28th April 2022

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

RE: INQUIRY INTO MATTERS RELATING TO DONOR CONCEPTION INFORMATION

Dear Committee Members,

I am writing to you as a person conceived via Donor Conception in NSW in 1990.

In NSW I am one of 15 conceived and I have unknown numbers of siblings conceived in other states in Australia as the remaining sperm was sold interstate. I found out that I was donor conceived last year at the age of 30 via Ancestry.com when an unknown half-sister contacted me. When I confronted my parents they confessed and said they had been told never to tell me.

This was a devastating revelation for me. I was scared and confused. Half of my DNA belonged to a stranger, and was part of a shameful secret that had to be kept from me and from everyone we knew as per the advice from the clinic. I no longer knew where I fit into the world and who I was. Where did I come from? Who had “chosen” my donor father? How many more siblings did I have? Have I ever dated a sibling? What is my medical history? Would my social father still love me? I knew that he loved me and I never would have known I was not his child biologically from his treatment of me, but I no longer understood “why”. It was hard for my parents to talk about because of the advice from the clinic and no one had prepared them for this conversation or given them the tools to help me. I fell into a deep depression, and spent some time talking to Lifeline and counselors to try and make sense of it all and feel myself again.

I realised then that I needed answers. Family has always been important to me, I was raised to be very family-oriented. Yet suddenly, I found out I have numerous siblings that

I do not even know the names of. A biological father somewhere out there and grandparents I might never get the chance to meet. I was filled with curiosity and a burning need for answers. Why did this man donate sperm to make me? What similarities do we share? At the same time I had to also grapple with the realisation that many of my donor siblings would not know they were donor conceived and that there was no recourse to find out unless their parents finally confessed or they happened to do a DNA test. And even in that case they were not bound by the normal social conventions of sibling relationships that result from the family socialisation process. What if they did not want to know me? What would I do if my donor refused to make contact with me?

I did not realise that being conceived in 1990 would mean that I had no legal recourse for information on my sperm donor or donor siblings. I contacted [redacted] Clinic where I was conceived and was first told there were no records. I called back again later because I was sure this was not correct and they had finally found the records and could give me the donor code and some non-identifying information. I really wanted some concrete medical information as I had been giving the wrong information to doctors all my life. I had flippantly disregarded some standard testing because I had no family history of these diseases, yet now perhaps I did? I was told the donor's medical history was unremarkable. But he would have been young, what is his health like now? What about his parents? There were no answers at the clinic for me. My donor sibling and I shared many of the same health issues, so surely there was something "remarkable" that had not been noted down. I registered with the NSW Donor registry, but as this was only for more recently conceived people the chances of any matches was very low.

I was informed that the rest of the sperm had been sold to [redacted] in Adelaide and to find out how many other siblings I had then I would need to inquire with them. I made several phone calls and was basically stonewalled. The records were with another hospital or they don't have the records or someone on the team will call me back but they never did. Until finally after five months of calls someone did call me back who was genuinely helpful. They did not have the records, but she could apply for them for me and retrieve them from the archives. I am currently waiting for these to discover how many siblings I have from there and where else the sperm has been sent.

In my quest, I have joined several other DNA websites and matched with another half-sibling, a brother who does not know he is donor conceived and works in the next suburb. My donor sister and I have managed to piece together our genetic father's family tree through matches on both his paternal and maternal sides. We used this to narrow down to two men, both of whom have several children of their own meaning more siblings for us. We discovered our grandparents had already passed away, but through second and third cousins we have received photos and information. It was uncanny to see my face reflected back at me in these pictures of strangers. I spoke with a second cousin on the phone and he remarked how my voice even sounds like other women in the family. My donor sibling and I were able to find many of our potential donors' children, our potential siblings, on Facebook.

And in all this I feel like we, the donor conceived children, are the only ones to have never been considered in the decision to create us. Why should we spend hours trawling electoral rolls, obituaries and marriage records to find out who our biological father is? Why did it fall to me to unearth this family secret and confront my parents? Why am I the one that now has to carefully craft messages to the donor and his relatives? Careful not to reveal too much to people who are close to him so that I do not disrupt his life. Why am I the one that is thinking about everyone else and their feelings and how this situation impacts them? No one thought about me.

