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Committee Secretariat

Legal Affairs and Safety Committee

Parliament House George Street

BRISBANE QLD 4000

lasc@parliament.qld.gov.au

Re Inquiry into matters relating to donor conception information

My name is Patrick Cronin, and I am a donor-conceived person. Please accept this independent submission outlining my lived experiences, personal opinions and position in relation to the Legal Affairs and Safety Committee Inquiry into matters relating to donor conception information.

I note the issues pertaining to this Inquiry are:

1. Rights of donor-conceived persons, including to know their genetic origins.
2. Extent to which identifying information about donors should be given to donor-conceived persons, taking into consideration the right to privacy of donors.
3. Access to historical clinical records and implications of retrospectivity.
4. Access to support and counselling for donor-conceived persons and donors.
5. Whether a register should be established.
6. Benefits, risks and implications on donor conception practices arising from any recommendations.

My Background

I am a 30-year-old male born and raised in Queensland. I discovered I was donor-conceived one year ago.

I have a 33-year-old sister, also donor-conceived, and we were raised by our mother and father. My parents separated when I was young and I remained with my mother, however I still maintain a loving relationship with my father.

I have two young daughters, 6 and 8, and I am expecting a baby boy in July. I make this submission for them.

I received a commercial DNA testing kit (Ancestry) for Christmas 2020 from my in-laws as they knew I was interested in my heritage. I received my DNA results in March 2021 and matched with three half-siblings.

I phoned my mum who immediately broke down in tears and said she needed to tell me something. Over the coming days I discovered I am a donor-conceived person.

I have had a year to reflect on my thoughts since this personal discovery. I have made connections with my newly found half siblings, I have found support in the donor-conceived communities, I have made personal discoveries relating to my genes, health and mental health.

I was fine discovering I was donor-conceived. I can work with that. However, one issue I was deeply disturbed by was the unethical and unregulated practices of the Assisted Reproductive Technology (ART) industry which has actively fought against the basic human rights of the children they “created”.

It’s not just the Queensland fertility industry who disregards your rights as a donor-conceived person, but almost every outsider who you share your story with. I don’t think there’s a person I’ve told about my situation who hasn’t responded with “Yeah but your dad’s still your dad”, “That doesn’t change anything”, or “You’re lucky your parent’s loved you so much”. I understand their intentions are innocent but it demonstrates how easy it is to miss the point entirely. I shouldn’t have to reiterate that I love my dad. That’s not the issue here.

We are a genetic reconstruction of one half mother and one half father. I have also inherited many personality traits from my dad growing up however there’s no denying that a part of the equation is missing. Being deprived of your donor’s information means being robbed of half of your genetic identity, ethnicity and origin.

I make this submission to improve this committee’s awareness and understanding of donor conception issues from the perspective of a donor-conceived Queenslanders.

My Position and Recommendations

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

I believe all donor-conceived people should have the opportunity to receive information, including identifying information, about their donor.

The positive physical and mental health implications of the release of such information would be immeasurable to donor-conceived people who, like myself, feel as though we are being withheld from a basic human right of self-identity.

Narelle Gretch was a donor-conceived person who died from hereditary bowel cancer in 2013. Before her passing, Narelle made submission to the Victorian Parliament in 2011 regarding their Inquiry into access by donor conceived people to information about donors (Submission DCP 67, 2011). As a result of her submission, the Victorian Parliament passed legislation granting the release of information to donor-conceived people referred to as “Narelle’s Law”.

Narelle wrote that if she had known that cancer was in her donor’s family, she could have been purposely screened and tested many years prior and that choice to be tested would have been her own. Think about that for a moment. Withholding this information is literally depriving a person of making informed life saving choices about themselves.

Parents of donor-conceived people who are ashamed to tell their children, despite now being adults, that they are donor-conceived and subsequently have been lied to their whole life, are also denying their children the right to fight for their own lives and that of their children’s children and so on. I have two daughters and am expecting a son soon. Although I stumbled across this information by accident, I am grateful I now know I am donor-conceived as I now have the ability to fight for

information that could improve my children's lives. Unfortunately many others, who are still being withheld the truth of their conception, do not have that choice.

I also believe donor-conceived persons should have the right to information relating to their siblings.

