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[REDACTED]**29<sup>th</sup> April 2022**

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

Dear Committee Secretary,

**Re: Inquiry into Matters Relating to Donor Conception Information**

I write to you as a donor conceived person to strongly encourage the Queensland government to enact legislation that prioritises the rights of the child in all Assisted Reproductive Therapy (ART) processes, of which donor conception is part. I was conceived in Canberra in 1988 so although laws in Queensland will not impact my situation directly, I believe that all donor conceived people (DCP) in Australia should have access to the same protections and supports regardless of their state of conception. Consistent, progressive legislation in all states of Australia designed around protecting the outcomes for DCP is imperative to increasing equality, reducing trauma and securing medical and human rights.

I will keep my complicated, long story as brief and factual as possible for this inquiry but I want to paint a picture of how not making laws retrospective will serve first and foremost to protect fertility providers who knowingly engaged in misconduct.

- I am grateful that I always knew I was donor conceived. I decided to look into my genetic history seriously in my early 30s - when I realised my own conception and lack of information would have major implications on my future children, and my own options for how to have them.
- I was conceived by a gynaecologist outside of a formal medical clinic who knowingly used fresh sperm (at the time this was against best practice due to the AIDs epidemic) and has now stated that they did not do any form of medical testing or vetting.
- Every vague statement my parents or I was provided about the health, educational and socio-economic background of the donor has been called into question through DNA testing. The most troubling of which is the prevalence of heart conditions in the donor family, the likelihood my donor was of aboriginal heritage and the possibility that his sperm was used without his consent while undergoing IVF with his wife. He may not even know he is a donor.
- My understanding of my cultural identity is undergoing significant reformation as a result. I am left with no support or avenues for resolution whilst trying to understand how to process the huge story of multi-generational trauma (being part of the stolen generation) my donor's DNA has imparted to me.
- The gynaecologist states they purposefully did not keep records relating to any donor conception they were a part of. So imagine, assuming my donor did know he was a donor, he finds out he has this genetic history of heart conditions and an indigenous heritage and story. He realises this is important information for his genetic offspring. He rings the gynaecologist and advises them. The gynaecologist cannot connect that information to any pregnancy and therefore my parents and myself cannot be notified. This is not a system or clinician worth protecting, it is one worth supporting

those of us who have been seriously adversely affected by to have our rights and supports reinstated as far as practicable.

- I now find myself realising in all likelihood I have been robbed of a cultural identity that is of huge importance to me, my descendants and my broader family/ies medically and emotionally. Moreover, the lies, evasions and omissions told to my parents and passed onto me by the gynaecologist created a false sense of security that prevented me reaching out and looking earlier. As time has marched on people have become sick and died, limiting my ability to get the answers I now find I need.
- Like Queensland the ACT currently has no legislation and so I am treated the way so many DCP across our country and in your state are. The system belittles, traumatises, gaslights, excludes, condescends and outright lies to us (and our parents). The clinicians can do this knowing we have no rights, and that their actions and responsibilities have no implications on them, their practices or ability to earn. It not fair and reasonable to limit me and place roadblocks in my path, to expect I bear significant financial costs to access the basic information others have a right to, that I need to spread my DNA across every private company online to ensure I connect with whoever I can that can provide the answers the documents and clinicians have kept from me.
- I was not traumatised by being a DCP. I have been negatively and constantly impacted by every interaction with the clinician, by their (knowingly) poor practices and lies, and by the lack of support and interest in my rights and wellbeing our society and government bodies currently have.

I have provided a brief statement for your consideration in response to each of the matters of the enquiry below:

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

- I encourage the Queensland government to apply the UN Rights of the Child and secure all DCP's rights to accessing their genetic and cultural history, medical history and relationships with their genetic family where possible.
- In the age of direct-to-consumer DNA testing, anonymity is a false concept. Anonymous donation no longer exists. Anonymous donation is not and should not be positioned as an option for any current or future donors. Open ID donations are clearly the best outcome for the child.
- All recipient parents (RPs) should be counselled on the rights of the child through their fertility process – ideally by specially trained and accredited counsellors to ensure the DCP implications and perspectives are understood by RPs and shape their decision-making.
- Fertility clinics should not be trusted to manage information, registries and appropriate advice to RPs. They have shown over 40+ years of operation that the conflicts of interests that arise cannot be managed by them. The opportunities for fraud, mismanagement and purposeful omission on medical documents relating to donor conceptions are well known and documented. The cost to DCP's of this mismanagement is too great to be trusted to a private, profit-focussed industry.

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

- As stated above, the concept of donor anonymity is not supportable either practically or ethically today. It was not 40 years ago and it is not now fair to remove the rights of a human being to their genetic identity, and if possible genetic relationships. An agreement between a parent, clinician and donor prior to conception is not sufficient to remove the rights of a DCP baby, child, teenage or adult. They have not consented to that removal of their rights.