It is a very difficult thing to try and make contact with a donor and potential siblings, people I would potentially want to get to know and form a relationship with. Although up to 21 siblings at this point is far too many to ever develop meaningful relationships with. I have to be careful not to “out” the donor, I do not want to disrupt his life and affect his marriage. And surely that would get us off on the wrong foot anyhow. I do not want to lie and start off a relationship with one of his children through deceit, but at the same time I need to know who the donor is and need my medical history at least. This is the position I find myself in now.

As a donor conceived person I do not want anyone else to suffer the way that I have suffered. A lot of this distress was caused by donor anonymity, large sibling numbers and non-mandatory disclosure of donor conception status.

Right to know genetic origins

- **Recommendation: Creation of a donor conception register that includes retrospective information including donor and sibling health information, names and ages and, with consent, contact information.**

Finding out my donor conception status as an adult caused significant stress and mental anguish for me. A lot of this distress was caused by the denial of my right to know my genetic origins and the continued denial of access to information.

I feel extremely disenchanted the more I find out about how records have been destroyed in a deliberate attempt to deny donor-conceived people access to information about who they are.

There are several rights enshrined under the United Nations Convention on the Rights of the Child which are currently not being upheld due to the lack of regulations around donor conception in Queensland, and in Australia more broadly. The child and their rights and wellbeing must be at the forefront of policy-making around donor conception.

Article 3 states that in all actions concerning children their best interests must be a primary consideration and that the States Parties should ensure this. It is thus a responsibility of the Queensland government to ensure that the well-being and best interest of children produced by donor conception are a primary consideration. Donor anonymity harms children. Lack of disclosure harms children. It is not in the best interests of children for them to have their genetic origins erased or hidden. This caused significant distress for myself and a crisis of identity when I found out as an adult because no one considered my well-being when I was a child and the negative effect that donor anonymity would have on me.

Article 7 grants the right to know one's parents and be raised by them as far as is possible. Donor anonymity does not allow children to enact this right as they are denied information about their donor parent and even denied knowledge that this person exists.

Article 8 grants the right of children to preserve their identity and family relations. This is not possible with anonymous donation and denial of access to sibling relations. Unnaturally large numbers of sibling groups also prevents developing meaningful relationships with all donor siblings.

Article 24 ensures the provision of medical assistance and preventative health care. Very limited medical history is given when donors are anonymous and health information is forever evolving. My donor's health was listed as "unremarkable" but this does not incorporate the totality of someone's medical history. There is a history of mental illness in previous generations and occurence of other hereditary diseases that were never recorded and I still do not have the full history. I have been unable to access suitable preventative healthcare because I have been giving the wrong medical information to doctors all of my life. Without knowledge of my siblings we were unable to share medical information and were unaware we had the same medical conditions which meant I did not access surgery to correct a shared congenital defect. I am aware this has affected other donor conceived people in more severe ways such as through missed cancer diagnosis.[1]

Article 29 directs the child to be educated to respect their own cultural identity, language and the countries from which they originate. If it is not mandatory to disclose children's donor status to them and if there is donor anonymity it is impossible for the child to fully realise this right as they are denied information about their heritage. They are denied the ability to create a fully informed sense of identity. I was never given the chance to learn about the other side of my heritage, which other cultures I was from, or the history of my biological father's family as they migrated to Australia.

---

[1] https://www.abc.net.au/news/2015-11-27/donor-dad-tracked-down-by-dying-daughter-backs-id-law-changes/6981982

Mandatory disclosure of donor conception status

- **Recommendation: All people conceived via donor conception should be informed so that this can be done in a safe and controlled environment with appropriate resources and counseling provided.**

Not knowing that one is donor conceived has many negative impacts on the donor conceived person and places them at risk.

