

Committee Secretary  
Legal Affairs and Safety Committee  
Parliament House  
George Street  
Brisbane QLD 4000  
23 April 2022

**RE: INQUIRY INTO MATTERS RELATING TO DONOR CONCEPTION**

Dear Secretary,

Thankyou for the opportunity to provide a submission to the inquiry. I would like to provide you with some background information about my story as a late discovery donor-conceived person and then provide my feedback and some suggested recommendations in relation to the issues being considered by your committee.

**BACKGROUND INFORMATION**

I was born in 1979 at the Royal Women's Hospital, Melbourne and brought up with my mother, father, and younger brother in a loving family home. When I was in my late thirties, I received a letter from a government organisation named Victorian Assisted Reproductive Treatment Authority (VARTA), whom I had never heard of before. The letter indicated they had some "information about my birth details" they wished to discuss with me and encouraged me to call the number listed.

Intrigued, I called the number, and after confirming my identity with them, the counsellor advised me that I was conceived using a sperm donor and my Dad was not my biological father. This came as a huge shock and surprise to me, as I have never even considered that the loving, caring man who brought me up was not related to me. The counsellor went on to explain that the reason I was receiving the letter now was a direct result of legislation passed in the Victorian Parliament in 2017 which allowed donor-conceived people and donors retrospective rights to contact each other. The counsellor explained I was receiving this letter now, because my donor had written a letter of his own to me and wished to make contact with me.

I went through a whirlwind of emotions as I listened to the counsellor explain the legal safeguards in place to protect me and the options available to me all the way from no contact to full contact. I was amazed that such a huge part of my life could have been going on without my knowledge and that I have never realised. I felt shocked and questioned who I even was anymore, but was also strangely excited to find out about this other side of me. They answered my questions and told me the letter

from my donor would be available for me to read if I chose to read it in the future whenever I was ready. I asked if they would read the letter to me during that first call, something that the counsellors advised against, saying most people waited a few weeks for, but I decided I wanted to hear it then and there.

Hearing the three-page letter from my donor was one of the most beautiful experiences of my life. As he described his life, it was as if he was describing my life and interests and it provided clarity for where so many of my talents came from. The letter also explained that I had a donor-conceived (DC) brother and sister, both born in the same year as me, and they had helped write the letter also. I instantly had 3 new family members! What an amazing day!

### **Developing relationships**

In subsequent weeks and months, I connected with my donor and DC brother and sister through Facebook Messenger and eventually met them all in Melbourne at my brother's film premiere at the Melbourne International Film Festival (he is a film producer who lives in LA, USA). Meeting my biological family for the first time was one of the most exhilarating times of my life. The energy I felt and continue to feel when I am around my donor is very intense and I instantly feel at ease whenever I am with him – we enjoy each other's company and can talk for hours. Likewise, when I met my siblings for the first time, we all felt like we had known each other forever and quickly developed a deep and strong relationship. We now all talk and chat regularly as we live in different cities and catch up in person as often as we can.

I am incredibly disappointed that I was not given the opportunity to know these people as I was growing up. Parts of my physical features that I hated or was teased about are now things that I see reflected in my biological family and I feel better about knowing where they came from and no longer hate those parts of me. I also now realised that subconsciously I knew that there was something/someone else out there that I needed to connect with, and I was searching for them, but I could never verbalise it and I wasn't even sure who or what I was searching for. When I was connected with my biological family this yearning has stopped. Now we are all trying to make up for 40 years of missed relationships and creating a relationship with a biological father who is in his mid-70s already!

I then had the difficult task of talking to my parents to let them know I now knew this information. They confirmed what I had been told: that they were told the donor was anonymous and there was no way they could ever find out his name. They were advised to go home and never think about it ever again, to tell no one, and indeed they never even spoke to each other about it until the day I

told them, over 40 years later. They were advised it would be detrimental to the child's health to ever tell them of their origins so best not to tell them, and they had followed that medical advice perfectly. If I had not received that letter, I still would not know about my genetic history.

I am still coming to terms with the new identity and changes to my life and have sought significant counselling to help me process this news. VARTA counsellors were incredibly supportive throughout the initial stages, and I was grateful for their help setting up meetings and interactions. I have also attended VANISH networking support groups and joined online support groups and met other donor conceived people through this and sought significant support through these avenues.

Subsequently, in 2021 I joined with a group of donor-conceived individuals around Australia to incorporate into a national support and advocacy group and have helped work towards setting up Donor Conceived Australia. I realised I am one of the incredibly lucky ones to be born in Victoria, the only state with laws that allow me to find out the way I did, and for my donor and family to choose to make contact with me in that way. I know I have these rights due to others who have fought and advocated for me in the past, and I want to continue to fight for those in other states and those who still do not know they are DC and are waiting for someone to tell them, because everyone deserves to know about their own genetic heritage.

Despite the shock of knowing none of this side of my family to instantly having three new members, I realised I am one of the lucky ones in the donor-conceived community. I did not spend any time searching for my family, trying to find records, I never yearned or wondered what my donor or siblings looked like, I haven't got hundreds of siblings, I never had to write or make contact and wonder if they would reply or like me, and I never had to put up with the rejection of family deciding they don't want an ongoing relationship with me after all. These are all regular problems and issues for members of our community, and we work to support those who need to work through the various stages of their journey.

