

Our Say: Pre 18 Contact with Donor Siblings

Introduction and Aims

As part of the Human Fertilisation and Embryology Authority (HFEA) review in 2023 into 'Modernising the regulation of fertility treatment and research involving human embryos', individuals, researchers and groups have been encouraged to 'have your say' by taking part in the online public consultation survey. Whilst people have welcomed the opportunity to have an input in the process, it has been noted by many that there are significant gaps in the consultation survey relating to the topic of donor siblings (children that have been born using the same egg, sperm or embryo donor(s)).

Whilst it has been noted that there is a whole section in the HFEA online survey dedicated to 'pre 18 contact with donors', there is no such section in the current survey framework that relates to the topic of pre 18 contact with donor related siblings.

Our campaign is aware that the current HFEA laws only allow donor sibling contact (via the UK Donor Sibling Link) when donor conceived individuals reach 18. However, there is a growing desire among parents and donor conceived people for this connection process to take place far earlier than that set by the current age requirements. The current law aims to protect children with age limits for connecting with donor siblings, but the latest evidence from donor children/donor conceived adults, recipient parents and researchers show that setting a limit of 18 might not be in the best interest of either the donor conceived individual or recipient parents, and that having the option to connect before this on an 'opt in' type basis could be beneficial.

Whilst the HFEA is making recommendations to the government for proposed changes to the legislation to ensure it remains relevant, we'd like to propose the HFEA also submit a recommendation for families to be able to connect with donor siblings through official channels (via the UK Donor Sibling Link) before the donor conceived person turns 18. In addition, these connections should be made possible retrospectively; meaning that parents who already have children born in the UK, under the age of 18, and recorded on the HFEA database can 'opt in' and connect with their children's donor siblings before their child reaches adulthood.

This paper is an overview of why we believe it is important to add the ability to connect with donor siblings (pre 18) into the HFEA review.

Key areas we will cover in more depth:

- Research: the latest research on donor sibling connections
- Problems: issues with current methods of seeking connections with donor siblings
- Testimonials: donor conceived adults and recipient parents
- Industry trends: other countries and gamete banks
- Moving forward: key stakeholders and other research groups interested in our campaign

Donor Sibling Connections UK – An Overview of the Campaign

The *Donor Siblings Connections UK Campaign Group* was formed at the start of 2023 by a number of UK based parents of donor conceived children who wish to advocate for changes to HFEA legislation; specifically to have the capability to be connected with their children's donor siblings via the UK Donor Sibling Link (DSL) before the child turns 18. The Facebook group hosting communication channels between members of the campaign currently has 73 members (as of 12/04/23). This number is steadily growing with new members joining every week.

Research shows that increasingly parents of donor conceived children desire to connect with other families who have used the same egg or sperm donor to conceive a child (their children's donor siblings) (Hertz *et al.* 2017). However, current laws in the UK governed by the HFEA prohibit clinics from sharing information about other families (who have used the same donor) even in the event of mutual consent and desire to connect (HFEAct, 2008). Despite the HFEA having donor sibling information stored on their database, due to laws surrounding anonymity, they are unable to release this identifying information until a child turns 18 (The Donor Sibling Link - HFEA).

As a result of these restrictions, many parents have resorted to the following unregulated methods to connect with donor sibling families:

- Commercial DNA testing (such as AncestryDNA, 23&Me)
- Pay for services like the Donor Sibling Registry (DSR) or My Donor Family
- Join unofficial Facebook/online groups designed to help match families

Whilst these methods can be successful, some UK parents would like to see the option to connect with other UK based families being achievable in a verified manner via official channels (ie the HFEA DSL). This is the key aim of this campaign group.

Relevant Research and Findings of Note

There is a growing number of adult donor conceived people speaking up about their experiences of connecting with their donor siblings, and providing anecdotal evidence of why it is important to have the opportunity to connect whilst young. This societal shift in attitude has also been documented and observed in a variety of research articles. For example, Persaud *et.al.* (2016) suggest that donor conceived adolescents may benefit from contact with others conceived using the same donor prior to the age of 18 due to issues surrounding identity formation. Hertz, Nelson and Kramer (2017) conclude in their study of 419 donor conceived people, that donor offspring are likely to view their donor siblings as members of their 'extended family'. Many researchers note that parents seeking contact with their children's donor siblings (and their families) while the children are still young have largely positive outcomes (Freeman *et al.*, 2009; Goldberg and Scheib, 2015; Scheib and Ruby, 2008). These examples are not exhaustive, with many more studies demonstrating not only the desire of pre 18 contact with donor conceived siblings, but arguing that early contact provides positive outcomes for both the donor conceived person and their wider family network.

