26th April, 2022

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Committee Secretary
Legal Affairs and Safety Committee
Parliament House
George Street
Brisbane Qld 4000
lasc@parliament.qld.gov.au

Dear Committee Secretary,

Submission | Inquiry into matters relating to Donor Conception Information.

I wish to provide my thoughts and experience to this inquiry regarding my recent journey of discovering that I was donor conceived in Queensland in the early 1980's.

My Story

Here is a brief summary of my story as a late discovery donor conceived person:

- In 2019, I was 35 years old when my terminally ill paternal grandmother told me I was not her son's daughter (and therefore not her biological granddaughter).
- All of my paternal and maternal family knew since my birth (and my younger brothers birth) that my parents obtained donor sperm through a clinic in Brisbane in 1983 and 1985.
    - This has added significantly to the complex trauma associated with this discovery.
- Both my parents had no intention of ever telling me.
- My mum passed away in 2006 from a potentially genetic medical condition, and even then my conception was not divulged by anyone on either side of the family.
- DNA testing has revealed:
    - I'm not related to a paternal aunty (private one-on-one DNA testing)
    - My brother (who I grew up with) is my half-brother (he has a different sperm donor)
    - Who my biological father is, along with three other donor-conceived half-siblings.
- My Birth Certificate has no acknowledgement of Donor Conception and I have never discovered any records or documents that indicate such.

Donor Conception and Non-Parent Expected (NPE)

It is really important to acknowledge that there are many (unknown number?) donor conceived individuals *who do not know* they are donor conceived. They do not know that a parent is not biologically related to them. Non-Parent Expected (NPE) (or Non-Paternal Event) or Mis-attributed Parent Event (MPE) situations occur when someone is not informed that their parent/s is/are different from their biological genetic identity. These can occur following a range of circumstances:

- Closed adoptions
- Gamete donations (sperm or egg)
- Secret affairs
- Sexual Assault (rape)

Below, in table 1, are three (3) groups of Donor Conceived people. I was in Group 1 for almost 36 years.

Table 1: Stages of Discovery for Donor Conceived Persons

	Group 1	Group 2	Group 3
Individual knows they are Donor Conceived	No	Yes	Yes
Individual knows who their biological donor and/or relatives are	No	No	Yes

As you can see, not all "Donor Conceived" people 'are in the same boat' and are at different stages of the discovery process (if any), and all groups need to be considered in any outcomes from this inquiry. Only groups 2 and 3 can advocate for group 1, as they will have no voice in this inquiry.

Late Discovery NPE/MPE

The late discovery of the true genetic origins of an individual is defined in many different ways, especially when talking about young children (eg. telling the child before 3 years old, or 5 years old, or 10 years old, or 18 years old). When referring to the situation in Queensland whereby anonymous donor conception occurred 20/30/40 years ago, these children are now adults. And many do not even know.

My perception from my own experience, reading the stories of others, and reviewing resources and literature relating to NPE/MPE's (including adoption), is that the late discovery of genetic origins can be a complex, traumatic and life-changing event that can have long-lasting impacts, including medical impacts for the individual and subsequent children. For me personally, the fact that I found out later in life is way more significant than the conception process that occurred. This inquiry should ensure that late discovery NPE's/MPE's (and also all donor conceived persons and families) have adequate support should any recommendations impact them.

My Submission

The committee has outlined it wishes to inquire and report on six (6) issues relating to donor conception information. This submission addresses the following issues:

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

It is a fundamental human right to know your genetic identity and origins. There is lots that has been published on this, including in the adoption space, which has many synergies to donor conception. People need to know and the secrecy and lies need to stop.

This website also has some good information: https://righttoknow.us/

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

Only if mutual consent is provided – meaning the donor consents to information being provided, and the Donor Conceived Person consents to receive that information.

- Not all Donor Conceived people want to find out who their donor is, and that is ok.
    - Not all children want to know their biological parents, regardless of how they were conceived. Any potential release of information needs to consider this option.
- Not all Donors want to find their biological children, and that is ok.

    - Not all biological parents want to know their biological children, regardless of how they were conceived. Any potential release of information needs to consider this option.

It is important to note here that it took me less than 30 minutes of researching following my discovery to work out that an Ancestry DNA test would be the easiest way to work out who my biological family was. Once my results were in, I was in the fortunate position where my likely donor has been identified through genealogical research connecting them to a distant cousin. Quick internet searches also revealed easily accessible information.

c) *Access to historical clinical records and implications of retrospectivity;*

Historical clinical records pertaining to records of the treatment my mum received are of little use to me. They would be interesting, however unlikely to ever the accessible, and likely not that important.

