesn't like them? What if they don't get along or have much in common? What if my child likes them better? How will the dynamics of our family be changed? What if my child realizes that I haven't been a "perfect" parent? None of us have been "perfect" parents- and meeting the donor isn't going to "out" this fact (those with teenagers can count on them to do this!).

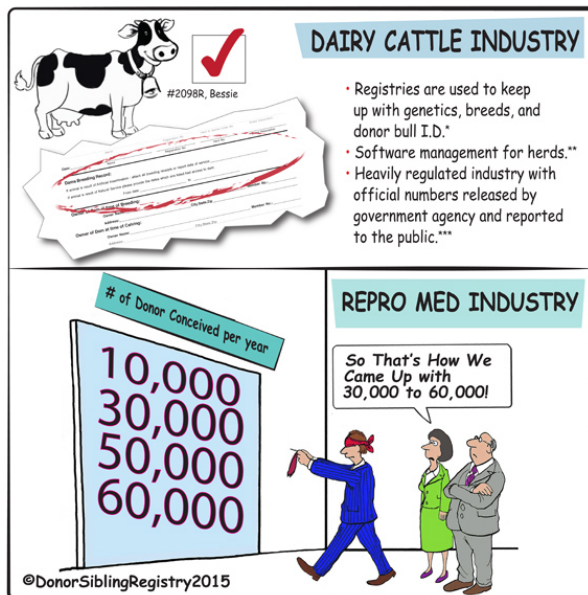
We have the opportunity in these situations, to make our choices coming instead, from a place of love. We can choose to see the opportunities in reaching out and connecting, cautiously and carefully, expanding our child's, and our own sense of family. We can be open to this new idea of family and see how it actually might strengthen our relationship with our child, not threaten it in any way. As parents, we can be confident and strong.

Will we have some fears and hesitations? Yes, most certainly. But we can realize that the benefits for our children can largely outweigh any concerns we might have. There are no guarantees of perfect family bonding, just as in any family, not everyone bonds or connects. But these connections do have the ability to empower us as parents and give us another platform in which to show our children confidence, love, and support when meeting and embracing this new family. Honoring our children's right to explore these new half sibling and/or donor relationships can only strengthen our own bonds with our children. And when meeting donors, having our children witness our sense of gratitude, can be a profound and life changing experience for all.

Parents can, and should put the needs and desires of their children to seek out and connect with half siblings and/or donors, above their own fears. This is the ultimate sacrifice that parents make for their children. It is also the greatest gift we can give to our children, and to ourselves.

There are two basic motivating forces: fear and love. When we are afraid, we pull back from life. When we are in love, we open to all that life has to offer with passion, excitement, and acceptance. We need to learn to love ourselves first, in all our glory and our imperfections. If we cannot love ourselves, we cannot fully open to our ability to love others or our potential to create. Evolution and all hopes for a better world rest in the fearlessness and open-hearted vision of people who embrace life. ~ John Lennon

30k-60k US Sperm and Egg Donor Births Per Year?



In [1988 the Office of Technology Assessment estimated that 30,000 children were born via donor insemination during the year 1986/87](#) in the US.

More than a quarter of a century - and no further research - later, '30,000 annual births' is still trotted out in academia, lectures [and the media](#). Sometimes the number is doubled, probably to allow for the passage of time, and occasionally a range of 30,000 - 60,000 is deployed.

Yet so much about donor insemination has changed during this time. Using either of the whole figures is scientifically unjustifiable, and the range is just as flawed.

The media, academics, and other “experts” should not be using such patently erroneous figures. Rather, they should be noting that there is no reliable method of assessing how many children are conceived via donor insemination each year. They should be pointing out that the USA has no accurate tracking or record keeping from which it is possible to make an educated assessment. *And please, the media (US and international) needs to understand that most people that use donor sperm do not utilize IVF!*

Instead of complacently relying on outdated best guesstimate figures from more than a generation ago, they should be demanding reliable, recent figures. They should be voicing outrage that neither the

fertility industry nor any other entity is required to collect data or report statistics on the numbers of human beings conceived using donor sperm.

Even though it is sometimes reported that numbers of egg donor children born are tracked, more than [40% of egg donor parents surveyed by the DSR](#) told us that they were never asked to report the birth of their child, and many had never done so, leading to incomplete egg donor birth tracking as well. This is in stark contrast with livestock insemination, which is much more tightly regulated and surveyed.

The donor insemination landscape has changed significantly from the 1988 report. In 1986 almost all recipients were heterosexual married couples; nowadays, straight married recipients make up a small minority. [Parents on the Donor Sibling Registry are 50% single women, 33% in LGBT families and now less than 20% are straight couples facing infertility](#). Whereas in 1986 the majority of donors were recruited directly by fertility doctors, (or fertility doctors themselves), most donors are now sperm bank recruits.

The number of sperm banks has rapidly increased since 1988, as has the number of donors. But the greatest change of all is the opportunity for kinship acquaintance. In 1988 it was essentially fantasy for donors or offspring to think they would get to know one another. Now, in the generation following the advent of the Donor Sibling Registry (DSR), and with DNA testing, such knowledge is almost an expectation. Only one thing remains the same: the general lack of comprehensive medical and genetic testing of donors, or any mandatory requirement to do so beyond testing for STD's and a small handful of other diseases like Tay Sachs. The result is that some banks, test some donors, for some diseases.

Over the last fifteen years, the DSR has collated the most comprehensive records that currently exist in the USA. With 47,600 worldwide members, including records of over 2,400 donors, it also includes details of hundreds of worldwide sperm distribution facilities. However, these records are very incomplete, as all have been obtained via voluntary registration.

For several years, the DSR has been applying pressure to sperm banks for them to maintain their own accurate record keeping system, but progress in that direction is slow. And even if individual sperm banks did create proper records, in order for them to be accurate and reliable they would need to be collated and integrated with the records of every agency that trades sperm, as [research has shown that 27% of donors donate to more than one clinic](#). This would require that the whole industry be accountable to one body.

This is a call to those quoting that one-time estimate of 30,000, and to those concerned about the pitiful lack of oversight within the US sperm donor industry, to speak up about the lack of reliable information

within the public domain. We need to demand that federal money be allocated to research, oversee and regulate this industry, and to do it in a thorough and comprehensive manner.

In the meantime, everyone using these figures should acknowledge that they are 28 years out of date, and even then they were only rough guesstimates.

Cartoon by Jen Moore.

**www.DairyCattleRegistry.com, 2015.*

***www.cattlemax.com, 2015.*

****USDA Report, 2012, also*

<http://www.cattletoday.com/archive/2006/May/CT478.shtml>

Article on Percentages of Dairy Cattle Conceived of AI.

Grandparents via Donor Conception



There are significant cross-generational relationships that gamete donation has engendered that haven't yet been talked about.

As donor conceived people and their donors (aka biological mothers and fathers) are finding each other more regularly through the Donor Sibling Registry and through DNA testing websites, there are members of a

third generation that are also connecting- the grandparents.

Donors are finding that when they connect with their adult donor conceived offspring, that many of those offspring are now parents themselves. These donors now have the opportunity to not only meet their biological children, but also establish relationships with their young donor grandchildren. And who better to lavish affection on a child, than a newly discovered grandparent?

In addition, parents of donors are learning that they have biological grandchildren, not as a result of the typical pattern of their children raising children, but rather because their son or daughter has been a sperm or egg donor sometime in the past. On the Donor Sibling Registry we have parents of donors who are interested in connecting with their genetic grandchildren.

Some, whose children are now deceased, are longing to know if their children have any children out there born from the donations. The very good news for the donor conceived community, is that these new grandparents are often welcoming their kin with open

arms and hearts, as for many of these donor's parents, these donor offspring will be their only grandchildren.

Sometimes, contact comes too late. One donor conceived woman recently explained the heartache of learning that her biological grandfather had recently passed away:

I found out this morning that my paternal grandfather through my donor unexpectedly passed away. I found my biological father earlier this year through 23andme and have been slowly establishing an email relationship with him, but things had not yet had time to reach a point where it would be the right time for me to meet that part of my family. I will never meet that grandfather now. I have to think that if ASRM and the folks involved in anonymous donation understood what anonymous donation really meant, then it would stop. There was no reason for me not to meet my grandfather. He was in his 80s. I'm in my 30s. There should have been plenty of time--and there would have been, if I had had a right to know my identity from birth, and if using known donors had been required when I was conceived. I can't believe that every day, doctors are creating more pregnancies this way. It blows my mind. ...It just blows my mind.

These new familial connections are reaching beyond the direct link to a half sibling or a genetic mother or father, and for many donor-conceived people, connecting to their genetic grandparents gives them a more concrete sense of their familial line, their cultural history, and their origins.

For some donor-conceived people like Susan, beyond the importance of meeting her own genetic father, was the knowledge that her son would grow up knowing two additional grandparents. She explains:

I myself realized that I was not my Dad's biological daughter when I was ten years old. I wondered from time to time. Who was the man who had donated half my genetics? There were seasons in my life when this question plagued me, and other times when it was merely a passing thought. It was not until I found out that I was pregnant that I felt any real regret at not knowing his identity and even then it was only because I would not have a complete medical history for my child.

When I did finally meet my biological father it was not a heart wrenching over the top experience, instead it was a sense of deep calm; as though a very important

piece was falling into place. Imagine you have a jar full of water and sand that you have shaken until it was cloudy, and then imagine you set the jar down and instantly the sand settles and the water clears. That is how it felt to meet him. It was an area of my life that had always been unclear and rather suddenly it was transparent. Here was a man with my nose and my hands, an artist and an empath.

As a mother myself now, my feelings have changed and my primary joy is in the fact that my son has two more grandparents, a child can never have too many grandparents! To love and be loved by so many is such a gift that I am humbled by daily. As I told my biological father and his husband when they asked me how I felt the first time we met, I am them and they are us, for better or worse, we're family. I'm so grateful we landed safely on the side of better.



And for some donors, meeting their grandchildren and having the opportunity to participate and be a part of their lives is a life-altering opportunity. Robert tells us about meeting Susan and his grandson:

I made contact with my daughter, who said that she had been looking for me since she was a child, and she wanted to meet me and to introduce my grandson. We recognized each other immediately, on first meeting, and I felt a familiarity and affection that has grown with each subsequent visit. I feel incredibly lucky.

In 2013 we conducted and published research* on the parents of sperm and egg donors. We wanted to know

about their experiences with connecting to children born from their children's donations. We asked respondents to indicate their thoughts when they first learned of the existence of a donor conceived grandchild. All but a few of the respondents wanted to learn more about, or to have some type of contact with, the child. For instance, 68% "wanted to learn more" and 42% "wanted to meet them as soon as possible."

We asked for the main reason for reaching out to their donor-conceived grandchild. Thirty-nine percent of respondents indicated, "Since they were created with my DNA, the child is part of me" as the main reason to reach out, and "They are my grandchildren" was selected by another 33%.

My own son Ryan was given the opportunity to meet his biological father and grandparents when he was 15. Because of this, he gained two additional grandparents who love him, and who have enriched his life. We are all extremely thankful that we've had the opportunity to share our lives with each other for

the past ten years. Both Ryan and I cannot imagine not having had this branch of our family as a part of our lives for the past decade.

At one point early on though, Ryan's donor-grandmother shared with me that while overjoyed about being able to establish this new familial relationship with her grandson, she did feel some sadness, and actually needed to grieve for the missed first 15 years of Ryan's life - the first steps, birthdays and milestones now long gone.

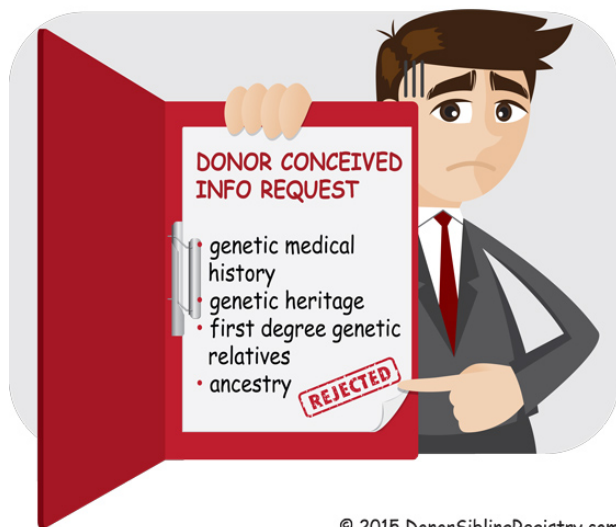
We can only hope that the reproductive medicine industry is listening to these stories, and will stop working so hard to keep these genetic relatives from knowing each other.