Evidence from the ConnecteDNA research study, based at the University of Manchester and led by Dr Lucy Frith, explores the social, ethical and legal implications of direct-to-consumer genetic testing (DTCGT) in relation to donor conception. The research study involved 61 in-depth interviews with 25 donor conceived people, 20 parents through donor conception, 19 donors and 2 relatives of donors,¹ with a focus on people living in the UK. The researchers conducted 3 stakeholder workshops which included the above groups, as well as professionals working in the field of donor conception. In addition, the study involved analysis of laws and policies for the management of information about donor conception in four jurisdictions (UK, The Netherlands, Sweden and Victoria, Australia) as well as analysis of DTCGT websites and terms and conditions. In summary, the findings support proposals for the amendment/removal of current age restrictions for accessing the Donor Sibling Link. Specifically, the ConnecteDNA demonstrates that:

¹ Some participants occupied more than one of these roles.

- Donor sibling connections are often highly valued by donor conceived people; this finding is further confirmed in other studies with donor conceived people (see e.g. Blyth & Frith, 2009; Indekeu et al., 2021).
- Based on their knowledge of this research and experiences of donor conceived people, parents through donor conception, particularly those embedded within donor conception communities, frequently value connections with same-donor families (seen as beneficial to their children).
- Drawing on a Euro-American kinship logic, parents often expressed a belief that if their child(ren) met donor siblings during their childhood, these connections would be easier to build and more likely to be understood as familial. Some parents feared that their children would 'miss out' if they joined a donor sibling group in adulthood.
- Currently, for parents using licensed clinics in the UK, there are few options for those who want to either build, or support their children in building, knowledge about, and connections with, same-donor families before their children are 18. The 'official' option of the Donor Sibling Link is not available to under 18.

Issues with current methods of under 18 connection with donor siblings

Currently, if parents of donor conceived children in the UK wish to connect with their children's donor siblings pre 18 they have a few (limited) options. One of the main options available to parents wishing to pursue these connections and/or respond to their children's expressed interests, is currently commercial DNA testing (e.g. Ancestry, 23andme) or unofficial registries such as the Donor Sibling Registry (DSR) or indeed volunteer-led facebook 'sibling matching groups'.

DNA testing of under 18 is usually seen as more problematic or riskier than 'official' routes (like the DSL or even the sharing of donor numbers via sibling registries or internet groups) for several reasons:

- o These sites will match them with any of their children's genetic relatives, meaning they may also identify the donor or donor relatives as well as donor siblings – which may not be wanted by the parents/donor conceived person or by the donor.

- o There is the potential for their child to match with other donor conceived people who do not know they are donor conceived.

- o It is not possible to distinguish between matches with donor conceived siblings and the donor's own (social and genetic) children.

- o Using commercial DNA testing sites to make connections requires parents to share children's genetic data – something which children may not be able to give meaningful consent for and future implications of which are unclear.

These concerns, coupled with a belief in the benefits of early contact with siblings, creates a moral dilemma for some parents through donor conception.

Interestingly, current age restrictions on accessing DSL do not actually prevent donor conceived people under the age of 18 from making contact with donor siblings (even if we exclude commercial DNA testing). This is because younger siblings of adult donor conceived people can identify and meet donor siblings through their sibling's requests to join the DSL. However, research found that younger siblings in this situation don't get access to support services and counselling and this process also places a burden on the older sibling to act as an intermediary (ConnecteDNA, in press). In addition, the practical (as well as ethical) difficulties with imposing age restrictions on accessing information about people connected through donor conception are emphasised in the recent report by researchers in the Netherlands (Bolt *et al.*, 2023).