### **Feedback on issues relating to donor conception – QLD Inquiry**

My comments and recommendations below are based on my experience in the Victorian system and working with donor-conceived people in other states who do not have the same rights as me. I do not believe the Victorian model is perfect, and I look forward to working with the Queensland Government to help provide an improved model, but it certainly provides a base model, and I am happy to provide further feedback and detail as to how it feels to be a participant in such a model.

**a. Rights of donor-conceived persons, including to know their genetic origins.**

All donor-conceived people have a right to know their genetic origins and it is against their basic human rights to withhold this information from them. I grew up not understanding certain parts of me, from physical features to hobbies and interests and I wish that the younger me had access to my donor and DC siblings back then to know that I wasn't weird and that there were other people like me out there.

**b. Extent to which identifying information about donors should be given to donor-conceived persons, taking into consideration the right to privacy of donors.**

The age of anonymity is long gone. Most donor-conceived individuals in Australia and indeed around the world discover their genetic family through direct-to-consumer DNA testing. It is incredibly sad that they need to pay a fee and give their DNA over to a multinational corporation just to have a chance of finding their kin. When a donor chooses to donate, they are giving away their anonymity and any donor conceived persons created from that donation have the right to identifying information about the donor, without having to go to a multinational corporation and without having to pay any money for the privilege.

**c. Access to historical clinical records and implications of retrospectivity.**

Any changes to legislation must be made retrospectively also, and this must be done immediately, and not as an afterthought. The first generation of sperm donors are getting older, and time is fast running out for donor-conceived people to create any kind of a meaningful relationship with their donors before they pass away. Please consider giving these people a chance at a relationship with their genetic kin before it is too late.

Victoria has successfully implemented a model which includes retrospectivity, and I am sure Queensland can improve further on that model.

**d. Access to support and counselling for donor-conceived persons and donors.**

Support and counselling for donor-conceived people is severely lacking in Australia. There are not enough experienced counsellors in Australia, because there are not enough donor-conceived people who currently know their DC status for counsellors to gain experience with. Consequently, donor conceived people end up with less-than-ideal counsellors with no experience and little idea of how

to support someone who is a late discover donor conceived person. I hope the Queensland government can support training and coaching of counsellors in the needs of donor conceived people as adults. Fully qualified, trained counsellors provided free of charge to the user (donor-conceived person, donor, recipient parent and even partners of each of these people) is a must as the trauma of a late discover donor-conceived person is significant. There must also be an option for independent counselling that the user may seek independently.

**e. Whether a register should be established.**

Yes, a register must be established as soon as possible, and it must be run by a government organisation to help with the linking. Other state registers are not fully funded and so are not effective or are not focused on the needs of donor-conceived people.

This register MUST link with other state registers and work closely with them (in the absence of a national register) as there were many gametes sent across state borders where siblings from the same donor can currently find out information if they are conceived in one state, but not if they were conceived from the same donor in another state. This must be fixed. There are also reports of donors travelling between states and this must be recorded in the registers also.

**f. Benefits, risks, and implications on donor conception practices arising from any recommendations.**

In regard to funding for all the suggestions above, I suggest that the government pay for retrospective and historical cases and that fertility clinics pay a levy to support more recent cases. The fact that fertility clinics seem unable to support parents past the time of birth, when bringing up a donor-conceived child/adult is a set of lifetime stages where the views of the donor-conceived person can change dramatically at each stage. Recipient parents and donor-conceived people require support at all these stages of their lifetime, not just at the birth stage.

A great deal of support is needed for these people as they are finding out their true donor-conceived status, and the government has an obligation to help these people through this stage of their life.

Victoria was able to provide world first legislation in this area and is currently looked to by jurisdictions around the world considering implementing legislation in the area of donor-conception. Now Queensland has the opportunity to go even further with their legislation and provide world leading legislation for the people of Queensland.

## RECOMMENDATIONS

1. All donor-conceived people have the right to know their genetic origins, of when or where they were conceived and should be told from birth to minimise any impacts to their identity. This is a basic human right.
2. Donor-conceived people have the right to access identifying information about their donor and be provided with the opportunity to create a meaningful relationship with both their donor and any siblings from birth, regardless of when or where they were conceived.
3. All gamete and embryo donors should have the right to access identifying information about their offspring regardless of when or where they donated.
4. All donor-conceived people should have the right to access identifying information about their siblings regardless of when or where they were conceived.
5. That the Queensland Government create a government run organisation responsible for keeping all records of donor-conception and all fertility clinics be legislated to hand over all records retrospectively with penalties for non-compliance.
6. The government organisation will create a register that will link fully with other state registers, particularly for the purpose of gametes sent interstate.
7. That the government organisation also provide independent counselling and donor linking services to all donor conceived individuals, donors and recipient parents at no cost to these people, with some of the costs to come through levies from fertility clinics.
8. That the government organisation ADVERTISE their existence extensively so that donors and donor conceived people are aware of their rights to make contact, and also run significant awareness campaigns to tell adult donor conceived people of their genetics before it is too late.
9. That the government organisation prepare to advise all donor conceived individuals of their status, to offer counselling and link them with their genetic heritage before it is too late for them to connect with their donor, beginning with the eldest DCPs.

Yours sincerely,

Aimee Shackleton