

Jessica Addley-Cook

19<sup>th</sup> April 2022

Committee Secretary  
Legal Affairs and Safety Committee  
Parliament House  
George Street  
Brisbane, QLD, 4000

Dear Committee Secretary,

This letter is my submission for the Inquiry into Matters Relating to Donor Conception Information. I write as a donor conceived person, conceived in Brisbane at the [REDACTED] Clinic 1992, to share my story and perspective on the considerations of the enquiry. I believe that a state government regulated donor conception register, like that in Victoria, is necessary to uphold the rights of donor conceived people to access information regarding their genetic identity and relatives (including siblings).

My parents first told me I am donor conceived when I was 17, after much deliberation from them about whether to tell me. Their decision was made especially difficult because the doctor who saw them for the treatments instructed them not to ever tell me. In fact they were told to 'go home, make love, and you never know, miracles happen sometimes', implying that they themselves should live as if I was my social father's biological daughter. This doctor has since become a well renowned expert in IVF and is now a Medical Director and Board Member of the clinic. I believe that to never tell me that I am donor conceived is a violation of my human rights, and the thought of never having this critical information about myself is extremely distressing and deplorable to me. I feel that to ensure that people are told the truth about their genetic identity the state government needs to take control of the information as the Victorian government have. I do not feel that clinics or mislead parents can be trusted with disclosing this information.

After my parents told me I am donor conceived I reached out to my clinic, now run by [REDACTED] IVF, for information. I was referred to a counsellor (paid for by my parents) who reinforced the idea that I should just be happy to have loving parents, a rhetoric that is often used on donor conceived people. The counsellor was helpful though in that she called in a favour with a nurse to obtain non-identifying information about my donor: level of education, favourite subjects, occupation, interests, a five-word description of himself, and his answers to 'how do you get along with other people', and 'how do you solve problems or make decisions'. I ask anyone reading this to

imagine how they would feel if this was the only knowledge they had about their biological father because this was what was chosen to be shared with them. This information also came as a surprise to my parents who were only told that the donor was a 'medical student', an obvious lie from their treating doctor as his file listed his occupation as 'ex-furniture maker'. Despite being dissatisfied with this little information, being taken aback by the notion that I should simply be grateful for what I have and being only a teenager, I did not press for more information.

Several years after my first time contacting the clinic, I became determined to get more information – I wanted the clinic to contact the donor on my behalf for an updated medical history (a lot can happen in over 20 years), and I wanted non-identifying information about siblings (how many, sex, and age). This time contact with the clinic was far more traumatic. I was referred to the same counsellor who I had spoken to last time, and she said she would do what she could. Dealing with her was incredibly difficult as she would not respond to my emails, or answer or return my calls. At one point after months of her not returning contact I successfully got her to contact me only after making a complaint as a public comment on the [REDACTED] IVF Facebook page. In response to my requests I was given more non-identifying information about my donor: physical characteristics such as height, hair and eye colour for himself and his parents, nationality/country of birth, marital status, general health and eyesight, and no history of cleft palate, spina bifida, cystic fibrosis, renal conditions, bronchiectasis, hypertension, epilepsy, thyroid disease, cancer, Huntington's Chorea, thalassaemia, or anaemia. Although I was happy to have more information, I was disappointed that this was not the information I wanted or requested, so I kept pushing.

I was even given a meeting with the Head Nurse of the clinic, who was very rude and pushy, telling me I should just be happy with what I have as it's more than most people get (as if I should feel special that they even gave me this much information), that my concerns about potentially dating an unknown sibling were ridiculous because they ran statistics based on Victoria and found that this was unlikely with the 10 families per donor limit that they enforced, and that diseases caused by genetics are uncommon so my concerns are unnecessary. I came out of that meeting, got in the car, and burst into tears, distraught from being so dismissed, talked down to and treated like a nuisance, and from knowing that this company who cared so little about me were the gatekeepers to information about my close biological relatives. I pushed on and was eventually told that it had gone to the Board of Directors, and they had decided that 'because it would be bad for investors' [REDACTED] IVF would not contact my donor on my behalf to ask for an updated medical history or give me information about my siblings conceived at the clinic. After this I gave up and pushed on with *Ancestry DNA* instead. When I think back to how distressing and difficult this all was I don't think I would ever choose to or even could go through it all again, even as my now older, more confident self. Donor conceived people should not have to go through such traumatic contact with clinics to get information, it should be controlled by a trusted third-party such as the state government.

Through *Ancestry DNA* I have found my biological father and six siblings. I have learned that my donor donated at both the [REDACTED] Clinic and the [REDACTED] clinic, and that samples have been sent from those clinics to at least two other clinics, both in New South Wales. This means that if the 10 families per donor per clinic rule was followed I could have siblings from as many as 40 families (including my own family). This weighs on my mind almost constantly, and every time I come back to the Brisbane area to visit my family I wonder who around me could be an unknown sibling. It is distressing to know that me finding my siblings currently depends on all of them being told that they are donor conceived, then realising that DNA testing is an avenue for finding relatives and deciding to pursue this route. It seems unlikely to me that I will ever find all my siblings in my lifetime, or even know how many there are - this is why it is critical that there is a central register where donor conceived people can access information about siblings and reach out to them (and donors) through this register to continue contact if both parties consent.

Due to my experiences I strongly believe that Queensland should have a government controlled central register of donor conception related information in line with Victoria's system. This register should include all information that clinics have about donors and donor conceived individuals, should allow these people access to information relating to their direct biological relatives (donors and siblings), and should mediate initial contact between these people. I think that Victoria provides a good example of a system that works well and demonstrates that such a system will not negatively affect the uptake of donor conception. I think it is important to consider that anonymity was not a choice that donors had, it was put upon them and not something that all donors want, nor was it an ethical promise for clinics to make. I think that this register should be paid for by clinics and/or government, not donor conceived people. Everyone involved in a person's donor creation (doctors, donors, clinics, and parents) got a say in and got to consent to this process except for the person conceived, so donor conceived people should not be the ones to have to pay to access information about their genetic identity and biological relatives.

I think it is also necessary for such a system to regulate use of donors to prevent so many uses from multiple clinics and regulate medical history that should preclude someone from donating. All prospective donors should also go through the system and give a comprehensive family medical history from their general practitioner, which should be updated yearly. Since finding my donor I have learned that his grandmother died from colon cancer and his father died from causes he will not disclose. However, when I asked for any significant family medical history he said that there was none, and it was only after I asked what his close relatives had died from that he mentioned his grandmother. I don't think that lay-people can be entrusted to fully disclose all relevant family medical history because they are not qualified to determine what is relevant. We make pilots go through a more rigorous and legally binding process to declare their medical records, so why do we trust someone's word when they're donating genetic material to create another human being?

My journey dealing with being donor conceived has been long and emotionally difficult, made so by the difficulty and fruitlessness of dealing with my clinic to get information about my own genetic identity. No person should have to go through this, yet through a donor conceived support group I have learned that this is a typical experience for donor conceived people (if not worse). I hope that through my experiences I have shed some light on why it is necessary for Queensland to have a government controlled central register with all relevant information for donor conceived individuals and donors, which will mediate contact between donor conceived individuals and their donors and siblings. I implore you to put the needs and welfare of donor conceived individuals above the wishes of the clinics which will not be negatively affected by such a register (as demonstrated by Victoria).

Sincerely,  
Jessica Addley-Cook