In the absence of any verified or regulated way to connect with their children's donor siblings, UK parents are increasingly looking for other means to make connections. Internet groups including social media networking platforms (i.e Facebook) and/or paid Sibling Registries (Donor Sibling Registry and My Donor Family) enable parents using a 'Donor ID Number' or 'Alias Names' to see if there are any other members who 'match' their donor details. Whilst these groups have enabled UK sibling connections to take place, this method of connection is unregulated, unverified and matches are not always accurate. These methods of connection are inherently problematic. Arguably, it would be safer and more efficient to utilise the existing, comprehensive DSL database, which, by its very nature, has been designed by the HFEA to connect donor siblings in a regulated fashion. Making the DSL accessible to parents of under 18s would negate many issues with seeking donor siblings through problematic, unregulated methods.

Examples where under 18 sibling connection services already operate within the context of sperm banks

Many Sperm Banks are now operating Donor Sibling Registries with positive feedback from those who have opted in. We have attached examples of a few:

Seattle Sperm Bank

SSB Connects is Seattle Sperm Bank's Donor Sibling Registry. The registry has been set up to help facilitate mutually desired contact between families who share a common donor.

California Cryobank

California Cryobank's Sibling Registry is now live, however they are still undergoing some improvements to ensure a positive experience for their families. In anticipation of a child's need for information, as well as the desire of families to stay connected, the California Cryobank launched a Sibling Registry, which allows siblings and extended families to find each other. Participation in the program is completely optional and therefore will not offer a comprehensive list of potential siblings. Once enrolled, families will have access to information of potential siblings who have chosen to enrol. This includes the posting of births of potential siblings, profiles and email contact information for potential siblings, and an online portal where siblings and families will be able to communicate regarding sperm donors and the insemination that took place. Because this information is organised by donor number, families can find each other easily.

Origin Sperm Bank Canada

In an effort to offer continued support to parents and children of donor conception, Origin Sperm Bank has built the ReproMed Sibling Registry to provide participating families the tools to identify, research, and contact each other in a private environment.

Testimonials

Testimonial #1 from Donor conceived adult who connected using the Donor Sibling Registry

'I just met my half sibling. I'm 29 years old. I wish I could have known him my whole life. It is really special. I am so glad I found him. I met him a couple of months ago. It was like we have known each other all along.'
(Name redacted).²

Testimonial #2 from UK Donor conceived adult who connected with their donor siblings via DNA testing

'I just can't help but think 'what if?' What if I had known my brother when I was younger, a teenager, a child even. So much lost time. So many points in my life where it would have been amazing to phone him and ask his advice. I feel like I've had this time stolen from us through no fault of our own. The UK system needs changing, it's wrong to stop siblings connecting from one another, 18 is far too late.'
(Name redacted).

Testimonial #3 from a Recipient Parent #1 who connected with other families using Seattle Sperm Bank Connect service

'On ##### I gave birth to my donor conceived daughter.³ I chose donor conception as a solo mom by choice, as this is one of the possible routes to becoming a mom. After giving birth I notified the Seattle Sperm Bank of my successful live birth and healthy baby girl. Once I did this, I was sent a notification asking if I would like to be put in touch with other families who used the same donor as me "#####". I agreed with pleasure, as I had not even considered that this would be an option so early after my daughter was born. I was then directed to a chat room portal where I was given an anonymous username. Not long after I created my username I was contacted by "#####" asking if I would like to be added to a message chat with some of the other families from the same donor.'

I am one of two siblings, although we are not close, and my daughter is my first and quite possibly my last child. Therefore, when I gave birth it occurred to me that my daughter would be alone – an only child, no cousins, and a very small family, just her and me. I have a small family myself and grew up creating family from distant relatives and friends. I suppose when I was younger I

² Testimonials have names redacted to ensure confidentiality as this document will be available in the public domain; identifying data can be disclosed directly to the HFEA if requested.

³ ##### denotes additional identifying redacted personal data such as date of birth.

dreamed of a larger family for myself, but that was not what fate had in store...or did it?

Only after ##### added me to the group chat did I realise the extent of this family Wren had created for us. When all was said and done there were 12 babies (with one on the way). Wren has 12 brothers and sisters, and while technically these are half siblings, it is still a remarkable thing. It means that half of her will be related to each one of these babies. They can grow together, travel together, celebrate each other, comfort each other and provide a family when all of us parents are long gone. She has siblings. Even writing this now, I get a bit choked up knowing this. And we all know that she won't get along with all of them, who does get along with all of their family, but even if there is just one, that's one more than I could have imagined.