**The Journal of Family Issues, DOI 10.1177/0192513X13489299 May 2013: [A New Path to Grandparenthood: Parents of Egg and Sperm Donors](#). Diane Beeson, Patricia Jennings, Wendy Kramer.*

Other reading: [The Vital Importance of the Grandparent-Grandchild Bond](#)

Donor Conceived People and the Reproductive Medicine Industry Disconnect

PUTTING THE DISS IN DISCONNECT



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It's an innate human desire to want to know where we come from. It's important for both our medical and psychological well being to know about our biological first-degree relatives, our ancestry, our medical backgrounds, and our genetics.

While there may be some donor-conceived people who don't have a desire to seek out their half siblings or biological parents (just as in adoption), many more do indeed desire to search for and to find their relatives. Some for medical reasons, and some also feel a deep and painful loss from being disconnected from their genetic kin. Rebecca H. explains (in the book [Voices of Donor Conception: Moving Beyond Secrecy and Shame](#)):

My feelings are difficult to explain to people who take their roots for granted. An adopted person once described the sensation of what is now termed

'genealogical bewilderment' as having to drive through life without a road map. I find it to be an apt description of my situation. People who know both of their biological parents find it hard to grasp the enormity of what I am missing. Simply having information about the sort of people they are, and what things they are capable of doing, creates a baseline that you don't realize is comforting unless you have to live without it.

For thousands on the Donor Sibling Registry, connecting with formerly unknown biological relatives has led to better medical care and screenings, a greater sense of self-understanding and has been a very important component of identity formation, and for many donor offspring, long before the age of 18. Proper acknowledgement, respect and attention for the people who are suffering most with this lack of genetic knowledge, both psychologically and medically is desperately needed.

Donor conceived people follow in the path of adoptees in the arena of disclosure, along with the right to search for and know about their origins. The Adoption Congress (2007) states the following in their Assisted Reproduction Technology Statement:

The [American Adoption Congress](#) believes that all individuals whose genetic and biological origins are different from those of their legally recognized families have the right to know those origins. This includes people created through the donation or sale of eggs or semen, the transfer of embryos, gestational surrogacies, or any other reproductive technology. Knowledge of one's origins can be vital to the psychological and physical well being of human beings. Denying a person this information can have potentially

serious consequences upon that person's family relationships, health and reproductive choices.

On the Donor Sibling Registry group discussion page, one donor-conceived (D.C.) adult explains:

Knowing that the fertility industry profited from the act of deliberately disconnecting me from half of my biological family has left me with a constant sense of having had my rights violated.

So much has been written by D.C. people about why losing a connection to a parent through parental romantic decisions and chance is not the same as having that connection severed by an industry that brokered your sale. D.C. people can be grateful to exist and to have been wanted by the parents who raised them, and still feel pain, frustration, and anger about the circumstances of their conception. I wish that the parents of DC people would stop seeing their children's pain, frustration, and anger as a bad thing or as an undesirable result.

Pain, frustration, and anger are natural and good responses to injustice. Sorrow and grief are natural and good responses to rejection by a biological parent. Our anger and our grief can be fuel to advocate for regulations that respect our rights. Our emotions are not the problem; the problem is having human beings being treated as a product by the fertility industry.

Donor-conceived people are being denied the basic right to know their origins, and have become a voiceless minority in our society, without the necessary information to make informed and competent decisions about their own psychological and medical care. The US Surgeon General reports on their [website](#):

A recent survey found that 96 percent of Americans believe that knowing their family history is important." To help Americans focus on the importance of knowing family health history, The US Surgeon General along with the Department of Health and Human Services created the "Family Health History Initiative." The website notes that, "Tracing the illnesses suffered by your parents, grandparents, and other blood relatives can help your doctor predict the disorders to which you may be at risk and take action to keep you and your family healthy.

The [American Medical Association](#) agrees with the importance of knowing your family medical history:

Gathering a complete and accurate family medical history is extremely important as genetic medicine explains more diseases.

In [Genetics Home Reference](#), the National Library of Medicine's web site for consumer information about genetic conditions and the genes or chromosomes related to those conditions, has this to say about the importance of knowing your family health history:

A family medical history is a record of health information about a person and his or her close relatives. A complete record includes information from three generations of relatives, including children, brothers and sisters, parents, aunts and uncles, nieces and nephews, grandparents, and cousins.

Families have many factors in common, including their genes, environment, and lifestyle. Together, these factors can give clues to medical conditions that may run in a family. By noticing patterns of disorders among relatives, healthcare professionals can determine whether an individual, other family members, or future generations may be at an increased risk of developing a particular condition.

The [Centers for Disease Control and Prevention](#) website says:

Family health history is a useful tool for understanding health risks and preventing disease in individuals and their close relatives.

The US Surgeon General, The CDC, The National Library of Medicine, The US Department of Health and the American Medical Association all stress the importance of knowing one's family health history. And the American Adoption Congress additionally acknowledges both the medical and the psychological importance of knowing about one's origins.

A donor's medical profile (sometimes included when a person buys sperm or eggs) is a snapshot in the life of a healthy young donor, and doesn't reflect what happens the next year, or afterwards to a donor or his or her immediate family (siblings, children or parents). Additionally, many medical and psychological diseases are adult-onset so donors couldn't possibly report them at the time of donation. Some donors are not sure about their relative's diseases, and some are not honest when filling out the medical profile, afraid that if they tell the whole truth, they will not be accepted into the donor program.

The Donor Sibling Registry's [Medical Page](#) lists hundreds of reported medical issues from donor-conceived people, their parents and the donors. Some of these medical issues, like Hypertrophic Cardiomyopathy (HCM), a serious heart condition, have been shared in large half sibling groups. The sharing of this medical information amongst half sibling families on the DSR has saved lives.

Research shows that 84% of surveyed sperm donors and 97% of surveyed egg donors say they've never been contacted for any medical updates. 23% of those sperm donors and 31% of those egg donors said that they felt that they, or close family members, had medical/genetic issues that would be important to share with families.

One former sperm donor, now a doctor, said in a letter to the Journal of the American Medical Association (the letter was never published by JAMA):

This practice was firmly entrenched in the medical community long before the DNA revolution provided the tools to discover genetic relatives and the basis of many human diseases. Our incomplete knowledge of these genetic factors implies that assessing the family history of ailments is still an essential element of medical diagnosis. Also ignored in these earlier procedures was the fact that the children resulting from anonymous gamete donation were deprived of the right to know half of their ancestry, which is now

recognized as a fundamental human right. From my viewpoint, medical doctors who took the Hippocratic oath, and who were either sperm or egg donors, are morally obligated to allow their biological children access to their family medical history.

Some donors say that they have called in a new medical issue to the bank or clinic, and have been promised that it would be passed along to families- but when the families have called in they have been told that no medical issues have ever been reported. The fact that fertility industry economics would subvert the medical and psychological care of a donor child is unconscionable.

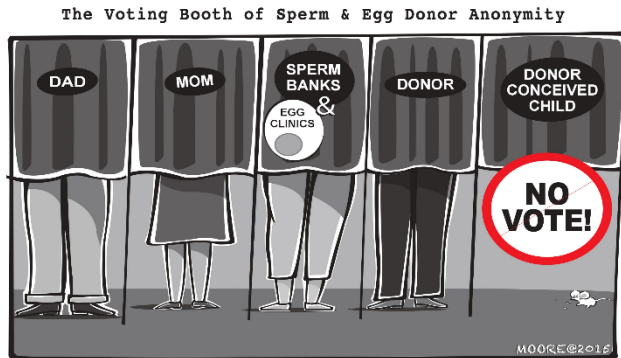
In addition to [conducting and publishing many research studies](#), the Donor Sibling Registry now has more than 47,300 donors, parents and offspring, many of whom have shared their stories. Where is the attention from the reproductive, medical and psychological industries, and the oversight to ensure that all donor-conceived people have the right to their own origins, genetics, ancestry and personal medical history?

Cartoon Illustration by Jen Moore, Outreach Director, Donor Sibling Registry, and mother to two teen-aged donor-conceived sons.

<http://www.hhs.gov/familyhistory/> Family History is Important For Your Health

<http://www.cdc.gov/genomics/public/file/print/FamHistFactSheet.pdf>

The Voting Booth of Sperm and Egg Donor Anonymity



"Nobody asked me what I wanted," said one donor-conceived young woman in her 20s. "I just wish the (sperm and egg banks) would consider this from the child's point of view."

A spirited Donor Sibling Registry group discussion began after my recent Huffington Post blogs were published.

Parents of donor-conceived children were overwhelmingly on the side of donor kids having access to their ancestral, medical and genetic information, with one dissenter parent pointing out that she feared that the sperm supply would "dry up" if anonymous donations were banned.

This is a myth perpetuated by the reproductive medicine industry and the media. In fact, since 2005, when the UK banned anonymous donations, or rather gave a donor-conceived child the right to know donor information at age 18, the UK's HFEA website reports that their sperm and egg donor numbers have grown significantly. The reasons why could be in part because the stigma and fears of the unknown in past anonymous sperm donation have dissipated, because donor banks may have stepped up their donor outreach programs, and perhaps better education about donating has spurred a new type of mature donor who can respect the need to be known by any children he helps to create.

Let's just say that ending donor anonymity in the US did result in a decrease in donors. Does the end always justify the means? We currently do not have enough organ donors either, but do not resort to unethical measures to procure vital organs. So, as with sperm

and egg donors, there might not be enough for everyone who would like a child. But that can't justify anonymous donation. We need to stop sacrificing the needs of donor-conceived people for the "reproductive rights" of parents, at any cost.

In the relevant discussion on donor anonymity, while the majority of donor-conceived parents in the discussion were in support of any and all information donor children wanted to seek out, one parent claimed that her 11 year old wanted nothing to do with knowing his genetic relatives or information.

Interestingly, one donor conceived adult then sheepishly admitted that she had always wanted to find her genetic relatives, but she had been afraid to tell her mother for fear of upsetting her. Several parents then echoed the same sentiments, and one said, "Children will often emulate behavior that they feel pleases the parent, while their true feelings can be buried under the basic need to be accepted."

After a heartfelt discussion, the group came to the conclusion that ALL children, especially donor conceived kids, absolutely have the right to know where they come from, no matter what the prior agreements have been with anonymous donors. Although disclosure, or "telling" may be the first step with donor children, it's just the beginning of the conversation. It then becomes important to both honor and support any curiosities that a child has to connect with their first-degree genetic relatives. It should be made very clear that the topic is open for discussion and any fears that a parent might have about connecting with unknown donor relatives should be placed on their back burner and/or dealt with through counseling.

Some parents stated that since that they made an agreement to use an anonymous donor, they felt ethically bound to stay away from trying to gain information, while several donor conceived children rebutted that these prior agreements were made only between the donor, the parents, and the sperm bank-- not the child, who has never had a vote in the matter.

Co-author Jen Moore, whose 2 boys were told that they were donor conceived in 2014, added to the discussion, "I've been asked repeatedly: 'Will I ever meet my donor?' and 'Will I ever get a picture of my donor?' It's really sad for a parent to know that there is no way to answer YES in good conscience."

In a DSR research survey of 751 donor-conceived offspring, 83% of them who are not in contact with their donors, wish to be. In addition, more than three quarters of all surveyed offspring strongly recommend that parents use an "open" or "willing to be known" donor.

To make a case for open donors, the Donor Sibling Registry research reports [LINK] that over 94% of surveyed sperm donors were open to contact with the offspring they helped to create. Sadly, some cannot get their sperm banks to even tell them their own donor numbers or release their information to searching children, even when both sides are actually asking to be connected.

No matter how long the sperm banks desperately hang onto the idea of anonymous donation, donors won't be in hiding, by choice or otherwise. Yaniv Erlich, Ph.D., an assistant professor at Columbia University and a core member of the New York Genome Center, surmised, "The recent estimates are that 3 million people were tested with FamilyTreeDNA, AncestryDNA, and 23andMe for the full autosomal tests. The number is growing quickly, and 23andMe added half a million people in the last year. It's been reported by the entities that operate third party websites to analyze genomic information, that the companies are experienced a doubling in the number of participants each year."

While none of the major sites reporting issuing future projections on DNA testing, using Yaniv Erlich's information, combined with the correlated numbers reported relative to 23andme.com [LINK] (300,000 genotyped paying customers in late 2013, 650,000 in early 2014, and over 1,000,000 in May 2015), the estimated populations that could have their genotype in some system by 2020 could exceed 14 million or more.

To bring things into perspective, a first cousin genetic relationship on 23andme.com can be between a 7%-13% genetic match. It would be extremely difficult past this level of transparency, with names and emails

being traded along with family histories, for any donor to remain anonymous.

Author and law professor Julie Shapiro also chimed in, responding with her own blog article entitled, "Facing the End of Anonymity." She writes, "It seems to me that questions about the value of anonymity, and the ways in which the law should/should not protect/promote it are being outflanked by reality." She goes on to firmly state that no one (sperm or egg banks) can truly promise anonymity anymore. "It's irresponsible, and perhaps even dishonest, to do so."