There is a significant risk of incest, especially when there are many prolific donors, such as mine, with large numbers of donor offspring. There is no “cap” on how many children can be produced by one donor as this is rather limited to “families” in each individual state meaning one donor can reach the maximum family cap in each separate state and these families can have multiple children each. Not knowing donor sibling identity places one at a significant risk of unknowingly forming a relationship with them. What is often not considered is that donor children will often have their own families one day, this means that there will be a large population of relatives out there with cousins, aunts and uncles not realising that they are related and potentially forming relationships. The lack of a national register makes identifying these relationships even more difficult.

I unknowingly went to university with a donor brother, we were in the same year together. For many years I have unknowingly lived just a couple of suburbs away from a different donor brother and have potentially crossed paths many times. My donor sister grew up in the same suburb as either our biological father or uncle so went to school with either cousins or siblings.

Mandatory disclosure of donor conception status to ensure that donor conceived people are aware if their parents have not told them is vital to upholding the rights of donor conceived people. This protects them from finding out later in life when the results are much more distressing, as I have personally experienced and which is supported by research.[2] It can also ensure that the donor conceived person is given sufficient support and information to process this revelation. I became severely depressed after I

---

[2] Riley H. Exploring the ethical implications of the late discovery of adoptive and donor-insemination offspring status. *Adoption & Fostering*. 2013;37(2):171-187. doi:10.1177/0308575913490496

discovered because I found out through Ancestry.com when I was far from my parents and I did not have the tools and resources to support me. I was lucky to have a good partner to get me through, I worry for other donor conceived people who would not have been as lucky as me in that regard.

Donor conception status has many vital medical implications. I did not realise my sperm donor had a negative blood type, this information was not even recorded on his non-identifying medical records that were provided to me last year. My donor sisters have a negative blood type and only found out during pregnancy when they were at risk of losing their children, one sister denied screening not knowing she was donor conceived. This could have been disastrous. We had all assumed that we would have positive blood types as that was what our social parents had. I have denied screening tests in other health areas based on the medical history of my social father and his family. Now I do not know what my medical history is. I have discovered my paternal grandmother died very young and I'm not sure why and what risk factors I have. My social grandparents lived long lives without hereditary conditions besides bowel cancer, so I have provided my medical history and consented to screening based on this information when it was false. I do not know if there is a breast or ovarian cancer risk in the family. Mandatory disclosure and provision of this information would be in the best interests of donor conceived people's physical health.

<u>Implausibility of donor anonymity in the modern age</u>

- **Recommendation: It would be in the donors best interests to remove donor anonymity retrospectively and into the future so that the revelation of this information is done in a way that protects the donor and donor offspring from disruption and negative mental health effects.**

It is implausible to assume that maintenance of donor anonymity is possible in the modern age with the proliferation of DNA testing for as little as $89 and spitting into a tube. I have matched with hundreds, if not thousands, of people from my donor fathers side on DNA websites. In my case, it was fairly easy with some detective work to go through the public family trees to discover my paternal grandparents and their offspring, two potential donor fathers. With social media it was then easy to find many of the potential donors' close relatives, including their wife, children and nieces.

It is irresponsible to assure donor anonymity when they are likely to be found in a way that disrupts their lives. The donor might not want their donor status disclosed to distant and close relatives. But with little recourse for information through other channels, donor conceived people have very few other options to find the answers that they need and that they are entitled to as basic human rights. This might be the only way to get in contact with the donor which reveals their donor status to a wider range of people than it otherwise would.

A systematic disclosure of information that provides both donors and offspring with access to free counseling resources and information on how to communicate with the other party would be beneficial. This would ensure that both parties stay “in control” of the information. The donor risks his entire family and social circle finding out through DNA testing and the donor conceived person attempting to make contact, when this would be avoided if donor anonymity was removed. This would enable both parties to communicate, make boundaries and parameters for the relationship including if there is to be one or if it is simply just to provide medical information. The donor conceived person then has their right to know their genetic origins upheld and has the answers they need.

At the same time there are many donors who wish to or have consented to contact with potential donor offspring but whose wishes were never carried out by the clinics. Retrospective removal of anonymity also gives these donors the chance for their wishes to be upheld.

