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

Dear Secretary,

Inquiry into matters relating to donor conception information

Thank you for the opportunity to provide submissions to this Inquiry. I have made recommendations in relation to the issues being considered by the committee in section 2. These recommendations have been informed by my lived experience as a person conceived via anonymous sperm donation in the 1980s as detailed in 'My Story' in section 1.

1. My story

When I was 27 years old, my brother and I visited our maternal Aunt for afternoon tea. It was a standard affair, with servings of homemade quiche and yo-yos prepared from old family recipes. The conversation stumbled across IVF and our Aunt reflected nonchalantly that my brother and I had been early IVF babies in the 1980s. This was the first time my brother and I had heard that we were conceived via IVF: "That's awesome" I remarked, "we're pioneer babies!" I then asked facetiously, not expecting a positive response, "Is there anything else we should know?". My Aunt's face revealed that there was indeed something else that we should know. She hesitated as she struggled to find the words: "Well yes... your Dad was infertile and you were conceived using sperm from an anonymous donor..."

My memory of the rest of the afternoon is hazy. We were in complete shock – it had been more than 14 years since the death of our Dad, and more than 8 years since the death of our Mum. Both from cancer. We did not expect to discover information about our origins so long after their deaths.

My brother is a detective with Victoria Police, and I am a lawyer: we both have a natural urge to seek truth. We needed answers. Our Aunt had only learnt of our donor conception after our parents' deaths, and the only information she could provide was the name of the clinic where we were conceived. Since that day, my brother and I have been through a roller-coaster of emotions and fact-finding missions as we attempted to uncover information about our genetic identity, as

well as information about why our parents chose to withhold such fundamental information from us.

Fortunately, my brother and I were conceived in Victoria. The IVF clinic which assisted my parents had kept accurate records and the Victorian parliament had enacted legislation to preserve those records in a central government register. In 2017 I applied to Victoria's donor conceived register and was provided with non-identifying information about our donor and 7 half-siblings. Unfortunately, neither our donor or siblings were on the voluntary register.

The Victorian legislation gave me the right to connect with my donor through VARTA; so now I had a choice. Do I reach out to him? What if I disrupt his life? What if I cause anguish for him and his family? Does he even know I or the other siblings exist? Will he reject me? Are there any family medical conditions I should be aware of? I had lost both my parents to cancer at a young age, so my mind turned to hereditary cancer risks...I decided not to reach out immediately and wait until I was emotionally ready.

In June 2021, the decision was thankfully taken out of my hands. My donor had stumbled across one of my half-siblings through an Ancestry.com DNA test and applied to the Victorian register for information about any other donor children. I had found him (or rather, he had found me!) – a doctor from Far North Queensland who was willing to connect. Prior to the DNA test he was not aware that I or VARTA existed.

The importance of knowing my genetic heritage

Since my first tentative email contact with my donor, I have met him and his wife, as well as his sister and her husband (my aunt and uncle). We are in regular contact, and I have greatly enjoyed learning about him and his life. He is in the process of reaching out to my donor siblings through VARTA, and so far, I have had contact with 4 out of 7.

I call my new family my 'bonus family'. Each new member is as lovely and respectful as the next – we often joke that decency must be in our genes! I feel very fortunate to be related to such wonderful people, particularly my biological father who has fostered beautiful connections between us all. The process of genetic discovery and connection with my bonus family has been overwhelmingly positive.

When I started searching for my genetic heritage, my goal was to find medical information, a name and perhaps see a photo or 2 of my donor. I did not expect the process to be so emotionally affecting. Since meeting my bonus family, I have questioned many aspects of my self-identity. I have always been somewhat unsure of myself and struggled with confidence, and now I have come out the other side of this self-discovery process with an almost blinding clarity of who I am and my place in the world. I am confident and centred. I have pieced together the web of influence

of my parents who raised me with my new genetic connections. What a beautiful gift the legislation and my biological father have given me.