Still, sperm and egg banks, who have enjoyed free reign to give and take away information from donor children, seem to remain blind, deaf and dumb to what is in front of their faces related to the advances of psychology, sociology and genetic science. We have to wonder - when the American Society of Reproductive medicine will start inviting donor conceived people into the discussion for setting policies and recommendations for their industry? How can it be that the very people who are being created by these reproductive methodologies still have no voice in the matter?

Regardless of the dimming horizon on anonymity brought by the ready-packaged realities of DNA genealogy, there remains the plaintive plea of the long-ignored donor child who, for generations, has been kept in a wondering state--wandering between what they know, what they can find out by digging, and what about the their ancestral, medical and genetic history is being hidden from them. They are left to wonder why the rights of the sperm banks and clinics (to make money) and the parents (to have a child) and the donors (who at the time agreed to anonymity) always trumped the rights of donor-conceived people to know where they come from? It's high time to humanize the donor conceived and allow them their own space in the voting booth of donor anonymity, with the "polls" already showing a sweeping victory in favor of known donors.

Co-written with Jen Moore, Outreach Director, Donor Sibling Registry, and mother to two teen-aged donor-conceived sons. Cartoon Illustration also by Jen Moore

References

Donor Sibling Registry (DSR) (2015). 15th Year Information Booklet. Retrieved online July 17, 2015 at <https://www.facebook.com/download/395409610650666/Law%20School%20Powerpoint%20FINAL.pdf>

2011 Human Reproduction: Offspring searching for their sperm donors: how family type shapes the process. Authors: Diane Beeson, Wendy Kramer, Patricia K. Jennings. doi:10.1093/humrep/der202

Julie Shapiro, Blog,

<https://julieshapiro.wordpress.com/2015/08/09/facing-the-end-of-anonymity/>

23andMe Blog, by Anne Wojcicki,

<http://blog.23andme.com/news/one-in-a-million/>

1. Excerpts from an interview with Yaniv Erlich, PhD, Assistant Professor of Computer Science, Columbia

University; Core Member, New York Genome Center New York, NY

2. How Many Paying Customers does 23andMe have? Alex Komenko, <http://www.quora.com/How-many-paying-customers-does-23andMe-have>

3. Average Percent DNA Shared Between Relatives

<https://customercare.23andme.com/hc/en-us/articles/202907170-Average-percent-DNA-shared-between-relatives>

Sperm Donors Who Wish to Remain Anonymous Just Shouldn't Donate.



My son Ryan and I were contacted by Family Tree DNA in 2004, as they thought that their new commercial DNA testing capabilities might be useful to Ryan, and to the others in our community of donor conceived people at the Donor Sibling Registry. At that time we thought it might be possible to find out more about one's ancestry and countries of origin. Ryan was excited to learn more about his "invisible" paternal ancestry, so quickly agreed to swab his cheek, send in his sample and see what he might learn. He became the one of the [first donor-conceived people](#) to throw his DNA into a public DNA database, making himself available to connect with previously unknown genetic relatives.

At first, he did learn a bit more about his paternal ancestry, specifically about countries of origin. He learned that he was mostly English, with some Irish and even a bit of Icelandic (which he thought was pretty cool). He also matched with people on his 12 and 25 Y Chromosome DNA markers, which meant that common ancestors related them from hundreds or even thousands of years ago. And for 9 months he was content with that little bit of information.

Nine months after submitting his DNA, he had his first matches on the 37 Y-DNA marker. He matched with two men, same last name, who didn't know each other, but who had figured out their same common ancestor who lived in the 1600's. Because Ryan matched with both these men, as they matched with each other, it was determined that Ryan also had the same relative from the 1600's. The two men, and this common ancestor all had the same last name. It was with this last name, and a birthdate from the donor profile (that the donor filled out at the sperm bank when he donated), that within days, (with Google and a public records database), we figured out who my son's biological father was. Contact was made, and our

family instantly expanded. When our formerly anonymous donor was given the opportunity to know my son, he gladly accepted. Many donors since then have also connected with offspring on DNA sites, as well as on the Donor Sibling Registry.

With the increased volume in the general public swabbing or spitting for DNA databases, now when donor conceived people spit into a cylinder or swab their cheek and send it in to commercial DNA testing sites like Family Tree DNA or 23andme, there is a very good probability that they will connect with distant, or even close relatives. This includes half siblings and or genetic mothers and fathers, sons and daughters. Donor offspring have every right to search for, and to make these connections, of course respecting the boundaries, wishes, and privacy of those they connect with, like any other person reaching out to their unknown genetic relatives.

For decades, the rights of donors to remain anonymous have been first and foremost. The reproductive medicine industry has worked very hard to keep donor offspring from knowing their genetic parents. Some banks and clinics even refuse to give donors their own donor numbers, making it difficult to make mutual consent contact on the Donor Sibling Registry. Some banks do not even connect donors and offspring who both call in to the clinic to request that they be put in touch with each other. Even banks and clinics with "open" donors, only sometimes connect offspring with donors at age 18, as there are no guarantees.

In this day and age of commercial DNA testing, here's my advice for prospective sperm (and egg) donors: if you don't want to be known to your offspring, just don't become a donor. Because even if donors don't submit their own DNA, chances are that some known, or distant unknown relatives of theirs, have spit or swabbed, and this makes donors very findable. My son may have been the first to locate his donor with this new methodology, but he certainly wasn't the last.

If you are a former donor and think you'll never be found, it might be time to start educating yourself about what donor conceived offspring are looking for

when reaching out to their genetic mothers and fathers. We have heard from thousands of them, on the DSR and [through research projects](#) and we know that they are not looking to invade or disrupt your life. They are not looking for an active parent. They are not looking for money. They just want to know where they come from - their genetic and medical history, along with their ancestry.

Some offspring do long to meet and to know their genetic parents. And, if relationships evolve after connecting, then that's icing on the cake for all involved. It's now time that the rights of donor conceived people to be curious about, search for, and connect with their first degree genetic relatives are acknowledged.

Roots and Wings for Donor Offspring

There are only two lasting bequests we can hope to give our children. One is roots; the other wings.

This Hodding Carter quote has been the tagline on my Donor Sibling Registry e-mails for many years now. This week I spoke with an egg donor mom who questioned me about it, asking if I interpreted the quote as meaning that donor conceived children's "roots" are from the genetic parent(s) and the parents that actually raise the child supply the "wings," saying that she felt like she was both to her adult son.

To me, the quote means that we parents owe our children both: roots and wings. It's not just one or the other. Parents who raise donor children do provide both roots and wings in the form of family, security and instilling our children with the confidence and the tools to fly on their own one day. Also though, we do need to acknowledge the "other" significant part of the roots that we might not be able to supply and that might be very important to our children.

So sure, parents who raise children certainly do provide both. But, there is another person who also contributed to our children's roots: half their ancestry, DNA, and medical history do come from the other biological parent.

Once again, we hit upon the notion that some parents like to think that the donor is just a "piece of genetic

material" or only a "donated cell." But in fact for many donor-conceived people, it's much more than that. They have an unknown person who contributed half their DNA, their ancestry and their medical background: three very important pieces that contribute significantly to who a person is.

Just like in adoption, some kids are not very curious, and some are extremely curious to know about the donor. And as in adoption, families need to be supportive with whichever type of child they get. Or you might end up with resentful offspring; angered that keeping the secret was more important than their right to the truth. Or, fearful offspring protecting the parents that haven't yet healed from the pain/shame of infertility. That's not their burden to carry. It's not their shame to carry on. Too many offspring come to the Donor Sibling Registry in secrecy, behind their parents' backs, afraid of hurting or angering them.

Secrecy does imply that there is something shameful about the methodology of conception. Donor conception can be talked about openly and honestly between loving parents and their donor children. Telling is just the beginning though. And having a curious child in no way lessens your importance or significance as a parent. It is an innate human desire to want to know where we come from.

The Ethical Sperm Bank: An All-Open Sperm Bank. An Idea Who's Time Has Come.



A cultural phenomenon is growing these days in the world of gamete donation. The voices of the donor-conceived are growing louder and clearer, and the vast majority express that knowing or having known the identity of their donors is better than not knowing, psychologically-speaking. From actively listening to them, we learn that having a complete sense of one's biological origins fosters a more whole identity, which can positively impact self-confidence (not to mention the importance of knowing one's family medical history). They also prefer knowing and connecting with their half-siblings, just as anyone would want to know their first-degree genetic relatives. Furthermore, the vast majority of surveyed donors show that they not only think about the children they've helped to create, but also indicate a strong preference toward being able to know them. The extant research corroborates these experiences (DSR, 2015).

Although anonymous gamete donation is banned in 11 countries at the time of writing, the United States still lags behind in making such an ethical determination. There are numerous obstacles to banning donor anonymity in this country. In the meantime, the availability of all-open gamete donation clinics would offer an alternative option to those who want to do the right thing for their children while supporting organizations that follow this principle as a matter of regular practice. Since many egg donation clinics are already offering ethical options, we offer a sketch of what an ideal sperm donation clinic would be like. It would differ from existing U.S. sperm banks in three major areas.

Openness and Contact

First and foremost, an all-open gamete donation clinic, which we'll call The Ethical Sperm Bank, would require

all donors to make themselves available for contact with their offspring at any age. The donors would share photos, answer questions, share information about themselves, provide family medical history, and, optionally, have some required in-person meetings.

The reason behind fostering contact at any age, and not just once the age of 18 is reached, is that identity-formation begins long before the legal age of adulthood. This is the age typically chosen by those clinics who profess willingness to facilitate contact as the acceptable time for first offspring-donor contact, strictly out of liability concerns; the age of 18 is not chosen because it is the healthiest age for offspring to find out where half of their genetics came from. Theorists on identity formation, such as Erik Erikson, state that the most significant period of identity formation is adolescence - years before legal adulthood (Brogan, 2009). Curiosity about donors and half-siblings has already been expressed by tens of thousands of donor-conceived people desiring to know their first-degree genetic relatives long before the age of 18 (DSR).

At The Ethical Sperm Bank, donor contracts would state that donors are required to maintain a posting on the Donor Sibling Registry (DSR), a 501c(3) charity helping more than twelve thousand five hundred donor-conceived people to establish mutual consent contact with both donors and half-siblings since 2000. This would provide donors the ability to connect, share and update information with families, and respond to personal messages. Using the system provides a sense of empowerment and safety to users as they can have complete control over all sharing of information, thereby safely connecting with donors/offspring/half-siblings and taking the process as slowly as is comfortable.

Families and donors on the DSR are anonymous to each other until they voluntarily share personal contact information with each other. This system is currently being utilized and promoted by many egg donation clinics and agencies. Should the donor refuse all contact with his offspring, he would be in breach of contract, and legal consequences would follow.

Similarly, the intended parents would sign a contract stipulating that they will also open a DSR account and add their posting when the child is born. Their contract would require that they not restrict their child from knowing of his or her genetic origins or making contact with the donor/siblings. Obstructing the prescribed process would be considered a breach of contract. As an added benefit, The Ethical Sperm Bank would maintain updated contact information for all donors and families and fulfill requests in an honest and efficacious way.

Besides mandatory posting on the DSR, donors and recipients would have the option of also signing a contract mandating that donors must meet their offspring in person at least once before the age of 10 (before or around the start of puberty), once more between the ages of 10 and 18 (for continued identity formation and development of self-knowledge through the teen years), and on any number of additional occasions if mutually desired. Evidence that the two required meetings occurred would need to be submitted to the clinic, in the forms of a photograph or video and letters from both parties.

The fact that donors relinquish all parental rights and responsibilities toward their genetic offspring, as per standard legal practice, would give parents peace of mind and relieve any fears over losing their child to the donor. The donor would also agree not to intrude upon the family's private lives, or be involved in parenting without the parents' express permission. In turn, the family would agree not to contact the donors' family, friends, employers, or other acquaintances, or publicize the nature of the donation without express permission from the donor.

The intended parents would be educated on the inherent desire, benefits, and importance of a person's right to know the identity of both biological parents and would give informed consent before proceeding with insemination. Any intended parent who does not agree to the terms would be disqualified from the program. But, because the practices and philosophy of the clinic would be well-publicized and displayed, only parents who are open to this way of raising their donor-conceived child would likely consider working with the clinic in the first place. As greater public awareness develops on this issue, the demand for such practices may rise over time.

Recording and Reporting Births

The second major difference from existing U.S. sperm banks is that The Ethical Sperm Bank would conscientiously record and openly report the number of live births per donor. This practice could foster greater responsibility because it would enable the bank to accurately limit the numbers of births per donor and give parents and offspring an idea of how many half-siblings to expect. Parents too may naturally veer away from creating a scenario of excessive numbers upon seeing that a donor already has numerous offspring.