Right to privacy Vs Rights of Donor Conceived People

I was conceived by multiple adults making adult decisions about me and my future. The donor was an adult who made the adult decision to donate. My parents decided to accept donor sperm. The clinic staff decided which sperm would be used and decided to tell my parents it was better to keep it secret. The clinics and governments decided to deny my right to even know I was donor conceived, let alone who my biological father was. I know in a lot of cases the staff also decided to destroy medical records so donors could not be revealed at a later date. All of these decisions were made for me, and nowhere have I been considered. Nowhere was my right to know my origins considered by those who brought me into existence. Nowhere were the negative mental and physical health effects on me considered, many of which would have been relieved through removal of donor anonymity and mandatory disclosure.

As I have detailed above, donor anonymity is implausible in the modern age with affordable and widely accessible DNA testing. This privacy no longer exists for donors, whether it is written on paper as something that exists or not. For donors, it is a timebomb waiting to go off until someone they know takes a DNA test. For a donor conceived person, it is much more than that. This information is a fundamental part of who we are and denying that information causes immeasurable distress and hardship. We have a right to know who our parents and siblings are.

Necessity of support and counseling services

- **Recommendation: Provide counseling and support services.**

Discovering I was donor conceived was one of the most difficult things I have dealt with emotionally in my life. This was compounded by finding out at an older age. Parents need to receive proper counseling and information to support telling their children from a young age so that it becomes part of the child's "story" rather than a shameful secret.

I was on hold with Lifeline for two hours waiting to speak to a counselor. I did not know where to look for information about this. My parents were not given any information besides to never tell me. I did not trust the clinic, but I ended up speaking to the counselor there a few times as I felt she was the only one that understood. But she only worked a couple of days a week and was often busy. There needs to be more support available for the people that are created using these procedures. I even feel as though parents who used donor conception should be retrospectively contacted and encouraged and provided resources to help them have these conversations with their adult children. It is a timebomb waiting to go off in these families because they were provided with the wrong information at the time and now do not know how to deal with it.

Limiting number of offspring produced by one donor

- **Recommendation: Limit the number of children produced by one donor and apply this nationwide through comparisons of state registers. Create a central state register to ensure donors do not flaunt mandatory limits by donating to multiple clinics.**

Finding out that one is donor conceived and then finding out that one has potentially dozens of siblings is extremely emotionally distressing. The larger the number of siblings the more overwhelming it is. I was raised to view family as important. I have connected with one half-sister and have developed a good relationship with her, we are similar in so many ways and look alike. I feel sad that we missed out on so much time together, we were robbed of the chance to know each other and form a relationship. I have at least 21 siblings, many of whom I do not even know the names of. It is impossible to form meaningful relationships with all of them even if I wanted to and knew who they were. Limiting sibling numbers would avoid added distress and decrease the risk of other issues like incest.

Currently, family limits apply in each state such that a donor can reach the maximum limit in each state. I would propose that states work together to ensure that these numbers are nationwide as opposed to statewide. My donor's sperm was sent to Adelaide when the NSW limit was reached. This practice can result in an even larger numbers of siblings. A donor registry in Queensland would ensure that states can compare the numbers of children produced by one donor to ensure sufficient genetic diversity and limit the trauma to donor conceived people so that they do not find out they have unnaturally large numbers of siblings.

Each state has different rules when it comes to donor anonymity and the rights of donor conceived people so if Queensland clinics decide to send or import sperm from other states and territories then children born in Queensland may be denied access to that information by other states. This is why I would advocate against international sperm importation and exportation. Importantly though, limits on sibling numbers must apply when sending sperm to other Australian states and to ensure that sperm is only sent or imported from other states and territories which would ensure the same access to information as in Queensland.

Concluding Remarks

Non-disclosure of donor conception status, donor anonymity, lack of a register and access to information and large sibling numbers have all caused significant hardship and distress for myself and other people who are donor conceived. I would implore you to please amend the laws to ensure that future donor conceived people are protected and that their inherent human rights are upheld.

Thank you for taking the time to read and consider my submission. I am happy to be contacted by the inquiry if they need further information. If publishing my submission online please remove my address, email and phone number.

Kind regards,

Alison Jones

[redacted]

[redacted]

[redacted]