

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

Submitted by: Carolyn Fox

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Submission to the Queensland Parliament's Legal Affairs and Safety Committee Inquiry into Matters Relating to Donor Conception Information

**Prepared by Carolyn Fox
BSW (JCU)**

To the Committee,

Thank you for the opportunity to submit to the Inquiry.

I am a recipient parent of a donor-conceived child and am also a fully qualified social worker (Bachelor of Social Work from James Cook University) and Commissioner of Declarations.

I have over forty years of experience as a Social Worker, particularly in the area of adoption, fostering and child protection. I have been an adoption assessor of applicants for adoption and a support counsellor for adoptees seeking information about, and contact with, biological parents and siblings. As such, I am well versed regarding the issues surrounding a child's need to know their genetic origins and the psychological and emotional issues attached to this need.

When I chose to conceive a child through donor conception, I attended a well known fertility clinic in Brisbane in 1990, later giving birth to a daughter. I was not required at any stage to confirm the live birth of my donor-conceived child to the clinic for record keeping purposes. I have, over the years, tried to answer my daughter's questions and address the issues impacting upon her as a donor-conceived person, questions and issues typical of most people that have been donor-conceived, adopted or who do not know their biological parents.

When my daughter was in her late twenties, she and I attempted to find out identifying information about her biological father, along with whether she had donor-conceived siblings. The fertility clinic in Brisbane however, refused to give us any information and this led to over a year of frustration and emotional turmoil for my daughter. As a consequence of this lack of information disclosure by the clinic, my daughter and I were led to explore other ways to discover my daughter's genetic origins. Through using commercial DNA testing and internet searches, my daughter was able to finally identify her paternal line and who may be her father. She then received information from the clinic, that they had contacted the donor and that he was willing to have contact. We have all since met and kept in contact. The donor has advised us that he had provided consent for contact to the clinic years prior to my daughter and I seeking information but despite this, they had not provided this information to my daughter upon her request.

Since learning of her father, my daughter has been able to release the sense of powerlessness she has felt of perhaps never knowing who her biological father is. She has also learned about the medical conditions she may be predisposed to. My daughter has expressed to me that she now feels much more 'complete' as a human being as she knows where she 'comes from'.

Commercial DNA testing also enabled my daughter to find a donor-conceived sibling. This information was inaccurately conveyed by the clinic who at first advised that there were no siblings born of the same donor, later advising that there was one. The sibling found through DNA testing was not the same person as that identified by the clinic. There are two donor-conceived siblings, one known and one unknown. However, due to a lack of record keeping, this number could be significantly higher.

With regard to the issues on donor conception being put to the Legislative Assembly for Queensland by the Legal Affairs and Safety Committee, I would like to address the following:

a) The rights of donor-conceived individuals, including to know their genetic origins

All children should have the right to know their genetic origins - to know where they come from. This is reiterated in the United Nations *Convention on the Rights of the Child* (1990) and in the UN Principles for Donor Conception and Surrogacy (2019). It is also stated in the Queensland *Human Rights Act 2019*.

Much research strongly indicates that every human being needs to know their genetic origins in order to develop a sense of identity. My professional, as well as personal experience also supports this research. Current practices around donor conception in Queensland do not support the rights and needs of donor-conceived individuals. Although there are guidelines around best practice, in actuality, efforts to protect donors' anonymity have meant that such guidelines have not prioritised the best interests of the donor-conceived person and actively discriminates against the right of donor-conceived people to know their origins. Additionally, anonymity regards the donor denies donor-conceived people the right to know if there are many medical conditions they may be genetically predisposed to.

The only information I and my daughter received over the years in regards to the donor was his hair and eye colour, his blood type and his education level.

b) Extent to which identifying information about donors should be given to donor-conceived persons

- Parliamentary laws and regulations must be in place to protect all parties with regard to donor conception practices. As in adoption legislation, all parties must have legal right to information release.
- Under the current Guidelines, donors are able to state their willingness to contact, but it is clear given my daughter's experience, that even where donors update contact details

and provide their consent to be contacted, clinics are refusing to give identifying information, preferring to obfuscate and deny donor-conceived people such information.

