

29 April 2022

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

Dear Secretary,

Re: Inquiry into matters relating to donor conception information

Thank you for the opportunity to make a submission relating to access to donor information. I write to you as a donor conceived Victorian who has utilised the Central Registry under the Assisted Reproductive Treatment Amendment Act 2015 and I hope Queensland is encouraged to implement similar legislative reform through this inquiry.

I hope to share my experiences as a donor conceived person who has profoundly benefitted from access to information and contact with my biological kin through donor conception.

I refer to the inquiry prompts:

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

In my personal experience and having spoken to many other donor conceived people, being denied access to information about who you are descended from and as a result being unable to access accurate medical history is a common challenge amongst donor conceived people and the source of feelings of pain, frustration and even a gap in our personal identities in many cases. Prior to reaching out for contact with my biological father/my parents' sperm donor, I felt almost haunted by the knowledge that I could be walking past people I was closely related to in my day to day life without knowing it. Knowing

information about my heritage and the people I had descended from was important to my sense of self, and missing this information whilst knowing that there were files locked away that were about me but I was excluded from felt dehumanising. Since meeting my biological father I've felt a profound and positive shift in the way that I understand myself and a sense of peace in filling in part of my story that I felt to be missing.

It's my opinion that identifying information is of key importance to donor conceived people, is vital for allowing medical history to be shared and that laws can be implemented in Queensland where privacy can be maintained without anonymity. I don't believe that vetoes with penalties are required to protect privacy because current laws already exist where privacy can be enforced if a person deems it necessary and there have been no reported instances of vetoes being breached following the Victorian legislative reform. On the contrary I believe that indicating a need for such vetoes implies that donor conceived people are likely to have ulterior or negative motives for making contact which I feel is unfounded and potentially inflammatory.

b. Access to historical clinical records and implications of retrospectivity;

Prior to making contact through the Victorian central registry, I had undertaken a direct-to-consumer DNA test in 2015. Through only a few emails with cousin matches I was able to identify who my biological father was (although I chose not to reach out at that time out of concern that contact out of the blue may be challenging and not be conducive to a positive response). It's now commonplace for donor conceived people, adoptees and others who have unknown family members to use these direct-to-consumer DNA tests to identify them and historical ideas or promises of anonymity have no bearing on whether or not that's possible. People are already making contact with their donor parents out of the blue and I believe it's imperative that the Queensland government seek to facilitate and support this so that donors and donor conceived people have access to support and resources in making contact, rather than turning a blind eye to what

is already occurring for those who can afford to access DNA tests and those with the time required to research family trees.

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

As mentioned above, these connections are already being made but without any support or counselling. I believe that the Queensland government and the fertility industry owes a duty of care to donors and donor conceived people and that providing services to assist and facilitate connections is the just course of action. However I suspect that support for connecting donors and donor conceived people is something which is not something for which many counsellors are adequately skilled and it would be apt for the government to look into counselling requirements or training provided in Victoria and other jurisdictions.

d. Whether a register should be established; and

In addition to identifying my biological father through DNA testing, I have matched with three donor conceived siblings through DNA testing also. Fortunately the records in Victorian were comprehensive enough that I have been able to identify that we are all linked on the Victorian registry. However we are also aware that it's likely that our biological fathers gametes were exported interstate. Knowing how many siblings I have is a simple expectation that I feel I have been robbed of by the lack of a comprehensive registry interstate. I feel grieved that I'm not permitted to know this information, let alone to make contact with all of my siblings. A registry to provide even the most basic of information to donor conceived Queenslanders is a step toward restoring a level of dignity and autonomy in allowing people to know information where available.

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

As this relates to historical donations (and that anonymity is already prohibited within Queensland in relation to gamete and embryo donation), I suggest that risks and implications on current donor conception practices will be minimal. However a benefit may be that

practitioners are able to glean a greater understanding of the psychosocial impacts of donor conception beyond the short term conception and birth of babies. While donor conceived people are not considered the patients of clinicians, none the less there is a duty of care to the broader family and the person conceived. Facilitating contact between willing parties may provide further insight in to how best to support families who are currently going through fertility treatments or who may utilise fertility treatments using donor gametes and embryos in the future. It is my belief that looking at this as a broader, lifelong picture is in the best interests of not only donor conceived people but also their parents who we could reasonably expect would want to ensure the long term wellbeing of their children. Parenting is, after all, about more than conception and birth but a lifelong bond between people and patients trust clinicians to provide care and information about the process as well as information that may be relevant for their child.

Thank you again for the opportunity to submit my experiences as part of this enquiry.

Kind regards,

Hayley Smith-Williams