Through commercial DNA testing I instantly discovered 3 siblings. One month prior to writing this submission, a fourth sibling appeared. How many are out there? As a donor-conceived person, this question can become absolutely consuming. Every person about your age that you meet for the rest of your life, you will find yourself closely analysing their features and considering if they could be your sibling. An ever-present feeling of uncertainty that donor-conceived people know too well and that regular people would never even consider.

If I knew the number of offspring created from my donor, how many siblings I have out there, I may have found closure with my newly discovered DNA match that he is the last one. I wouldn't have to look twice or three times at everyone I ever meet.

Another fear among the donor-conceived is the potential for consanguineous relationships to form unknowingly. Although unlikely, it is possible. As a donor-conceived person, I share this fear for my children and their children. I am placing a responsibility on the Queensland Government for the prevention of such relationships through the release of sibling information to donor-conceived people. A right so basic and fundamental that regular people don't even realise they have.

I have missed out on 30 years of life knowing my siblings. We have all connected and many aspects of my life finally make sense. A genetic connection may not seem important to those that take it for granted. However I believe that it is important to know those who you share such a large part of your makeup... or at least be afforded the right to choose to know them.

The accessibility of commercial DNA testing is improving however it is not the be-all and end-all. Our records are being held in archive rooms across the country. Records that are being lost, damaged or destroyed as everyday passes. Only those records hold all the information we desperately seek.

I propose the following for consideration:

- a) The Queensland Government recognise the rights of donor-conceived persons.
- b) The Queensland Government adopt and implement "Narelle's Law" legislation as previously passed by the State Parliament of Victoria in 2016.
- c) A Notice of Donor-Conceived Status should be sent to all QLD donor-conceived adults advising them if they are donor-conceived.
- d) The full disclosure of donor and sibling information to donor-conceived people.

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

The welfare of any child born through assisted reproductive technology should be of paramount importance. It has been established that the continued secrecy of this vital information can adversely affect the welfare of these children throughout their lives. Children who did not have any say in the matter to which they are front row and centre. Surely any privacy concerns can be overridden and mitigated to protect the welfare of the party most vulnerable to the adverse ramifications; the donor-conceived children.

One common fear among donors includes the rights of their offspring regarding inheritance, their assets and parental contribution. I have met and spoken with numerous donor-conceived people and

not one has expressed any interest whatsoever in claiming any entitlement over a donor's assets. We do not want this! As a donor-conceived person I will support the Queensland Government passing a legislative clause to protect donors from any such attempts from offspring to claim assets or inheritance. It goes without saying in the donor-conceived community that any claim of inheritance is completely unreasonable and only a fear tactic once used by the ART industry to promote anonymity and subsequently increase supply and profit.

Another countermeasure to minimise any unwanted interference in the lives of donors, is the ability for donors (and donor-conceived people) to lodge a contact veto or contact preference statement. This fair and balanced approach will ensure the privacy of those donors is maintained.

I propose the following for consideration:

- a) The Queensland Government effectuated the release of information by fertility clinics to all donor-conceived persons.
- b) Information released should include identifying information of donors subject to their ability to lodge a contact veto or a contact preference statement. Donor-conceived people should also have the opportunity to place a contact veto if they wish.
- c) The onus of lodgement of contact vetoes should be placed on the donor. All information should be released unless a lodgement is received. If this is not the case, donor's (including deceased donors) may be uncontactable which would prevent the release of this information.
- d) Release of information should be retrospective and granted regardless of when the donor donated or when the donor-conceived person was born allowing for fair and equal rights to all donor-conceived people.

3. Access to historical clinical records and implications of retrospectivity.

Anonymity was promised by clinics to donors and although deeply unethical it was legal and contracted. Legislation makers should consider the legal protection of fertility clinics if information release legislation is passed. I believe this would minimise the resistance from the industry who have been the lead combatant against the rights of the donor-conceived.

As previously stated, I believe that in addition to legal protection, the ability to lodge a contact veto is a fair and balanced approach to this issue and would allow for the retrospective release of information affording equal rights to all donor-conceived people.

I propose the following for consideration:

- a) Release of information should be retrospective and granted regardless of when the donor donated or when the donor-conceived person was born allowing for fair and equal rights to all donor-conceived people.
- b) Without preventing the release of information to donor-conceived people, legal protection should be afforded to donor's and clinics.
- c) I plead that this process be expedited and any unduly delay be avoided as with every year, records are disappearing, being lost or damaged.