Historical clinical records relating to information (age, gender, date or year of birth) regarding other siblings who I share DNA with would be of some/limited use, however my experience and research on this indicates that clinics kept little to no records, and some records are even incorrect.

- So if you know you are donor conceived, or donated gametes, then do a DNA test through a commercial provider.
- Unless some people do a DNA test for other reasons and accidently discover they are donor conceived, then it will be generations in the future that these connections may be possible.

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

This is particularly relevant to me, and one I have found frustrating. A series of events over a number of months relating to this discovery resulted in the feeling of being completely and utterly overwhelmed and subsequently searching for some help. There was very limited available. I found:

- The Victorian Assisted Reproductive Treatment Authority (VARTA) helpful for an ‘in-kind’ or complementary session of support, even though I am not Victorian. They had no scope to assist any further.
- Jigsaw Queensland Inc. “work with and for everyone affected by adoption, regardless of where or when the adoption took place and also provide support and information for those affected by donor-conception”. After engaging with them (in 2020/2021) it became evident that ‘support’ for donor conceived people was really just referring to their website and resources (their funding was more centred around adoption). At the time, they advised they were advocating for a funded service for people who are donor conceived and their families.
- Qld Family Support had a psychologist who specialises in this space – for $190/hour.
    - Why should I pay for a situation that I had absolutely no say in, including no influence in the subsequent journey of discovery? And there was a two month wait.
- I also did enquire with another counsellor in Brisbane, however they were unable to provide a telehealth call, and I live 1000km’s from Brisbane.
- I mentioned it to my GP, and the only suggestion was a ‘Mental Health Plan’ with a general psychologist. I was really looking for someone who specifically specialised in late discovery adoption or donor conceived, and/or trauma.

- There is an Australian DC Facebook Group, however although welcoming and somewhat useful, most of the discussion is around opinions on recent news articles related to gamete donations, LGBQTI+ related issues, legislative rights and access to information. For me, it's not a space to talk about my story and journey and the dealing with the 'here and now' type issues – also due to related siblings also being in the group. And also, it's been a space where if your thoughts on your own journey 'are not the same' as some others in the group, then you are not welcome. Everyone's journey is different, yet some people have very strong views about how 'you' should feel about it – perhaps that is due to a lack of understanding even amongst donor-conceived people that some have known 'forever' and some are late discoverers. I find they are world's apart when it comes to processing this discovery.
- The best external support I have found is in the United States, via a safe forum and service that is not linked to Facebook.
- There is also an abundance of support related research and articles in the Adoption space, and I found this avenue more helpful. Self-support is sometimes very effective.
- The best support though was my husband – even just having someone to just listen, and not judge, is valuable.

It was clear that there was very little support available in Queensland, let alone Australia that I could access. Due to the complex nature of some discoveries and often dismissive responses from others with no exposure to NPE/MPE situations, specialised support to work through thoughts, processes, reunions etc is vital.

- *If nothing comes of this inquiry, at least advocate for some funding for psychological, counselling and mental health support to be installed into an existing organisation whereby Queensland Donor Conceived Persons and their families can access when needed.*

e) *Whether a register should be established; and*

A register is only as good as the information available from clinics. If it's not complete, missing parts, or contains incorrect information, there will always be gaps and associated issues. And every connection should be confirmed by a DNA test anyway.

If a register is a way to gather and safely house information available from clinics, then yes – this information should be stored securely and available to access through 'Right to Information' (RTI) legislation or other means.

If a register, containing all available data from clinics is to be used with the goal to ensure all donor conceived people know of their origins, then yes – but that is going to need a set of functions and guiding principles similar to the *Victorian Assisted Reproductive Treatment Authority (VARTA)* https://www.varta.org.au/about/functions-guiding-principles.

If a register is just for 'interested parties' to 'log' their details in the 'hope' of a 'match' (no provision of data from clinics), then no – do a DNA test. Funding would be better spent on support.

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

Anonymity is long gone, and the recommendations to ensure donor-conceived persons (and adopted children) know of their origins is now well known. I don't think any recommendations from this inquiry would have any impact on current donor conception practices.

I hope this submission is of use in understanding more about this journey. I'm available to provide more information if required (details provided via email).

Kind Regards,

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