Today through our group chat we support each other; laugh at the baby videos we share, try to find what all the babies have in common, talk about why we chose the donor, plan for in-person gatherings, and just ask each other "how are you doing?" And let's be clear, while this is amazing for my daughter, it is also amazing for me. I have a bunch more mom friends who I am connected through something magical, something genetic but also more. We are in this together. And for a solo mom, this is even more amazing. I have a family. More family than I could have ever imagined. And I haven't even talked about the extended family we all have, all those grandpas and grandmas and aunts and uncles for our babies. I am sure for some, they have enough family, but for many of us, me included, I can't get enough.

When I chose "#####" I did so because he looked good on paper and sounded great in a recording. His genes were good and seemed like a good choice. I had no idea it was going to bring into our lives this miracle of family. And if it weren't for the Seattle Sperm Bank's system of an anonymous opt-in introduction platform I would never know that these other babies existed. Again, there may be some who don't opt-in – some who might have even used the same donor as we did – but for those of us who do want to know it is life changing. I wish every solo mom by choice, and really every family who uses a donor, could be given this choice: A choice, not a requirement, but an opportunity to be connected to "family" this way.

*Thank you'
(name redacted)⁴*

⁴ Excerpt from Seattle Sperm Bank (2023).

Testimonial #4 from a Recipient Parent #2 who connected with other families using Seattle Sperm Bank Connect service

'My wife and I chose to use donor sperm to conceive, and after going through reciprocal IVF we were incredibly lucky to fall pregnant with our son.

During the pregnancy, we spent a lot of time learning about the experiences of donor conceived people. We had previously felt unsure about the idea of connecting with donor siblings, however listening to DCP voices made us realise how meaningful it can be to make these connections (and as early as possible).

We contacted the London Sperm Bank to find out whether they facilitate sibling contact, however they explained that due to data protection they are unable to share any details between families who have used the same donor, even with their consent.

Fortunately, through following several DCP accounts on social media, we found out about groups on Facebook that enable contact between recipient parents who used the same donor. We immediately joined the London Sperm Bank's sibling search group. As our donor was imported to LSB from Seattle Sperm Bank, we also joined their respective Facebook group.

A few months before our son was born, we were contacted by an American SMBC on the SSB group. She had used the same donor as us and had given birth to a daughter earlier in the year. We were overjoyed to connect with her and to know that our son would have the chance to know at least one of his donor siblings from birth. This SMBC also let us know about Connects (an opt-in sibling link service operated by SSB) and told us that another American family who had used the same donor as us was also registered there.

We were very excited about the prospect of linking with another family, however when we attempted to join the Connects platform we were advised by SSB that, due to GDPR regulations, UK families are not currently able to utilise the service. However, SSB agreed that a member of their team would post a message on our behalf, and shortly after this we were able to connect with the second family. They too had given birth to a daughter several months before, and we were delighted to have connected with a second sibling to our son.

We are now in regular contact with these two families; sharing photo and video updates, discussing similarities and differences between our children, and simply celebrating the unique bond that we all share. We are even planning a trip to America for our first in-person meeting.

Connecting with our son's donor siblings has been an amazing experience that has enriched our lives, and we have absolutely no regrets. We truly believe it is in our son's best interest to be connected with others that share this side of his genetic makeup (as well as the shared experience of being donor conceived) and we hope to connect with as many of his donor siblings as we possibly can.

What saddens us is that so far we have only managed to connect with donor siblings living in America, despite knowing that our son has at least one sibling here in the UK. It is even more disheartening to know that although this information is held by the HFEA they are restricted from sharing it with us, even if both families provided consent.

We would absolutely love our son to have the opportunity to build close connections with his donor siblings as he grows up, and these relationships would be much easier to build living in the same country. While we are delighted to have contact with our son's siblings in America, it feels a great shame not to be able to have the same contact with any siblings living here in the UK. An opt-in sibling link service for under 18s in the UK could change this, potentially giving our son the opportunity to build meaningful lifelong connections with other children with whom he already shares such a unique bond.'

(Name redacted).

