

Submission to the Qld Government Legal Affairs and Safety Committee Inquiry into matters relating to donor conception

My name is Cath Grassick. My email is [REDACTED] I live in Canberra with my partner. My partner and I are the parents of donor conceived children born in 2001. I am writing this submission on behalf of my partner and children.

We pursued artificial insemination using donor sperm provided by an accredited, well-known fertility clinic located in Queensland. Our interaction with the clinic occurred through a Canberra based fertility clinic. In 2001 we gave birth to twins. There was no formal advice from either clinic regarding follow on information recording the births to the original providing clinic so my partner reached out to the Queensland clinic to advise them of the births for their records. At the time the clinic advised that they were only aware of births if people contacted them, and that they had no formal arrangements in place between centres to capture this information. At the time we thought this odd wondering how anyone would formally track the number of donor conceived children attached to a donor and more importantly how information would be tracked for later advice to donor conceived children to enable contact or finding important medical information if required.

When the twins reached the age of 18, when (according to the existing NHMRC guidelines) they had a right to identifying information about their donor, we reached out to the clinic but were advised by the clinic that it was impossible to provide this information. This surprised us as we had previously connected with another parent (through social networks realising same donor had been used) who had used same donor sperm many years previously. She had been in contact with the Queensland clinic and had been told that the donor had agreed to contact once the children were 18. We have maintained a relationship with this parent and her donor conceived son, who is technically a half sibling to our twins albeit 20 months younger.

We continued to persist, and were advised to fill out a number of forms and a statutory declaration and provide a letter from the Canberra clinic confirming my partner was a patient. Once we submitted the requested documents we were again advised by the clinic that it was impossible to provide the information. It was so confusing and distressing and we didn't understand why they requested all the documents from us. When we queried as to why, the clinic advised that our donor had donated before 2004, and therefore he would not have provided consent. We pressed the accuracy of this information given the information provided by the other parent (that she had been advised that he had agreed) and then the clinic said they had in fact been unable to contact the donor. It turned out he had, in fact, given consent, but because his location had changed in the 20 years since donating, the clinic said they were unable to follow up and find him. The clinic refused to provide any details about their efforts to contact the donor. While the clinic would not provide details of any searches they made, they finally provided information that there was a total of 20 offspring from the donor, and provided gender and dates of conception based on their information.

The clinic consistently refused to provide information to us including clear advice re any governance outlining their policies. Contacting them can only be described as 'pulling teeth'. Numerous emails had to be sent to obtain an answer. No information was ever offered until specifically requested. This included non identifying information such as number and age of siblings which is legally required to be provided. This process was confusing and distressing for our family and at many times we felt helpless to prosecute our issues with the clinic.

We have now found the donor and connected successfully using DNA Ancestry tests. The donor advised that while he has updated his details with the clinic we have not been separately advised by them that they had the updated details to pass on. The donor also confirmed that he had updated his consent details many years previously but it appears the Queensland clinic was unable to accurately recall/administer this record.

Since this contact the clinic in question has provided some updated information re other half siblings seeking contact however the information is intermittent and unless we follow up we do not get updates regarding where the process is up to ie our contact details being passed on or any queries from the other donor conceived person. We feel the clinic while representing themselves as a gatekeeper is not providing much confidence for us to feel they are being rigorous with their procedures and record keeping. This includes clear governance, auditable records and systems and clear handover and training procedures for incoming staff.

My partner and I are extremely grateful for the ability to pursue medical assistance that led to our children being born. We do understand medical and privacy concerns for all those that participate but feel there needs to be greater access to both non identified and identifying information and better regulation of medical clinics that wish to operate (and profit) in this realm. It is important that there is better collection of medical information and for that information to be available at any time from pre conception and onwards for DCP and their guardians (if under 18). For example through contact with the donor we have accessed more medical family history which is invaluable for managing and monitoring medical conditions of our children (especially for our children as they progress into adulthood and consider their own relationship connections). This includes cancer diagnosis in grandparents, mental health conditions and scoliosis diagnosis in the donor.

Since contact both our children and ourselves feel much more complete in being able to fill this hole that has existed in our family for years. We always knew our donor was a wonderful and generous person that allowed us to complete our family and now we have connection willingly to the other half of our children's genetic picture, history and promising future beneficial relationships.

We hope this inquiry will provide greater protections for DCP including the right to access all relevant information related to their genetic and medical history. We also believe that there should be a government regulated system similar to that established in other States to allow DCP to register and connect with half siblings. Allowing private corporations to hold information without proper oversight creates unnecessary barriers and interferes in basic human rights. Any legislation should also consider the importance of formalised recording of offspring if donor material is provided interstate.

If required I am happy to provide further information to the Inquiry.

Cath Grassick