My bonus family are a welcome *addition* to my story; they do not replace or detract from the family that raised me. This is an important point to make, as I am aware that many recipient parents fear their child connecting with their biological family. I would have loved to have had the opportunity to discuss my donor conception with my parents, and particularly, to reassure my Dad that I still loved him dearly. Unfortunately, the culture of secrecy which began at my conception, and that was perpetuated for decades by my parents, IVF clinics and legislative inaction prevented me from having that important conversation with my Dad.

Redressing a culture of secrecy

In the months after learning of my donor conception, I found it difficult to understand how my parents, who had been very open with us through our childhood, could lie to us about something so fundamental to our identity. I struggled to reconcile this with my memories of loving, caring and progressive parents.

With time, I have accepted that my parents were likely to have followed the advice of their treating physicians which was common at the time of my conception in the mid-1980s: your children do not need to know; they need to be protected from knowing about the nature of their conception; they will never be entitled to identifying information about their donor. This advice created a culture of secrecy which still permeates the Australian IVF industry and influences the decision of many recipient parents to not inform their now-adult children of their origins.

In Victoria, I'm aware that many recipient parents and donor conceived persons had approached clinics for information prior to the legislative change. Many of these people were told that the records never existed, were destroyed or lost, or that the person had no right to access those records. *Note*: at times these statements were later proved to be inaccurate when clinics were compelled to handover donor records to the central register. For many of those recipient parents and donor conceived persons, this was the end of their search. Indeed, for some recipient parents, the knowledge that their children could never access identifying information was enough reason to continue keeping the secret of their genetic origins.

Despite the change in Victorian law, many donor conceived persons and recipient parents are unaware of the change in accessibility of donor records. Moreover, many are unaware that historic claims made to them by IVF clinics (i.e. that records had been destroyed, lost or non-existent) may be inaccurate.

The Queensland parliament has the power to redress this culture of secrecy (which also existed and continues to exist in Queensland) through legislation as detailed in my recommendations in section 2 below.

2. Recommendations for legislative reform

I have considered the 6 issues outlined in the Inquiry Overview and make the following recommendations for future legislation which addresses these issues:

- i) All donor conceived persons in Queensland, irrespective of when they were conceived, should have the right to access identifying information about their donor
- ii) All gamete donors who donated to Queensland clinics, irrespective of the time of their donation, should have the right to access identifying information about their biological children
- iii) All donor conceived persons in Queensland, irrespective of when they were conceived, should have the right to access identifying information about their donor siblings
- iv) Contact between donor conceived persons and their donor or donor siblings should be by mutual consent, with protections available for any person who does not want contact. This ensures that privacy can be protected whilst lifting the veil of anonymity
- v) All fertility clinics or medical professionals in Queensland that practice or have practiced donor conception should be required to handover all historical records to a governmentcontrolled donor conception authority as a matter of urgency. The records should be checked by the clinic for accuracy where possible. This obligation should attract penalties for non-compliance
- vi) That the donor conception authority referred to in recommendation (v) establish a donor conception register
- vii) Once the donor conception register in (vi) is established, the donor conception authority should be required to commence outreach services to all donor conceived persons with donor records. Outreach services should involve notification of the existence of donor records, and notification of the right for donor conceived persons and donors to access identifying information and make contact through mutual consent. Counselling should be available to donor conceived persons, and to their recipient parents so that they may be counselled on the updated advice and research which confirms the importance of genetic origin information to donor conceived people.

This submission may seem controversial. However, the increasing popularity of Ancestry.com and other DNA testing sites shows that anonymity can no longer be assured. It is preferable that donor conceived persons learn of their genetic history with counselling services available

viii) That independent counselling services be freely available to donor conceived persons, donors and recipient parents, and

ix) That costs for the above proposals should be mostly covered by the Queensland Government, with the potential for also collecting a special levy from IVF clinics.

Should you have any questions or would like to discuss any aspect of my submission, please do not hesitate to contact me.

Yours sincerely,

Cate Smith