Careful limiting of the numbers, guided by research, would allow for the avoidance of consanguinity and social overwhelm on the part of donors and offspring; there would be a lower chance of half-siblings, cousins, or other unwitting relatives dating each other and becoming physically intimate, and donors and siblings would be less likely to feel the need to meet a challengingly high number of relatives. Most clinics do not accurately track births and, without such tracking, no consistent limits can be placed on births per donor. At the time of writing, the largest half sibling group on the DSR hovers around 200, and the donor listed on the DSR with the most offspring connections has 75 of them (DSR). There may be cases of even higher numbers.

Genetic and Medical Testing

Thirdly, The Ethical Sperm Bank would carry out comprehensive genetic testing on both recipients and donors, and conduct medical examinations to avoid, at all costs, the creation of offspring with serious diseases or health conditions. Many existing clinics claim to do so, but news stories attest to the fact that this practice is neither thorough nor comprehensive at all clinics. Currently, some clinics test some donors for some diseases, apart from the FDA's mandated practice of STD testing. Parents should know what they are getting into, medically speaking, when they choose a specific donor. For a clinic or donor to hide a condition that the donor may pass down is unethical and potentially tragic.

Additionally, sperm recipients should have complete information available about their own genetics to make sure they are compatible with their donor's genetics, particularly to be sure that they are not both carriers of the same problematic recessive gene(s). Knowledge of inherited physiological and

psychological predispositions can be a significant element in a person's healthcare, particularly in preventative healthcare.

Currently, there is little to no medical follow-up with donors, and information is rarely shared and updated with families. Sperm banks tend not to have records on all the families with children from a particular donor, exacerbating the situation. Families only have a snapshot of one day in the life of a healthy donor's self-reported medical information, with no idea of what has occurred after that date. Because many medical and genetic issues are adult-onset and the medical issues of a donor's offspring are relevant to multiple parties, the importance of establishing contact with a donor to ensure a free-flow of updated medical information cannot be overstated. Every family that includes children from a donor with a serious medical condition needs to be updated with this information so that the appropriate medical screenings and treatments for the children can be sought.

Concluding Thoughts

At the time of writing, existing sperm banks offer only anonymous donors or both anonymous and "open" donors. The latter claim can be misleading, since sperm banks often fail to follow-up on requests for contact, tell families that donors who were chosen as "open" are now anonymous, or claim to not be able to reach the donor 18 years after donation. And banks claim that intended parents continue to request anonymous donors, leading them to provide that which is in demand. In other words, they want to make sure business is good by meeting the desires of their clients. Therefore, they refuse to drop anonymous donation as an offering. We know that, when intended parents are properly educated and counseled on the psychological need of knowing one's genetic origins, they will naturally choose to do what's best for their child, putting their own fears aside.

Currently, most clinics do not emphasize the psychological well-being of their service's non-consenting "products." The reason is that, until now,

the focus has been on the rights of the clinics to sell gametes and prosper, the right of a parent to have a child, and the right of a donor to remain anonymous. Now is the time for the needs and rights of donor-conceived people to not only become a part of this conversation, but to become first and foremost in this conversation. Only they can provide an accurate understanding of their own experiences - not the conjecture of detached medical professionals or unknowing parents. The Ethical Sperm Bank would require this child-centered focus of all its clients.

The reproductive medicine industry has claimed that banning anonymous donation would decrease the numbers of available gamete donors. While this has not been true in countries such as the UK, it is certainly a possibility here in the U.S. We currently do not have enough organ donors in the U.S., but that does not give us the right to procure these organs through unethical or illegal (payment) methodologies. The case may be that, sometimes, in the name of ethics, there just might not be enough donors. The end does not always justify the means, and anonymous donation is not ethically justifiable as a means for parents to form a family and for clinics to make profits.

There will likely still be some intended parents who would rather take what might appear as the path of least resistance, based on their own fears and lack of education, and for their own convenience and comfort. But the growing cultural movement toward openness with one's children, along with adequate counseling and education, will eventually place pressure on such parents to do the right thing. These are the only solutions in the absence of government regulation. Perhaps in time and as public pressure mounts, regulation will follow. Either way, The Ethical Sperm Bank is an idea whose time has come.

Co-written with Laura Strong.

References

Brogan, R. (2009). Major processes in identity development. Published on education.com. Retrieved online July 17, 2015 at <http://www.education.com/reference/article/identity-development/>

FINDING OUR PEOPLE: Wendy and Ryan Kramer's Story by Ellen Glazer

One of the ways that we try to enrich the lives of our members, as well as to educate others about donor conception, is to tell stories. We offer you a voice and believe that when you share your stories of discovery, you embolden others to “find their people” and to understand their own feelings about donor conception in new ways. Each family story is different, but there are themes that run through many stories and inform us. DSR founders, Wendy and Ryan Kramer have a story that now spans more than 2 decades and expands all of our understanding of donor conception. It is a story of ups and downs, twists and turns, determination and patience. It is testimony to the magnificence you may encounter when you open yourself to possibilities.

The Beginnings...

“Here we go again...” Since 2000, Wendy Kramer has been helping people whose lives have been touched by donor conception connect with each other. Every day new members join the Donor Sibling Registry (DSR) and most days 2 or 3 or more people are connected with their own, or their child’s first-degree genetic relatives. Each new connection is exciting and in some way, Kramer celebrates alongside those who are newly matched. But at the beginning and end of the day, this indefatigable head of the DSR is “just a mom.” *“In some ways I am no different than any other parent on the DSR, signing on to see if any new half siblings have joined.”*

The history of the DSR, and Wendy and Ryan Kramer’s personal history are inextricably linked. Wendy recalls the evening of her own donor insemination, lying in bed quietly repeating the words *“Pick me. Pick me. Pick me.”* Two weeks later she learned she was pregnant. By the time Ryan was two years old, it was clear that he was exceptionally intelligent. By three he was asking, *“did my dad die, or what?”* after noticing that other children at his preschool had both moms and dads. By age six he was clear he wanted to meet his genetic father. Had a different child picked a different mom, it is unlikely that the DSR would exist:

the organization was conceived and gestated because one curious little boy asked questions that one loving and determined mom could not answer. And the rest, as they say, is history.

Wendy and Ryan’s personal history of exploration, discovery and connection along with their experiences as the public faces of DSR chronicle major shifts in the practice, public perceptions and private journeys of donor conception. Their story, which began Labor Day weekend 1989, with Ryan’s conception, was last updated this 2016 Labor Day weekend when Ryan, who waited seven years for his first match via the DSR, had another. The first time it was a sister. This time it is a brother. There have been others in between. Each experience is new, different and comes with its own brand of pleasures and challenges.

The history of the DSR is linear—it is an organization that began small—tiny to be exact. Wendy posted a small notice on a Yahoo group, *“I’m the mother of an awesome 10 year old donor child—I know that he has at least three donor siblings and we would love to connect with them. We are looking for donor 1058 from California Cryobank and hope that this will help others looking for their children’s donors (or their own).”* By the end of 2000, there were 6 members. After a year, there were 14. By late 2002, membership numbered 37 and as of November 2016, 52,500 people in 105 countries are members of the DSR. Steady, strong, magnificent growth in membership and alongside it, influence in laws, policy and ethics surrounding around donor conception.

The Kramer’s family story is not linear. Yes, Ryan has grown from a young boy asking questions to a 26 year old product manager at Google answering questions. Yes, Wendy has evolved from a mom trying to help her son “find his people” to a dazzling leader of a large and influential non-profit. However, their family story of donor conception and donor connections is one of meandering journeys in kinship. Along the way, there have been connections with Ryan’s biological father, donor, “grand parents, and an array of half donor

siblings. Some matches have been “easy” (relatively speaking) and others, frustrating.

We are grateful to Wendy and Ryan for sharing their story and hope that it will help DSR members and others see and appreciate their own stories in new ways. For in the words of sociologist and dad through donor conception, Joshua Gamson, *“Stories help make things make sense. They put things in order. This is how it happened. They are also the stuff from which identities are built. Creation stories, in particular, are about selfhood. ‘In telling the story of our beginning, as an individual, a nation, a people,’ as the sociologist Francesca Poletta puts it simply, ‘we define who we are.’ This is how it happened.”*

Modern Families, Joshua Gamson

PICK ME, PICK ME, PICK ME

Donor conception has changed exponentially since Wendy and her then husband chose “DI” when they learned that he was infertile. *“Over 27 years have passed but I can still remember that August day when the doctor told us, ‘You will never have children together.’ I felt like I’d been kicked in the gut.”* Always a person of action who does not know what it means to procrastinate, Wendy picked herself up, dusted herself off and along with her ex, moved quickly to the next step. *“In those days people seeking sperm didn’t get baby photos or questionnaires, voice recordings or ‘staff impressions.’ We met with a woman at our local clinic who took a look at my husband’s coloring, height, weight and asked about ethnicity as she tried to make a match. By Labor Day weekend, I was undergoing two inseminations having no idea at all about the man who would be the genetic father of my child.”*

Wendy says that many people have gone on the DSR website or seen her on TV and have assumed that she was a single mother by choice. On learning that she was married when Ryan was conceived, they ask about Ryan’s “father”. Wendy explains that her ex-husband was Ryan’s dad for Ryan’s first 18 months but from that point forward, Wendy was Ryan’s only parent.

“This makes people really uncomfortable,” Wendy says, *“They understandably worry about the idea that a non biological parent can have his/her parental rights and responsibilities removed.”* Wendy goes on to explain that her ex’s exit from Ryan’s life had nothing to do with genetics—they divorced because of

substance abuse issues and because Wendy had other worries about Ryan’s safety. Wendy’s goal was for Ryan to grow up in a safe and happy environment and looking back, Wendy believes that this was her ex’s goal as well. *“I believe he gave up his parental rights and responsibilities in part because he knew it was best for Ryan. In so doing he was able to leave our lives and return a few years later as a friend.”*

Having had her son with a husband and having taken the extraordinary steps of ending his fatherhood, Wendy says prepared her to respect and respond to Ryan’s desire to know his genetic dad. This was not always how donor parents felt though. She reminds us, *“In those days people did not ask questions. Those of us who used donor sperm had no idea we had the right to be curious or the right to search. Similarly, donors assumed they had no rights.”* But back to Wendy on the exam table receiving sperm, origins unknown.

“I just lay there looking up at a poster of Kevin Costner on the ceiling and mumbling to myself, ‘Pick me. Pick me. Pick me.’ I wanted this more than I could have ever imagined and within a week or so, I knew that my plea had been answered. An early pregnancy test was positive and on May 22, 1990, I gave birth to a beautiful baby boy.” Wendy, who is neither a religious nor a spiritual person, felt certain that Ryan had picked her. And so she was not surprised when at 3, her young son said to her, *“You know, I picked you.”* So there they were—an exceptionally bright and curious boy and a mom who had mortgaged her heart forever.

One of the first things every parent learns is that the child you get is not likely to be the child you anticipated. In Wendy’s case, the surprises began with Ryan’s remarkable mind. Wendy and her then husband had requested a donor that resembled him physically, never asking for anything particular in regards to academics or intelligence. Wendy jokes, *“I put in for regular, but they gave me premium.”* And so Ryan’s exceptional intelligence came as a complete surprise. By the time he was in first grade, testing confirmed that Ryan was profoundly exceptionally gifted. Along with this news came the psychologist’s prescient observation, *“People like Ryan don’t usually find ‘their people’ until they are in graduate school, have graduated from college.”*

Wendy took the psychologist’s words to heart and early on had a profound respect for what she anticipated would be Ryan’s need to find “his people.”

Ryan had tutors and mentors and a wonderful big “Big Brother” who was a scientist. This also meant navigating an educational system that isn’t set up for a child who needs to accelerate or a boy who begins as a full-time aerospace engineering student is academically college ready at 14. It also meant responding to Ryan’s stated desire, beginning at age six, to meet his biological father. Unable to offer him this, Wendy did what she has now had lots of practice doing: she followed her son’s lead and tried to figure out a solution.

“From the start, Ryan and I were clear that we didn’t want to search for someone. Instead we wanted to make it possible for us to be found. Even then, at a time when people understood little about donor conception and the need that some have to find genetic kin, we knew this was not the realm of private detectives. It had to be grounded in mutual consent.”

But how does someone go from knowing nothing to know something and more? Wendy says that her path—and Ryan’s—began with her contacting her clinic when Ryan was three and asking if they could tell her anything at all about the donor. The woman who spoke with them offered this startling reply, *“Oh, you never received the long form? You were given Donor 1058 from California Cryobank.”* With that she requested that the long form be mailed, and when a thick envelope arrived a few days later from California Cryobank, Wendy let it sit on the counter for a few hours. *“It was daunting to think that it included all sorts of information about Ryan’s biological father—and hence, about Ryan.”*

When she did open it, Wendy found, as expected, that it contained much that would be important to Ryan. *“Perhaps the most profound experience was simply seeing his hand writing. Donor 1058 was no longer a vague hint of a person—he was real!”* Wendy goes on to say that reading about hobbies and interests, talents in school and physical characteristics of the donor and his family would all prove important to Ryan over time. *“It wasn’t like we combed the profile daily but we did look at it from time to time. Ryan would go to it when he had a new interest or learned something more about himself. It helped so much to begin to put the pieces together. It was an important part of Ryan’s identity formation.”* Wendy offers, as an example, hair and eye color. Wendy and her family all have dark hair. Ryan was very blond as young child, a feature that constantly called attention to the family.