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

Since discovering that I am donor-conceived, I have worked through a number of personal struggles such as, questioning my personal identity, feelings of betrayal, helplessness, and most of all, feeling less than equal due to the lack of rights for the donor-conceived.

Majority of these issues could be alleviated by the implementation of Narelle's Law and the release of information to donor-conceived people. We would know our full genetic identity, it would put an end to ongoing lies, it would help us understand why many of us have felt lost or out of place in life, it would allow us to once again look ourselves in the mirror knowing who we are and where we come from and it would let us feel equal with the rest of humanity.

The struggles endured by donor-conceived people are difficult to understand or appreciate and easy to dismiss with platitudes. I believe many donor conceived people would benefit greatly from psychological support and counselling.

I propose the following for consideration:

- a) With the release of information to all donor-conceived people, counseling services should also be offered.

5. Whether a register should be established.

A Central Queensland register should be established, maintained and enforced under legislative requirements.

Upon their DNA discoveries, two of my siblings have independently reached out to the same fertility clinic where they were conceived. They sought any information available and expressed an interest in their information being passed on to any future siblings who make contact. When the second sibling contacted the clinic, she was advised that there were no others who had made contact.

I'm not surprised that the industry, who 30 years ago recommended to my parents that they never tell me the truth, would continue to lie and withhold information despite the wishes of those involved.

I believe that the Queensland Government must establish a register, maintained by an independent and experienced authority. Reporting requirements should be audited with transparency and enforced to give all donor-conceived people equal rights and access to the benefits of the register.

I propose the following for consideration:

- a) The Queensland Government establish and maintain a central register and oversee the release of information to donor-conceived people.
- b) Mandatory reporting requirements of information to register by Assisted Reproductive Technology Clinics.
- c) Identifying information of donors to be maintained on the register and released to the donor's offspring.
- d) Sibling information should also be maintained on this register.

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

In Queensland an adopted person can apply for information about their birth parents. For only a small fee, an adoptee can fill out a simple form and obtain information from the Registry of Births Deaths and Marriages regarding their biological parents' names and details.

I know that my parents went through assisted reproductive technology because they loved me and wanted me and that the donor had good intentions in helping parents create loving families. Sadly, at times this is not the case for many adoptees.

The Queensland Government has already accepted that adoptees have the right to know their biological parents even though the circumstances surrounding their adoption are most likely far more tragic than that of the donor-conceived. Due to this, I don't believe the risks of releasing such information to donor-conceived people would be any greater than that for the adopted. A precedent has been set. Adoptees have been afforded these rights retrospectively regardless of the anonymity their biological parents may have wished. I call on the Queensland Government to uphold this precedent without decrimination to the donor-conceived.

The privacy of the least affected party has always been the top priority no matter the severe implications to the most affected party; the children, who had no say from the beginning.

I understand people's concerns from both sides regarding their anonymity however the transparency proposed by new legislation does not mean your name and donor/donor-conceived status will be shouted from the rooftops. It will only be passed to those affected, son, daughter, brother, sister and there will be countermeasures such as contact veto/preferences. This information can save people's lives.

Past leaders should have more thoughtfully investigated these issues during the emergence of assisted reproductive technology decades ago to prevent the anonymity of donors. It's time to make amends to those donor-conceived people.

If this information is still available, the Queensland Government has the responsibility to grant people an equal right and allow people the right to know one's genetic identity, ethnicity, origin and family.

I propose the following for consideration:

- a) This committee appreciates how the benefits of the release of information to those mostly affected greatly outweighs the risks, which can be mitigated through various countermeasures.
- b) Consider present QLD and other state legislation regarding adoption and the release of information to adoptees. The Queensland Government should recognise the needs of donor-conceived people to access information of their biological parents just as previously recognised rights of adoptees.

Thank you for reading my submission. I did not write this in the hopes of finding my donor; I have already found most answers through DNA matches. I wrote this submission because I know the true torment faced by donor-conceived people. I feel it. Someone needs to stand up and say we are human and deserve to be treated with equal rights. I make this desperate plea for my two girls and my baby boy. I am not ashamed of who I am or where I come from. So please, just let me know.

Yours faithfully,

Fellow Queenslander, Patrick Cronin

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