- All present day donors should donate understanding this, and be counselled appropriately to make the decision. Donors should be empowered to make choices about how and where their sperm can be used, on-sold and distributed. By this I refer to the number of children/families created, the state and clinic in which this occurs, (etc). Through this process they can be counselled to understand the implications of their decisions and supported to require more transparency from clinics.

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

- All DCP regardless of year of conception deserve legal protections to their right of access and knowledge to genetic and medical history.
- In many cases, the destruction, loss and mismanagement of records is so great that clinical records will not help older DCPs. However, the law should uphold their rights so that what is available is open to them. It is time for the governments and legal systems of Australia to recognise and provide equal rights to DCP's, as they have to members of the adoption community.
- Historic donors (and clinicians/clinics) have found themselves in the one of those difficult places in history whereby had they had better information, they may have made other choices. These times in history are not uncommon and have been experienced in the adoption community, LGBTIQ+ communities, minority communities (etc.) at many turns of history. The world changes, we learn more and in the transition between the old way (excluding rights of the group) and the new way (including rights of the group) uncomfortable situations may occur for some groups who previously had protections for their actions, or felt their actions were fair and protected. Historic donors who feel strongly about their privacy should be counselled and supported, but the rights of DCPs should not be further aborted to avoid their discomfort.
- Many donors were too young to make the decision, misled and influenced in their decision-making and the responsibility for that is on the fertility clinics and individuals, not the donors, RPs or DCPs.
- Retrospectivity is vital, as shown in my personal story, and the discomfort of the few donors in righting this wrong can be dealt with as it has been dealt with in the adoption space.

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

- From a wellbeing point of view DCPs, donors and RPs have too long been overlooked. The lack of support and the financial implications of accessing the support have been major compounding factors to trauma and relationship breakdown. Purpose-designed support and counselling is crucial to all and should be independent, possibly accredited, and financially and geographically accessible.

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

- An independent, retrospective state register should be established as soon as possible to allow donor, sibling and DCP matching.
- It must be managed independently of clinics and consist of regular prompts (5-yearly) to donors to ensure all their relevant knowledge that would impact a DCP is up-to-date. Such as medical history and cultural history.
- Ideally, this register would one day form part of a National Register, but at minimum all possible attempts should be made to cross reference it with other state-based registers.
- This is important as gametes are collected and distributed broadly across the country and internationally. 'Family limits' (the number of families/people created from each donor) matter to DCP, donors and RPs immensely. There is no benefit to 10s or 100s of closely genetically related people being created and able to interact unknowingly. A national register or state register cross-referencing would allow

clinics using gametes and individuals operating across state-lines to be identified and prevented from ongoing donations or uses of donations that will create these mega-genetic networks. Such networks are psychologically damaging.

- All donors and DCPs (and RPs in regards to their offspring) have a right to knowing how many close genetic connections they have out there, and where they are/what gender/what age so they can manage interactions mindfully. The possibility of having 30-100 half-siblings and not ever being able to confirm that number makes operating in the world highly stressful.

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

- The use of international gametes and surrogacy should be considered and limited/regulated. At minimum, all conceptions using internationally sourced surrogates/gamete donations should be expected to operate under and deliver the same rights for donors and DCPs as assigned in the law of the state the conception takes place. The DCPs born as a result of imported gametes will face extraordinary barriers and expenses in accessing their information. This issue needs to be the focus of education and counselling in clinics and used only as a last resort, where donations are not anonymous and the rights of the child are protected in the country of origin of the gametes.
- Education for RPs and donors outside of clinics must be paramount and all family limits should be applicable in any donor conception situation. RPs and donors are vulnerable to individuals not acting in good faith, and without lived experience, do not know how to ask the questions they will later find themselves wishing they had asked to guide decision-making.
- Resources, workshops, (etc) for prospective RPs and donors outside of clinics should be available, creating a safe and gentle space for RPs and donors to learn and consider the implications of their decisions on their future offspring.

Creating and enshrining the rights of DCPs in legislation is the first step to the socio-cultural change we need to have around donor conception that will protect future generations of donors, RPs and DCPs alike. The industry can persist but it can do so much better protecting the outcomes for DCPs, donors and RPs and it is the role of government to ensure this is the case through:

- Progressive and broad legislation centering the rights of the child;
- Ongoing, independent review and auditing of the practices of ART providers;
- Public education and resource creation for prospective donors and RPs;
- Independent, accessible support services for DCPs and their families, RPs and donors at every stage of their lives/the process.

Thank you for the opportunity to submit to the enquiry.

Sincerely,

Eleni McIlroy