“Where did he get that blond hair?” strangers would declare in wonder. Wendy remembers shrugging and answering quite honestly, *“I have no idea!”* Reading the profile and learning that Donor 1058’s brother had blond hair and dark eyes was immensely helpful.

The questionnaire included a message from the donor to future offspring that read *“Educate the child Raise him/her without biases of any kind. Teach him/her to trust in others but to rely on self. Instill in him/her a sense of humor and the ability to enjoy life.”* To Wendy and Ryan this spoke volumes. It assured them that Ryan’s biological father was a good person and the message spoke to his maturity and sensitivity. Ryan’s interest in meeting him increased and mother and son began to think more seriously about how they might put themselves in a position of being found. *“We didn’t want to intrude upon him but we wondered if he might feel as we did—a desire to make contact. We wanted to let him know that Ryan existed, and give him the opportunity to choose to connect.”*

Over the years Wendy had called California Cryobank with some regularity. *“I would ask them if there were any updates, any changes in policies, any-anything.”* Eventually Wendy would have a call that hit pay dirt but in the meantime, she wondered if it would help for Ryan to write a letter. *“My first goal was to help Ryan feel that he had some control of the situation. Sadly, I’ve heard from so many DSR members that they feel powerless as their sperm banks, doctors, medical clinics, and egg donor agencies work very hard to withhold some of the most important information that a donor child can desire. I suggested to Ryan that he write a letter to the sperm bank. Although I knew the letter would likely end up in a file and never be shared, it was the process of writing the letter and sending it off that I felt could be empowering for Ryan.”*

How do you ignore the poignant letter of a seven-year-old child? California Cryobank did and their non-response further provoked Wendy Kramer’s ire. She upped the volume in her yearly calls to the sperm bank. Sadly, her pleas on her son’s behalf yielded only, *“we promised our donors anonymity and our obligation is to maintain this.”* *“But what about an obligation to the resulting children? They never signed any agreements.”* Wendy wondered. Unnerved and unwilling to remain passive, Wendy began honing her detective skills. Over the years she has mastered them.

Wendy looks back with amusement at her first foray into searching, when Ryan was three, long before the Internet. *"A friend put an ad in the LA Times misc. classified section that read, 'Donor 1058, we want to thank you.' It included our phone number. We placed it and we waited. A week later I received a collect phone call from the LA County jail. Surprised, I reminded myself to be open-minded. I said to myself, 'Ryan's donor is a good person who must have made a mistake.' I accepted the call and soon realized that the voice on the other end was an African American man. Although Ryan sure did not look African American I went with this information as well—ok....so Ryan's genetic father was African American and is in jail. Ok, I can be open-minded! It didn't much matter—what mattered was that he was contacting us. He wanted to be found."* As it turned out, it was a wrong number. The caller was responding to an ad for a Christopher Darden (attorney in the OJ trial) look-alike pen pal.

A few years later, Wendy obtained some startling news from a lady at the sperm bank and her mother quickly passed it on to Ryan before she had time to fully process how to tell a child who would immediately want answers. *"I had wanted to wait a bit,"* Wendy says. *"I knew that he would become over-the-moon excited by it and I wanted to have a plan before telling him."* The information, which Wendy had learned somewhat inadvertently, was that Ryan had several half-siblings "out there." The information had come from an atypically talkative woman at California Cryobank, that usual fortress of secrecy.

As anticipated, Ryan was fired up by the news that he had half siblings. *"If I want to know them, then maybe they want to know me? How can we know about each other if the sperm banks won't put us in touch with anyone?"* Like many parents and their children, Wendy and Ryan had their best conversations in the car. *"We used to brainstorm in our commute from Nederland to Boulder, and back."* Wendy remembers. *"We would try to figure out ways that Ryan and his half siblings could find each other. Then Ryan began learning about Yahoo groups and we decided to give it a try."* Their first message, *"I am the mother of an awesome 10 year old donor child. I know that he has at least 3 donor siblings and would love to contact them. We are looking for Donor #1058 from the California Cryobank. I hope that this board will serve others looking for their children's (or their own) siblings."*

And that is how the Donor Sibling Registry was born. In its earliest, embryonic form it was the Yahoo group, and that very first message that Wendy and Ryan launched on September 3, 2000.

"The Yahoo group helped get us started," Wendy remembers. *"But the process was cumbersome—we had to make all the connections ourselves. Fortunately, I'd made contact with Sheri, a computer savvy mom through the group and she offered to build us a matrix. That matrix—which led to our website—enabled us to be way more efficient and effective."* And so the DSR website as most of us know it was born.

Looking back, Wendy identifies herself primarily as a mom on a mission. She had a child with questions and she was fearless and determined to do whatever she could to get Ryan's questions answered. She felt that she had brought Ryan into this world with this particular set of circumstances, and she therefore owed it to him to do whatever humanly possible to help him find the answers to the questions that he had about the missing pieces of this his identity. However, somewhere along the way, Wendy realized that what she was doing and what she was building went beyond her family story. *"In many ways, I had no idea what I was doing. I was creating something out of nothing. It was something that had never existed before. It did not fit in any existing category. Putting one foot in front of the other, I decided to talk with a lawyer and form a non-profit organization."*

There have been a few people who have been instrumental in helping Wendy and Ryan grow the DSR. One was a former donor in the UK who sent Wendy a \$1000 donation to help her get the DSR off the ground. Another was an attorney, a woman who provided vision when Wendy had none. As they talked together, Wendy remembers the lawyer saying to her, *"You will be writing papers and talking at conferences and educating the public."* Wendy remembers glazing over and thinking the lawyer was a little crazy when she heard these words—words that felt so foreign to her at the time. *"The lawyer offered me vision when I had none."* The lawyer also offered the legal expertise that enabled the DSR to gain non-profit status in 2003, after 9 months of wrangling with the IRS.

Today the DSR website is a very lively place. There are emails literally flying around the world, among people in 105 countries. Each day matches at least 2-3 people. But at the beginning, things moved very slowly. Wendy and Ryan, two people who thrive on action,

had to wait patiently for three months after their first Yahoo post before hearing from another donor mom. She, too, was seeking her donor or her son's half siblings. **donor conceptions**. To this Wendy, who was beginning to learn to wait, replied, "It may take some time."

And it did take time. These days some people who sign on to the DSR and have an instantaneous match. But many wait. That second mom to sign on with the DSR waited twelve years before her son's biological father finally signed onto the DSR. For Ryan, seven years would pass before he became the 2,910th person to match on the DSR. But that does not mean that in the interim, his mom embraced patience. In 2002, with only 37 members on the Yahoo group, Wendy "took the show on the road." After sending emails to Denver's three local TV stations, telling them about Ryan and of his quest to find his biological father, the NBC affiliate decided to run a story. **Two weeks after thaal TV stations to air Ryan's srory, worked and within twot,, Diane Sawyer was interviewing Ryan and Wendy on Good Morning America in New Yorkher show.**

OPRAH FINALLY CALLS

Appearances on the other major talk shows and newspapers followed and with them, Wendy and Ryan's voices were heard across the US and beyond. Along the way, they realized that their quest was not only to find "Ryan's people," but also to educate and support all those whose lives were touched by donor conception. "Before then," Wendy remembers, "People did not know they had rights. Donor offspring and parents did not know they had the right to be curious, the right to search, or the right to connect with their first-degree genetic relatives. Additionally, the donors, who were promised (or forced into) anonymity, also had curiosities and desired to know about the children that they had helped to create."

Wendy sets her sights high and although proud and tickled to have a national audience, she would often quip with family, "Oprah still hasn't called..." The words may have been said half in jest but Wendy acknowledges full force delight when her phone rang with the caller ID *HARPO Studios*. A few weeks later she and a 12-year-old Ryan were in Chicago taping their first Oprah (Harpo spelled backwards) show.

The Oprah show was transformative. On a personal level for Wendy and Ryan, Oprah was simply affirming.

She took them seriously. She respected and admired Ryan's search and understood his need to be known. She told Ryan, "I believe you will find your biological father." And Oprah was kind and gracious with Wendy, taking her by both hands and jubilantly greeting her as "Ryan's Mom, Ryan's Mom, Ryan's Mom."

Wendy, Ryan, and Wendy's mom Jacki shared the excitement of being on Oprah all over again when the show aired on May 22, 2003, Ryan's 13th birthday. Going live at different times in different time zones, the family spent hours watching the TV monitor and running between 2 computer screens where flocks of people were joining the Yahoo group. There, in the midst of frantically signing people on, Wendy received the email that mattered more than any of the others. It was titled, "Donor 1058?" Ryan had not identified his donor's number on Oprah.

Having beamed his story out into the universe, Ryan was overjoyed to have someone beam back. The content of the email read, "Was that your Ryan on Oprah today?" To this Wendy replied, "Yes!!!" And the writer beamed back, "I guess I knew that when I saw him. I gave birth to his two half sisters. They are 10 and 7. Like him they are brilliant and beautiful..." Wendy, Ryan and his grandma all hugged, laughed and cried together. Ryan's birthday celebration was now in Technicolor. He was over the moon elated to know he had two half sisters, to see photos of "two little girls who looked like me with wigs" and perhaps, most of all, to be known. On hearing of his two half siblings, he replied to their mother, "I am screaming with joy. We are all screaming with joy. Please write back as soon as is humanly possible." And off the family went to Ryan's birthday dinner, his head hanging out the car to declare to everyone in his home town world, "I have two sisters! I have two sisters!"

The story of the DSR is one of twists and turns, joyful moments and frustrating setbacks. And so it was to be with Ryan and this first contact. No sooner were Ryan and his mom thinking about flying to the east coast to meet his sisters, then their mom beamed back a devastating message, "We have not told our daughters that they were donor conceived and we do not plan to do so..."

Had Ryan picked a different mom, it is easy to imagine the story ending there. How much hurt and disappointment and frustration was he to take and was this quest leading anywhere good? Fortunately,

Wendy's unbridled feistiness and immeasurable patience kept them going. There is no other way to say it than that Ryan was crushed. So much had happened in so short a time. He had gained a national voice. He had been heard. He had been found. He had taken a giant leap forward towards finding "his people." And now this gigantic setback: the girls were out there but not only couldn't he meet them, they could not even know that he existed. But as one door closes, another opens. Before moving on to that next door, a bit of follow-up...

Although Ryan has not met these two half sisters and they do not know about their own biological origins, or about him, he and his mom have been able to learn more. Their mom exchanged more emails with Wendy and it was she who provided them with Donor 1058's updated profile, a document that proved instrumental in later sleuthing. She also told them more about the girls and even provided a photo. Perhaps even more helpful has been Facebook. Wendy and Ryan have been able to follow the girls and at least see updated photos.

"BUT THAT'S JUST ANECDOTAL"

Although their original goal was to help people who were genetically related make mutual consent contact, Wendy and Ryan discovered early on that other important connections were happening. A community was forming. When the DSR website emerged as the place where matches were made, the Yahoo group became the place that people went for conversation, news and advice. Information was shared. People told anecdotes. Issues were raised. Themes emerged. Much of this was warm and enlightening—participants affirmed the need to know each other. However, some of what they learned from each other was troubling: sperm banks were not keeping records. Medical information reported to them was being ignored. The sperm industry did not seem to care about its constituents. Troubled and ever eager for change, Wendy took her concerns to the American Society for Reproductive Medicine. *"I expected they would be glad to hear from us and would have our backs with the sperm banks. Instead their spokesperson said that he didn't value the information coming from the DSR as the reports were purely 'anecdotal'."*

One does not say no to Wendy Kramer. In her words, *"I drive the train and when I am driving the train, it always leaves the station. And on time."* That said,

Wendy was an accountant/business manager and restaurant owner who did not know how to conduct formal research. Enter Dr. Susan Golombok, Director of the Centre for Family Research at Cambridge University, in 2006. *"Dear Wendy,"* Dr. Golombok began, *"I was interested to read in the UK papers about your website....."* Conversations followed, Wendy travelled to Cambridge and research partners came to Wendy's home. Golombok and her colleagues from Cambridge were on board and the research train could leave the station. The Cambridge group offered their academic expertise and their belief in the significance of the DSR and its work. Within a short time, the Cambridge University—DSR collaboration was publishing research that was being presented at conferences around the world. People were listening. Maybe not the ASRM. Surely not the sperm banks or egg clinics. But others were listening and the voices of the donor conceived were being heard- both anecdotally and via peer reviewed published research in prestigious academic journals.