Testimonial #5 from a Recipient Parent who connected with other families using Facebook

'When I was considering becoming a solo parent through donor conception I thought long and hard about the donor, what my child might want to know about them and if they might want to contact them when older.

Once I became pregnant I realised I hadn't thought too much about the sibling situation other than knowing my child may have siblings out in the world, and this hadn't been discussed at any point along my Fertility journey other than to inform me of the UK limit of 10 families.

I wasn't sure what was in my child's best interests; should I try to find siblings early or leave it until my child was enough to discuss it with them? It was then that I started to look for and listen to stories and views from adult DCPs.

It was listening to donor conceived people (in Facebook groups, interviews and podcasts) that made me decide that on balance it seemed that making connections with biological relatives early was beneficial.

So I started by writing to the HFEA to see if there were any siblings and found out that 1. Yes my child had 4 other siblings in the UK and 2. The HFEA only keeps records for siblings born from treatment in the UK and there was no other way of finding out about other siblings around the world.

I emailed the sperm bank I used to ask if they could tell me how many siblings there were (making it clear I wasn't asking for any identifying information) and they said they couldn't tell me.

So I resorted to looking on the unofficial Facebook groups that I had discovered and I put my name and the donor's pseudonym up on 3 Facebook pages and waited.

I was soon contacted by a person who was then pregnant with the same donor and we connected and started chatting and video messaging.

My child was only 2 at the time and although I told him that this baby shared some of his genes it didn't mean much to him then, but he enjoyed saying hi to the new baby over video calls.

Slowly more parents began to contact me. At this point I became wary, how could I be sure they had used the same donor. I wouldn't want my child to become attached only to find it was a mistake. So I decided to ask them to describe the donor's baby photos and send me a copy of the receipt from the sperm bank.

This wasn't a foolproof process but it seemed the best I could do to lower the risk of matching with people incorrectly.

Soon there were 6 of us in the Facebook chat. None of these the other 4 families I knew were in the UK. Together with us that meant there were now at

least 11 families, when I thought there would only be 10 families from each donor (an issue that wasn't discussed at the time of my fertility treatment).

I contacted the sperm bank again to ask if they could give me an idea of how many sibling families there might be and they said they couldn't tell me.

I asked if they could tell me their self imposed world wide limit (having learnt there were no enforced worldwide limits) and they said they wouldn't tell me. I explained how I should be able to tell my child if they might have another 10-20 siblings or 60-70 and that this should be in the child's best interests, but they still wouldn't tell me.

We have now made contact with 11 other families who have children with the same donor and know another 5 exist.

We don't talk often but we send each other updates and ask questions relating to our children's health and development. My child will look at photos and ask questions about them.

And us parents were able to support each other when we were informed that the donor had been found to be a carrier of a rare genetic condition that our children could be at risk of.

I liken it to a distant cousin relationship. As a parent I can be there to keep the lines of communication open and explain where these people fit into our family story, and my child can decide how much or how little they want to interact, but importantly they know these people exist and they know they can ask more or contact them if they wish.

It won't be a shock to my child when he grows up to find he suddenly has multiple siblings, it will be something he grows up knowing and it'll be a normal part of his story.

With this in mind I really think it is in my child's best interests if there was a regulated way we could connect with his genetic family if all parties are in agreement and that this should include connecting siblings.

And I believe it's in the child's best interest to be able to find out how many siblings they may have in the world and in each country.'
(Name redacted).

Moving forward - key stakeholders and other research groups interested in our campaign

Whilst the *Donor Sibling Connections UK* campaign is primarily composed of parents of donor conceived children, we have been in discussion with a number of other stakeholders within the field and sector of donor conception. Looking into the future, we are keen to build on these connections and relationships that we have already made with researchers at the ConnecteDNA Project (namely, Dr Leah Gilman) the Donor Conception Network, Paths to Parenthood (founder Becky Kearns), The Stork and I (founder Mel Johnson), Laura Bridgens (Current Co-Chair of the UK Donor Conceived Register) and members of The British Infertility Counselling Association (BICA).

Members of this campaign group would like to extend an invitation to representatives of the HFEA to engage on this matter further and welcome future discussion on how the Donor Sibling Link can be opened to also include under 18's. We look forward to hearing from you.

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