- Donor-conceived people cannot currently be given any information at all, without the written permission from the recipient parent. I personally, as a recipient parent, had to provide this permission for my daughter to ask our clinic for even non-identifying information as the donor code was recorded under my medical records. Information relating to their genetic parent and siblings should be reclassified as also being the medical records of donor-conceived people and they should have access to this without requiring recipient parent consent.
- Donors must be advised that identifying information may be sought by any children conceived through their donating and that is a right of those people.

c) Access to historical clinical records and implications of retrospectivity

- Donors have always been assured of anonymity by clinics, but this supersedes a child's best interests and the right to know their origins. A child's best interests are served by their knowing who their biological parent/s are and their genetic background for developmental, psychological, emotional and medical reasons.
- Donors decide to create human life by their actions and should take responsibility for how that human life develops. Although donors' rights to privacy need to be respected, it is a basic human right for all people to know their origins. Social justice principles around fairness, as well as research into human development confirms this.
- Additionally, as many donors donate numerous times, the risk that donor-conceived individuals may meet and form romantic relationships without knowing they are closely related, or in fact donor-conceived at all, would not only break social taboos/mores, but mean that any child ensuing could be genetically compromised.
- Valid and effective statutory regulation enabling the retrospective release of identifying information is necessary, despite the fact that past record management practices have not been consistent nor carried out with consideration to retrieval to assist donor-conceived individuals.
- Clinics must be approached to submit their records on the donor, both non-identifying and identifying, as well as information relating to recipients and confirmed births (i.e. siblings). As is evident from past and current practices, guidelines are not sufficient in ensuring clinics responsibly manage this information. Historical records and identifying information must be held in secure perpetuity so no information is lost and there needs to be legitimate consequences for clinics who do not provide this information where it exists.
- Retrospectivity must be handled with sensitivity, with all parties being aware of the issues/implications that may arise.

d) Access to support and counselling for donor-conceived persons and donors

- Support and counselling needs to be available for all parties involved in donor conception, including the families of the the donor and donor-conceived, as life changing issues will arise and human feelings, emotions and actions are complex.
- Research, as well as my own experience, especially in the area of reunification of adoptees with their biological families, strongly indicates the need for support and counselling to be available to all parties.
- This support must be provided by professionally qualified and experienced workers.
- Counselling must be voluntary and accessible.

e) Whether a register should be established

- The donor conception process needs to be managed and overseen by a central body/register backed by laws and legal processes.
- Queensland has only ever had guidelines to the whole process that have been subjectively interpreted and managed, and often not observed, leading to a hodgepodge of decisions and actions that do not meet the best interests of the people the system aims to create.
- Donor conception is also offered by a range of clinics that have differing policies, procedures, and business models which include differing information management practices. Donor information is not collected or stored securely for potential retrieval and has, in many cases, been lost or destroyed. There is certainly no predetermined mandate by clinics to protect information on behalf of donor-conceived children.
- An independent body which is statutorily responsible for enacting the laws and regulations around donor conception is needed, including the provision of identifying information, as well as support services for all parties involved.
- All clinics involved in donor-conception must be legally required to lodge with the register, information on donors and the children conceived by donor conception, as well as recipient parents, so that records and information can be kept securely stored in one place in perpetuity.
- The register needs to prioritise the best interests of the people conceived and their rights to know their origins.
- The register would manage and oversee donor-conceived individuals' requests for identifying information and facilitate contact, taking into consideration the rights of the donor-conceived individuals to information.
- A register would place responsibility upon clinics to provide due care and diligence and ensure that all relevant information can be properly collected, stored, and retrieved,

avoiding possible loopholes that may be used to deny donor-conceived people information and ensure that the process is transparent, above board, and timely.

- Donor-conceived individuals are likely to have siblings and may be interested in knowing who they are. A register should also be responsible for linking information so that siblings are able to identify one another and where all information about a particular donor and resultant offspring can be recorded together.
- The register could also be responsible for following up on births of donor-conceived children with recipient parents and/or governmental records to facilitate a full and comprehensive record of all donor-conceived births. As it stands currently, recipient parents are not required to report live births to clinics or any other body, resulting in incomplete records and the facilitation of secrecy.

f) Benefits, risks and implications on donor conception practices arising from any recommendations

- Legislation requiring donor-conceived individuals to be given identifying information on their donors would mean that donor-conceived individuals' rights would be met and their best interests served. Their best interests would be paramount, as is the case for all other children in this country.
- Donor-conceived children will be better able to form their own self-identities, resulting in an improved capacity to grow and develop into well-rounded human beings.
- A system and processes that are legally mandated will be in place and this will ensure proper record keeping practices as is in place with all other medical records.
- Donor-conceived individuals will have access to medical information that will advise them of any medical, physical and psychological conditions they may experience.
- A statutory body/register for donor-conceived people which oversees the whole process of donor conception as well as information collected from clinics and the provision of support and donor-linking services would require state/federal funding and relevant auditing and oversight.
- Queensland as a state will have 'caught up' with other Australian states and has the opportunity to learn from the changes made in other states to establish a system that operates in line with evidence-based best practice.

Thank you for considering my submission.

Regards

Carolyn Fox