A DOOR OPENS ENTIRELY UNEXPECTEDLY

2004 brought major changes in Ryan and Wendy's lives. Ryan graduated from high school at age 13 and somewhat unexpectedly, soon became a full time undergraduate in the University of Colorado's Aerospace Engineering program. It was also a year in which commercial DNA testing sites were just getting off the ground. When one of these sites, Family Tree DNA contacted Ryan and asked if he would like to submit DNA, he did a cheek swab and sent it off with low expectations. He was told that it might give him insight into some paternal information, like countries of origin. Wendy and Ryan were always up for another route, another try and in 2004, he submitted DNA to Family Tree DNA. Indeed, he soon learned that his paternal heritage was mostly English, some Irish, and even 4% Icelandic, which he thought was pretty cool. What he could not have anticipated was that nine months later a connection with two very distant relatives would set him on a path to finding his donor. This path began with the following email from a man named Michael C.

"I am part of a C. family DNA project. I was just checking my closest Y-chromosome matches and came up with two people who were a three-step mismatch with me on the 37 marker test; Robert Gene C. (the one person in the project that I know to be a relative) and Ryan Kramer. I then checked Robert C.'s results and his closest match, a two step mismatch, was also

Ryan Kramer.” Michael C. then goes into some genetic details and continues, “In other words, Ryan falls between Robert and me as if he were from a third branch of our family. We are descended from two brothers from North Carolina, Alexander C. (b. 1710) and Thomas C. (b. 1722)...”

Things got interesting quickly. Michael C. wrote on, “I did a web search for ‘Ryan Kramer’ thinking that if he was into genealogy, he might have posted on one of the message boards or even have a website devoted to his family history. Instead what I found was a Denver Post article from last November about Ryan and his situation. A second search using your email address posted with Family Tree DNA confirmed it was the same Ryan Kramer....”

The plot was thickening. Ryan, who had been waiting as patiently as he could for four years on the Yahoo group, was now several steps closer to knowing the identity of his donor. Because Family Tree DNA identified links via the Y chromosome and names are passed down traditionally from father to son, Ryan’s donor’s last name was likely to be C. or some variation. The irony of all this did not escape Wendy and Ryan. They had established the DSR as a place for mutual consent contact, not wishing to track down or “out” anyone who wished to remain private. Prior to Wendy and Ryan’s going live on Good Morning America and Oprah, few acknowledged the rights of donor offspring to seek genetic kin. By contrast, Family Tree DNA and countless genealogy groups fully supported the pursuit of one’s “people.” How fitting that Ryan’s most significant lead would come from a distant genetic relative curious about genealogy. The mother and son Kramer amateur detective agency was in business.

Looking back, Wendy is lightly amused by the unexpected supporting cast of characters that were there to assist Ryan in his search for his donor. There was the “lady who answered the phone” at the sperm bank who let them know there were many offspring. Diane Sawyer helped and Oprah helped more. And there was the mom who wouldn’t tell her daughters they are donor conceived but provided Wendy and Ryan with the secondary donor profile that contained the exact birthdate of donor 1058. Now there were the two C. men beaming in help from distant shores. In their own way, Wendy and Ryan had assembled their team of helpers but it was this mother and son detectives who were leading the way.

Wendy and Ryan now had three critical pieces of information that would lead them—without much further delay—to their donor. The additional California Cryobank donor profile passed along by the mom of Ryan’s half sisters offered his exact birthdate and place of birth and thanks to the genealogy sleuths on Family Tree DNA, they had the lead on a last name. They requested a public list from in Los Angeles County of all male births on that particular day a couple of years before, and had tucked it away in a drawer. Wendy remembers that eerie feeling of pulling out that list of around 250 names and knowing one of them belonged to the man who had given her Ryan.

And there it was. Lance C. Born on that exact date. The pieces fit together but Wendy, ever the accountant, is one who covers all bases before reaching conclusions. She taped up a large piece of white paper on the wall and drew a line down the middle. On one side it said, “Donor 1058” and listed all they knew about him from the donor profile. On the other side, “Lance C.” and all they were learning about him. Everything that matched on both sides of the middle line, would be highlighted in bright yellow.

Wendy and Ryan knew what engineering degrees Lance had and approximately when he had earned them. And they had researched about possible colleges or universities he attended based on areas of study and geography. Ryan called the three or four institutions that were likely matches and told his story, asking if anyone named Lance C. had earned a degree there within a likely three-year period. Bingo—the name and the year and the degree matched up. Lance had earned his Masters of Engineering in 1990. This news transformed the white paper to a blaze of yellow. But there was to be remarkable icing on this richer and richer cake: Lance’s degree was dated May 22, 1990, the very day that Ryan was born.

So there they had it. Ryan’s donor had gone from a distant blur to a person in the form of Donor 1058 to real, live Lance C., living in San Francisco and working for Google (he would, of course, be amused when he later asked Ryan how he had found him and Ryan’s one word sheepish reply was “Google.”). Ryan became the first donor-conceived person to locate a formerly anonymous sperm donor via DNA testing. But what to do next?

Wendy is bold but she is also cautious. Had things been left to her, she would have let Lance’s identity

marinate in her mind and in Ryan's for a few days or more and then they'd figure out what to do next. But Ryan was a 15-year-old teen who had just completed mission impossible. For him, there was no waiting. He woke Wendy up in the middle of the night to let her know he had written a letter to Lance and he'd already pushed "Send." Wendy remembers thinking, "So much for collaboration!"

Wendy remembers reacting with fear. She had seen her son go from the ecstasy of learning he had two sisters to the crushing news that they might never know him. More hurt could surely follow with Lance. Wendy worried that Ryan, bright as he is and wise beyond years, might have put Lance off by his letter. She was relieved and quite proud when she read Ryan's letter and felt somewhat hopeful that it would be well received. "I wanted one thing," Wendy recalls, "I wanted Lance to be kind." For 48 hours her mantra was, "please be kind, please be kind, please be kind." Two nights later Ryan awakened her a second time to jubilantly announce, "he wrote me back!" Wendy knew the answer to her question when she saw her son's smile mixed with tears but still asked the question. "Was he kind?" The answer was a resounding "YES!"

Ryan has shared his letter to Lance, a few excerpts from Lance's reply and his second letter to Lance.

On 6/14/05, Ryan Kramer wrote:

Lance,

Where to begin... my name is Ryan Kramer, I'm 15 years old and I live in Nederland, Colorado I just completed my first year at the University of Colorado, majoring in Aerospace Engineering. Recently, my mother Wendy and I have been doing some research trying to complete my family tree. As you understand in a moment, I have been missing a large chunk of my ancestry. After much work, DNA tests, private investigation and public record searching, I believe that I have finally found the man I'm looking for. You may want to sit down for the next part.

*15 years ago my mother was impregnated with a sperm donation from California Cryobank Donor 1058. According to the brief amount of information we have about him, he was born ****, 1967, is 6 feet tall, has light brown hair and brown eyes. He holds a BS in industrial engineering and an MS in Engineering Management. His father is an urban*

planner and his brother is a pilot. He likes poetry and his favorite place to eat is the In and Out Burger. You and this man, I believe, are one in the same, which incidentally, makes you, my father.

Now, before you jump to any conclusions, I'd like to reassure you of a few things. 1st of all, I am not contacting you for money, I am not looking for you to put me through college, nor do I seek any other form of financial aid. Secondly, I respect the fact that when you donated as a teenager, you signed up for complete anonymity. Thus, I am not asking for a relationship, nor am I asking you to become a father figure or a part of my life if you are not comfortable with it. While getting to know you would be the best case scenario for me, the level on which we connect is entirely up to you.

Because I advanced 4 grades and went to college early, The Denver Post did a rather large article about this past November. It contains almost everything you could ever want to know about me, so I am attaching the link:

http://www.denverpost.com/boywonder/ci_0002556220/ci_0002556220.

When you are ready, you may contact me by whatever means you feel most appropriate. To start with, I would like to hear a bit more about you. What are your hobbies? Interests? Are you married? Where do you work, and what do you do? Where did you go to school? Grow up? Since I started asking about you at the age of 2, I have always been curious about you. Anything you are comfortable telling me about yourself would be more than I know now.

With that, I leave the ball in your court. I look forward to hearing from you, and hope you are well.

Sincerely,

Ryan Kramer

Excerpts from Lance's reply:

Dear Ryan,

I'm very pleased to hear from you.

My great hope is that you will use your gifts for the service of mankind, solving the problems that threaten the survival of the human race in the long run, or building tools that will enable others to solve these problems. "With great power comes great

responsibility," as they said in Spiderman. Moreover I hope you will work to enable us to be more intelligent as a race.

I hope you'll cultivate a love for reading, especially about leadership: the world needs smart leaders.

You look a little like me at your age in your picture.

I have an above average IQ, but so does virtually everyone I work with – smarts are helpful, but methodology and people skills are also vital in life.

I don't want ANY publicity for being a sperm-donor father right now, but I am thrilled to be your genetic father.

I'm happy to exchange emails with you for now, but we will have to build any relationship slowly.

Best regards,

Lance

Ryan responded....

Lance,

I am very pleased to hear from you as well. Your email was very inspiring, and you seem like a very good person, the kind I would get along with. I don't know if you remember this or not, but on the profile you filled out when you were 19, you said "Educate the child, raise him or her without any bias of any kind. Teach him or her to trust in others, but to rely on self. Instill in him or her a sense of humor, and the ability to enjoy life." I was blown away by your intelligence and insightfulness at such a young age. It was one of the few things on that profile that was personal, not just a physical characteristic. I always took it to heart and used it as a golden rule for life.

1st of all, thank you for answering my questions, I could not help smiling as I read your responses. We share a lot in common, and it is no surprise. I often see things in myself that clearly did not come from the maternal side of my family, and wonder about their origins. Things I'm interested in, physical traits, ways I move or speak, foods I like or (more often) don't like, and much more. Learning more about you will be an enlightening experience for me, no doubt.

In regards to your questions, college went very well last semester. My 1st semester (fall 2004) was actually quite shaky. I took General Chemistry, Calculus 1, and Introduction to Aerospace

Engineering. I got an F, C, and A respectively. The truth is, college was a kick in the teeth at 1st. I had become so accustomed to being bored in high school, when I started college, I had a rather large rude awakening. Chemistry (which is not my favorite subject, to say the least) was the most difficult for me. Calculus was very fun and very easy to understand, but due to a few stupid mistakes on exams, I ended up with a C. Intro to Aerospace, however, was very easy and enjoyable. Second semester was a lot easier. I took Chemistry again, and just for the GPA, I took calculus 1 again as well. I also added an Engineering Projects class. This time around, I landed A's and B's.

My projects class proved to be quite enjoyable. I was the leader of a team of 5, and we had the semester to design and build a "sustainable development project". My team built a hydrogen collection and storage system, using electrolysis.

This summer, I plan to relax and ride my mountain bike. In May, my mother and I spent two weeks in Turkey, which was very fun. We spent some time in Istanbul, then a few days on the Mediterranean coast, as well as a 5-day boat ride. We have traditionally gone to Europe every year since I was 8 with the exception of last year. Traveling has

been perhaps the greatest learning experience of my life. I've learned so much about history and culture, much more than I could ever find in a textbook. I am grateful to her for providing me with that opportunity.

For this fall semester, I am registered for Calculus 2, Physics 1, Introduction to the Humanities, Introduction to Civil Engineering, and a 1-credit work group. I have been set on Aerospace for many years now, but recently have developed an interest in Civil. I am taking the intro to see if it's really what I want to pursue a degree in or not. I am also looking forward to physics, as it was one of my favorite subjects in high school.

Finally, I have a few more questions for you, if you don't mind answering them. For starters, what kind of music do you like? Music is a large part of my life, and my iPod is usually running at least a few hours a day. I recall you liking modern rock on your profile. I'm a classic rock kinda guy... Led Zeppelin or Bob Dylan would be my favorites. How about movies? I like *The Thing*, *The Shawshank Redemption*, the

original Star Wars and The Shining. You said that Keyboard was to be a “future hobby” of yours. Did you ever pick it up? I began playing keyboard when I was 5, and played until I was ten. I then studied violin for a year, and then cello for a few years. I recently bought an electric guitar and have been learning a few things on it here and there, but am looking forward to learning the bass as well. You also mentioned playing ultimate Frisbee. Do you play on any sort of a team, or just for fun? I ask because it one of my favorite sports. Anyway, I hope I didn't overload you with questions. Remember, you don't have to tell me anything your not comfortable with.

Also, I would like to assure that that I completely respect your request for no publicity. I understand completely, and I will make sure not to mention any of this to anyone other than close friends and family. Your requests are my top priority.

Anyway, the picture in the Denver Post was kind of small, so if you're interested in seeing a larger picture of me, I have attached one. It is of me hiking walking in a river in turkey. Anyway, I'd better go, but thank you again for your response, and I look forward to hearing from you.

Ryan

P.S. I was happy to see that you mentioned spider-man in your message :).

Ryan and Lance communicated by email over the summer months following their initial exchange but the length and frequency of messages diminished during that time. But Ryan was buoyed by all the positives that had happened—he had found Lance and confirmed that Lance is a good person. Lance was kind towards him, and Ryan now had a complete medical history. He was jubilant also to have freed himself from the control of the sperm bank. So all was mostly good. Ryan reminded himself that even if contact petered out, *“when I turn 18 I can get on a plane and go shake his hand.”*

As it turned out, Ryan would not be waiting until age 18 for a visit with Lance. In August, a surprise email arrived. In it, Lance wrote the following, *“Would you like to come to California to meet me and your grandparents?”* This unexpected invitation, with it's clear declaration that Ryan and Lance's parents are kin, sent Ryan and his mom over-the-moon with excitement. Their state of wonder increased

exponentially when Lance sent detailed, yet Mission Impossible-type instructions for their travels. Determined to keep Oprah out of the picture, Lance was sending them to a specific airport, with continued instructions to rent a car and check in at a specific hotel to await further instructions. Wendy and Ryan, veterans of some “our lives feel like a movie” moments when they went on national TV, surely felt this all the more as they dutifully followed Lance's instructions.

“Check it out. See that kid? He's my son.”

Wendy remembers cascading feelings of gratitude when they arrived in their hotel room and were greeted by a basket of treats and a sweet note from Lance's mom. A retired teacher and art professor, she provided them with an educator's welcome—there was advice on where to go and what to do and just the right mix of “munchies” for a teenage boy and his mom. She also included her phone number. Later that evening Wendy called the number. The two women spoke for about an hour, with Wendy taking detailed notes for Ryan to read while he (literally) bounced around the room. The following afternoon, after a visit to the museum that Lance's mom had suggested, and while waiting in line at Banana Republic, another call came. Caller ID declared this one was from Lance.

“You answer it.” “No you!” “No you get it.” “No YOU!” Wendy and Ryan ended this comical rapid-fire phone volley with Wendy taking the phone and hearing Lance's voice for the very first time. He gave instructions to meet in one hour in the lobby of the hotel. Wendy and Ryan raced back to the hotel to change and then moved rapidly into meeting-our-donor-for-the-first-time rehearsal mode. Ryan again was (literally) bouncing off the walls as they prepared for the meeting- jumping from one bed to the other and doing flips in over-the-top emotional and physical exuberance.

“We decided we'd time it perfectly so that we would exit the elevator and casually stroll into the lobby. There is only one chance to make a first impression and we were on it. We wanted that first impression to go well. We wanted to look a lot more nonchalant than we were actually feeling. So we rehearsed- we took the elevator down, found no Lance, took the elevator up and repeated this drill several times. I wanted to instill some humor into a potentially stressful scenario for Ryan, so the comedy routine really helped. Ultimately, we opted for perching

ourselves behind the adjoining bar, giggling all the while, and making our 'casual' entrance from that direction." And then it happened.

Young men walked in and out of the hotel lobby but when he arrived, there was no mistaking Lance. He was tall and physically similar to Ryan but the real giveaway was his smile. As he came closer Wendy noticed, "he has Ryan's teeth!" and then, "he has Ryan's eyebrows!" And there they were moments later; Wendy is shaking the hand of the man who "*is just as much related to Ryan as I am.*" It was humbling for her to be with "*the other half of Ryan's DNA*" and utterly magnificent to be able to watch her son's dream come true.

Mom, son and donor dad proceeded to a restaurant where Ryan and Lance promptly raised their hands to touch each other to compare, then their feet. Wendy observes, "*I guess it is a 'guy thing.' This was how they first connected.*" She, meanwhile, was fascinated to see how similar their walks were and as they strolled to the restaurant, Wendy staying behind a few feet, amused at how other women were watching Lance.

So what does a teenager, who has been searching for years, say to this man he has finally found and what does a man, who never sought to be found, say to his newly discovered biological son? Theirs was, not surprisingly, simple conversation. Lance asked Ryan about school. They asked each other about interests, tastes, preferences in music, food, etc. The three talked for more than an hour and then Lance offered up another unexpected invitation: to his parent's home for dinner.

Dinner with Ryan's biological grandparents, like lunch with Lance, went very well. Wendy recalls both visits beginning primarily with nervousness, giddiness and light conversation—people simply getting to know each other. Yes, there was no mistaking that Lance had identified his parents as Ryan's grandparents but at this initial visit, there was no defining or categorizing of relationships. This was simply a time of getting to know—and like-- each other. In the first few minutes Wendy gently and with humor acknowledged the nervousness felt by all, as Lance's dad quickly offered up a glass of wine.

As the evening unfolded, everyone became more relaxed and when the doorbell rang there was even a moment of levity when Lance quipped, "*That better not be Oprah.*" In fact, it was the pizza delivery guy.

Although things got easier and more relaxed over the course of that first visit, Wendy says that it would be a long time before she would see her son relax and truly be himself with his newly found genetic family. "*For one thing, the stakes were high. They could not have been higher. Ryan needed and wanted them to like him. For another, we are very different people. Ryan and I and our family are all expressive, exuberant people who are not the least bit reluctant to show our feelings. Lance and his parents tend to be more reserved. At one point, years later, Ryan's donor grandmother said to me, 'we're just not very funny people.'*" Which Wendy actually thought kind of funny.

The final morning of that weekend visit was breakfast again at Lance's parent's home. "*I remember the smell of cooking French toast, watching Ryan and his grandfather sitting at the piano, grandfather playing a beautiful tune, with Lance looking on.*" Wendy adds that it was all with a sense of unreality and disbelief and sheer wonder. This was a family gathering together. This was all so natural and yet so wildly unexpected. "*The icing on the cake or the cinnamon on the French toast came when Lance's mom pranced into the room wearing an apron, spatula in hand and began singing. I'm not sure how—or if—I held back tears at this point. I was witness to Ryan's most fervent dreams—and then some—coming true.*"

More than eleven years have passed since this initial meeting and by now, Lance's parents and Ryan have long since established a grandparent-grandson relationship. How did this unfold? It advanced when they all came to Colorado for several vacations, including for Ryan's graduation and celebrated with the Kramer family over the course of a few days. And it was surely catapulted along by Ryan's decision to attend graduate school at USC (obtaining the same engineering master's degree as Lance), a very short distance from the grandparent's home. It was furthered also by his decision to rent a place only a bike ride away from them and by their gracious welcome and offers of delicious home cooked meals. And Ryan's gracious response to his grandfather's questions about his printer helped a lot. No longer was Ryan walking on eggshells. They were all off good behavior. The man who somewhat reluctantly introduced himself to Ryan's landlord as his grandfather, was increasingly comfortable peppering his grandson with computer and printer questions and offering valuable grandfatherly advice.

Ryan remained in Pasadena, living near his donor grandparents for 18 months, finishing his master's in engineering and then onto a job at the Jet Propulsion Laboratory. Long since secure in his relationship with his grandparents and they with him. Meanwhile, Wendy had grown close with Ryan's new grandmother and that relationship has flourished over the years. *"Ours is a relationship that cannot be defined by words,"* Wendy says. She goes on *"it cannot be said to be 'like a daughter-in-law or like a sister-in law.' She is the grandmother to my child, and I am the mother of her grandchild. It's a unique, stand alone, one of a kind special bond."*

Ryan's relationship with Lance was also helped along by geography and by mutual effort. Ryan moved to San Francisco in 2014 for a new job, making it easier for him to get together with Lance "as friends." In 2016 Ryan took a job at Google's Life Sciences division called Verily. These days the two men might meet after work at a bar, as San Franciscans do and there are times when Lance includes Ryan in a party or gathering he at his house. Wendy has on occasion been part of these visits and one bar outing in January 2015 as a stand out event.

*"I was in town visiting Ryan and Lance suggested we all meet for a happy hour party at a bar in downtown San Francisco. We arrived to a packed house but spotted Lance at a distance. Ryan and I began snaking our way through the crowd and as we got close, I heard Lance say to a few guys around him, 'Check it out. See that kid? He's my son.'" Wendy realized then how much she had longed for Lance to be proud of Ryan and there it was, loud, clear, determined confirmation of that pride. **"Check it out. See that kid? He's my son."** Words that this mother, who had done it all, had waited 24 years to hear.*

It got better. Lance continued and expanded his praise of Ryan and seemed to absolutely delight in peoples' responses to Ryan including, *"You guys look alike. Are you two brothers?"*

And as much as Lance relished bragging about Ryan, he did not, for a moment, attempt to take any credit from Wendy. Only too happy to give credit where credit was surely due Lance told all that would listen, *"She gets all the credit. She raised him. She is Ryan's mom."*

Sibling Connections—Found and Not Found on Oprah and 60 Minutes and the DSR

Although finding his donor was Ryan's original goal and remained central, the Donor Sibling Registry's name speaks to the significance that sibling connections took on along the way. As of this writing, Ryan and Wendy are aware of seven half siblings. These include the two girls whose mom contacted the Kramer's with the email heading 1058 and include one half-brother whom they learned about only recently. However, it was the connections made with four young women between 2005 and 2008 that have also been important in Ryan's experience of "finding my people."

First came Tiffany in 2005. She is 6 months younger than Ryan and born to a single mother who later married. In telling her she was donor conceived, Tiffany's mom admonished her from ever searching. But as a bright and curious teen, Tiffany searched on her own and found Ryan. She contacted him and a flurry of excited emails followed between the two half-sibs. Ryan was jubilant, as until this point, the only siblings he had "found" did not even know they were donor conceived. Wendy, however, was cautious. She told Tiffany that they would have to bring her mom into the loop.

Timing can be everything and for a time, it seemed that timing offered Tiffany an ideal way of telling her mom. The previous fall, Wendy and Ryan had been contacted by 60 Minutes and the tape of their show was going to be aired in March 2006. Tiffany told the Kramers that she would watch the show with her mom and that when Ryan came on, she would say, *"that boy—he is my brother."* On board with this plan, Wendy sent Tiffany a note for her mom, explaining who they were, and how this connection between the two kids could be a positive experience for all. She and Ryan watched 60 Minutes with multifaceted excitement—they were thrilled to have yet another national and respected voice and they were equally eager to get Tiffany's call.

First, the good news. The 60 Minutes show was a huge success. It brought 28,000 visitors to the DSR in March, up from the usual 8,000. And more important, in a typical month there are 30-50 matches. In March of 2006 538 people matched. Another big triumph for Ryan was that he was able to successfully navigate some delicate territory of privacy and secrecy. Lance had made it very clear that he would cut off contact if

Ryan acknowledged he had found him but aware that 60 Minutes would have to ask the donor question, Ryan came up with the following response to the “did you find your donor?” question. *“I prefer not to talk about my personal situation with my donor because it could compromise any future contact I might have with him.”* Correspondent Steve Kroft agreed that this answer was acceptable.

Now the tough news...the call from Tiffany never came. As they waited for the phone to ring, Wendy and Ryan came to realize that something must have gone wrong. Indeed, Tiffany’s sweet and innocent efforts to share her good news with her mom fell on harsh ears. Her mother declared, *“Those people are not your family”* and with that, took Tiffany’s phone and shut down her MySpace account. A few months later Tiffany sent Wendy a lovely Mother’s Day card accompanied by a sensitive note. There were a few additional communications but Tiffany eventually stopped all contact.

Ryan has always felt different—he was exceptionally intelligent and donor conceived—and he longed to connect with others like him. “Like him” could be through genetic connections but their experience on the DSR reminded both Wendy and Ryan that this was not all about genetic connections: simply meeting others who were brought into this world through anonymous donation would be helpful. And it was with this knowledge of what it meant to “find his people” that Ryan became an honorary member of Donor 66’s offspring group. It happened something like this...Wendy received a call from a mom who had two children through Donor 66. She had connected with a mom whose twin girls also came from Donor 66. She was calling to say how grateful she was to the DSR and to ask advice about the family’s first meeting. And then came along two other moms and two more kids. Six Donor 66 offspring and Ryan. Four Donor 66 moms and Wendy. They all lived in the Denver area and they enjoyed spending time together. The pieces of Ryan’s complex identity puzzle were beginning to fit together. It was meaningful for him to be with others who had the donor offspring experience regardless of who their donors were. And he continued to seek genetic connections. He would find his people in both groups.

Getting together with the Donor 66 group was been easy for Ryan and Wendy as they live in the Denver area. They got together on a fairly regular basis

enjoying barbecues, media events, holiday celebrations and in some instances, strong friendships. Although not connected genetically, for Ryan the Donor 66 teens and young adults are very much his people.

February 2007: Ryan becomes the 2,910th person to be matched on the DSR. Enter Anna.

Wendy was at work when the match came on her computer screen. Her initial surprise and delight was soon clouded by fear. Seeing that Anna, who was born three years to the **day of Ryan**, was only 13, Wendy feared that they would have yet another Tiffany situation. She was relieved to quickly learn that Anna’s parents were on board, so much so that it had been with her dad that she signed on to the DSR.

Anna’s mom’s initial email:

Dear Wendy,

My daughter, Anna just responded to a posting by you regarding donor number 1058. This is the first time we have explored the registry and are very anxious to find out if your son is indeed a match.

My husband and I allowed Anna to register herself last night, with our supervision. She is 13 years old, and was born on May 22nd, 1993. Our donor was an Engineering student. He was born in 1967. He has one brother who is a pilot. Does any of this sound familiar to you?

As you can imagine, we are looking forward to a response and hope to hear from you soon.’

Regards,

Ann Marie (Anna's Mom)

Robert (Anna's Dad)

“When I read this I was giddy. And in shock. Ann Marie and I spoke by phone and during our call, I told her that even though we’re essentially strangers, that we shared something so precious. We quickly shared a little about each of our kids, and Anna asked to speak with me so that she could ask questions about the other half siblings that we knew about.”

Later that evening Ryan and Anna connected online via instant messaging. Over the next few weeks Ann Marie and Wendy had several phone calls and eventually they all had a group phone call. They talked about meeting and all wanted that to happen ASAP.

ABC's Primetime had expressed interest in updating a story that they had done more than four years ago on Ryan and the beginnings of the DSR, and they thought that Ryan and Anna's meeting would be a perfect update.

A month later, Wendy and Ryan flew to NYC and almost in front of live cameras (the camera folks were thankfully a bit off track), Anna and Ryan met in Central Park. Wendy remembers it as if was yesterday, *"We were all extremely excited. Ryan bought Anna a University of Colorado sweatshirt. The morning of the meeting each family had a camera crew to walk with towards each other in Central Park. They had set a meeting place, but because of disorganization, our two families basically bumped into each other walking along the park road. It was tremendous. We all hugged, and the smiles on Anna's and Ryan's faces were telling. There was an undeniable bond and recognition of the familiar in one another. The parents were scouring the faces of the kids, looking for similarities. It was very emotional for us, and amazing to meet this young girl who had bits and pieces of my son in her. I was overwhelmed with gratitude for Anna's parents that they had been honest with Anna and honored her curiosity and need to search for and connect with Ryan. While Anna's mom and I had a more obvious bond, I felt extreme gratitude for Anna's dad. I was so impressed that he had put any possible fears or concerns about Anna finding biological family to the side, instead honoring his daughter's needs to connect to that invisible and unknown part of herself.*

"We spend the first hour or so asking each other questions, taking pictures and comparing notes. Ryan and Anna's smiles seemed permanently adhered to their faces. There was a sense of peace about the both of them.

"We spent the next 48 hours getting to know each other and marveling at the similarities (and differences) in Ryan and Anna. It was clear to us, that even though we had just met, that we were connecting as family. Strange to be getting to know family for the first time. We were laying the groundwork for a connection that could last their lifetimes. We made it clear that Ryan and Anna would be defining the relationship and that there was no pressure for it to look any certain way. We also made sure the kids knew that their relationship at 13 and 16 would certainly change and develop as they years went on. For now, the parents would most likely make the logistical

planning, but this would only be based on the desires of both Anna and Ryan. Anna wore her CU sweatshirt with pride, despite the 75 degree weather."

The two families shared a lovely weekend and Ryan finally had his long awaited half sibling. A year later they got together a second time celebrating Ryan's 18th birthday and Anna's 15th. They would be together again for Ryan's college graduation where Anna and her parents would get to meet Lance and his parents. Although Lance had earlier on "banned" photos, Wendy is happy to report that she has any number of photos of any number of family mixes at Ryan's graduation party.

2008 and another Oprah show. As with the first, the show brought many new members to the DSR and among them were Natalie and Kristina who turned out to be Ryan and Anna's half sisters. Their mom had watched the Oprah show and reached out to Wendy about *"that lady and her son I just watched on Oprah,"* not fully realizing that Wendy was "that lady"! The mom posted her two daughters onto the DSR as she and her husband were in full support of their right to be curious and to know their donor kin. Since they lived in Boston and Anna and her family were in New York and all wanted to meet, Wendy and Ryan flew east for another NY meeting.

"By this time Ryan and Anna were pros." Wendy remembers. *"They led the way and made it easier for Natalie and Kristina. They provided the girls with medical information and answered questions they had about Lance. They also helped set the pace and tone for how the four teens would get to know each other and begin to establish sibling bonds. Games were played, and teens hung out, as teens do. As Ryan had long since learned, "It begins with simple conversation."*

It would be so nice to be able to report that all proceeded smoothly and uneventfully with Ryan and his half sisters but this has been a story of joy and disappointment, unexpected delights and some bumps in the road. While they have enjoyed some good times together, including a weekend in which all three East coast girls spent a weekend at the Kramer's home in Colorado, one bump in the road came via DNA testing—the very tool that had led Ryan to Lance.

In 2012 Wendy was contacted by a new DNA testing company who were offering a new testing tool that could be of great benefit to donor families in

particular. The company—which will surely go unnamed here—needed three donor family groups to test the mothers and the half siblings. Wendy and Ryan signed on, Anna and her mom joined in, as did Natalie and Kristina along with their mom. The curve ball that no one ever saw coming was the news that Anna was “not genetically related” to Ryan, Natalie and Kristina. This scientific untruth, tested twice, and declared “100% accurate” by the noted scientist at the DNA company, sent all the participants into a tailspin. It was confusing and hurtful to all but most difficult for Anna who had her unfolding identity temporarily challenged and snatched away from her. Ultimately and only after Wendy’s sheer grit prevailed, Anna’s genetic connection to the others was confirmed.

As with many half-sibling groups, distance can be a main factor when determining the progression and closeness of newly found genetic relatives. Having half siblings spread across the country (or the world) can make the connections more difficult to deepen, as spending time together is more challenging. As with any family, it’s the people you see most often, and those with whom you have the most in common, that you seem to hold most close. Ryan and his half sisters now have busy adult lives, so get-togethers just don’t happen as often as everyone wishes.

And Here We Go Again...

Over the years, Wendy and Ryan have had many conversations about how many siblings he might have. They have worked with various numbers and somehow landed on “between 20-30.” Wendy explains that they really don’t know. At one point, California Cryobank had told them “one.” Then the talkative woman there told them “many.” The bank told Lance 12. Those were the reports. Then there were the facts. Lance donated three times a week for five years. Each donation could have been split into between 8-24 sellable vials. When Wendy and Ryan ran the numbers, they found that there could have been as many as 18,000 sellable vials of sperm. “We’ll go with 20-30.” Wendy said.

In 2008 Ryan was aware of 6 half sisters, the three he had met, the two whose parents would not tell them that they were conceived with a donor, and the one whose mother had forbid all contact. Wendy says that in some ways, this was enough. Ryan had had his questions answered and he also felt that he and the DSR were visible enough that others could find him. “*Still there was some curiosity,*” Wendy says. “*Why all*

girls?” Ryan couldn’t help wonder if he was the only male offspring. August 2016: enter a new half brother.

The email came August 22, 2016. The heading was familiar. “Donor 1058?” It was another mother writing. She had read an article about Wendy, Ryan and the DSR in the NY Times and asked, “*Is your actual donor number 1058?*” Wendy replied that it was and within moments the two moms were talking by phone. The other mother explained that she had a son, who is a year younger than Ryan, who did not yet know he was donor conceived. His parents would soon be telling him about his conception and about Ryan.

Wendy would soon learn that it is very different when people are matched as adults than as children. And she observes, “*men do things different than women.*” While Wendy and Ryan’s new half brother’s mom are forming a really nice friendship and have enjoyed long telephone conversations, Ryan and his new half brother have thus far had limited contact. They have exchanged emails, and spoken by phone but neither seems eager—at this point—for more. Although close in age and sharing ½ their DNA, they are in different places in their lives and have had vastly different life experiences regarding donor conception.

What the experience with the new half brother and his mom confirms for Wendy is that donor conception connections come in all flavors. She is especially fond of this new mom and they seem to have a lot in common that goes beyond their sons’ DNA. Wendy hopes they will forge strong bonds. In some ways this is similar to her experience with Lance’s parents—she is close with the grandmother, Ryan is close with Lance and his parents and Ryan’s half sisters and their families have no on-going contact with Lance or his parents, although one half sister recently expressed interest in reaching out to Lance and his parents. Wendy is friendly with one of the moms, but not so much with the other (since the DNA debacle). All flavors. All shapes and sizes. Ever changing.

Lessons Learned: Why Tell One Family’s Story

Looking back at the 26 or 16-year point depending on how you count (from Ryan’s birth or from the birth of the DSR), Wendy and Ryan have learned a lot that they feel is relevant to other donor families. While every family is different, these are some of the messages that they want to pass on to others.

1. Parents need to listen to and hear their children and trust they will guide them. As they look back

on the origins of the DSR and on Ryan's search for his donor, Wendy and Ryan both acknowledge that theirs has been a journey in which she follows his lead or they move forward together. In Wendy's words, "Ryan and I held hands and jumped off the cliff together. We didn't know who we would find or who would find us but we were able to take each step—and make each leap-- because we had each other's hand."

Sadly, Wendy and Ryan have encountered parents who in Wendy's words, "*act out of fear not love.*" "*It is not enough,*" Wendy observes, "*for parents to tell their children they were donor conceived. They must also accept and honor their child's right to be curious, their right to search, their right to find and to connect with their first degree genetic relatives.*"

2. Wendy is often puzzled when people ask her why she didn't close down the DSR when Ryan found his donor. She is equally puzzled, when people assume that for her, the DSR was simply a business venture. It was neither a business venture nor a tool just for Ryan. As the DSR has unfolded, it has become clear to Wendy and Ryan and all those active in it, that the DSR's mission extends beyond searching. It includes support for the donor family community, education and advocacy. Wendy can easily remember a time when sperm donors were often women's gynecologists, when sperm banks offered almost no information about donors and surely when no one considered the rights of donor offspring. Change would not have come and will not continue without education and advocacy.
3. Many assume that the donor conceived people posted on the DSR are only interested in knowing about who their unknown biological relatives are. For many though, it's much more than that. It is a desire to be known. Ryan wanted to find his donor but more importantly, he wanted his donor to know that he existed. It also mattered a lot that he could seek and search on his own terms and not be dictated by the sperm bank's seemingly self serving rules. The age 18 is arbitrary, as many donor-conceived people, like Ryan, have established enriching relationships with their donors long before the age of 18. Ryan did not feel it was right for a sperm bank to withhold essential information about his ancestry and

biological relatives, not even offering up a possibility of mutual consent contact.

4. Donor conception relationships cannot be named. People may try to say, "It is like a special aunt" or it is "like a close cousin" but donor kinship cannot be named. Donor family connections rely on mutual consent. This was something Ryan fully understood at a young age. As Wendy and Ryan identified donor sibs, there were times when there was mutual consent and sadly, times when it was absent.

It has also been interesting to Wendy and Ryan to see how Ryan's half siblings have responded to connections. Anna, for example, met Lance and his parents at Ryan's college graduation and all shared a warm family weekend together. And yet, to Wendy and Ryan's knowledge, there has been little follow-up. Lance's parents are very clear that Ryan is their grandson. In fact, Lance's mom says she went through a grieving period over having missed the first 15 years of Ryan's life. By contrast, they do not seem to regard Anna as their granddaughter, nor does she reach out to them as grandparents. Take away message? Sometimes genetic connections lead to a strong sense of kinship and other times, they do not.

5. Living in an "instantaneous" time makes it difficult to wait. Being on the DSR involves waiting. Not for all. Not all the time. But long stretches of time can pass when one is simply waiting. Ryan Kramer is Exhibit A—he founded the DSR and waited seven years to become the 2,910 donor offspring to match. His half sister Anna matched the very second she joined the DSR.
6. Navigating donor relationships always involves the balancing of privacy and secrecy and sorting out when, if ever, the "rights" of the donor supersede the rights of the child.
7. Language is powerful and can be unsettling for donor families. Wendy's approach, from the start, was to have Ryan take the lead with language. From the time he was in preschool, she listened as he tried on and experimented with ways to tell his story. She realized along the way that he needed to try words on, to experiment with them, to determine for himself, what felt right. She knew that words are just words and they do not define relationships. She stood by as

Ryan tried on words like “dad”, “donor dad” and “father” and “grandparents,” knowing always that nothing Ryan would say would diminish his relationship with her. In fact, at one point he said to her, *“You know that I have only one parent and that is you.”* There have been times, also, when she has seen that words can be used for convenience. For example, Ryan was at Lance’s home for a small party recently. Another guest

walked in and said, *“Hey Ryan, where’s your Dad?”* Ryan remembers pausing for just a moment and then responded with a smile, *“He’s in the kitchen.”* Wendy’s advice to other donor parents is to take notice if there is a word that really troubles them and if so, to think about why it sets them off.

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