



29 April 2022

## **Submission by Donor Conceived Aotearoa to the Inquiry into matters relating to donor conception information (Queensland)**

### **1. Introduction**

#### **1.1. About Donor Conceived Aotearoa**

Donor Conceived Aotearoa (DCA) is an advocacy group representing donor conceived New Zealanders. DCA's goal is to ensure the needs and experiences of New Zealand donor conceived people are considered and supported in all aspects of legislation, policy and practice reform relating to donor conception in New Zealand. DCA aims to help shape New Zealand into a world-leader in rights for donor conceived people, which includes ensuring existing rights and protections for donor conceived people are maintained and improved wherever possible.

DCA is currently working with Births, Deaths and Marriages New Zealand and fertility clinics on matters relating to challenges associated with implementation of current legislation and areas for improvement. DCA also educates current and prospective recipient parents worldwide through DCA's public Instagram account (@donorconceivedaotearoa).

#### **1.2. Rights of donor conceived people in New Zealand and applicability to Queensland and Australia**

Australian and New Zealand donor conceived people share many of the same challenges relating to current and historical practices around donor conception and access to information. DCA considers supporting improvements to rights for donor conceived people in Australia, especially relating to rights to information, as a significant and complementary cause alongside DCA's New Zealand based advocacy. Sophie Turner, the author of this submission on behalf of DCA, is a Queensland-based donor conceived person from New Zealand.

Furthermore, the experiences of donor conceived New Zealanders due to the introduction of the then world-leading *Human Assisted Reproductive Technology Act 2004* (HART Act) and the lessons from the operation of this act, particularly in relation to registers and information for donor conceived people, are critically relevant to the considerations of this Committee in relation to the Inquiry.

#### **1.3. DCA's request to the Committee**

In relation to the Inquiry into matters relating to donor conception, DCA requests the Legal Affairs and Community Safety Committee (the Committee):

- **Consider** DCA's submission, including DCA's views on issues relating to access to donor conception information (refer section 2).

- **Note** DCA's support for submissions from Donor Conceived Australia, which DCA considers to be the peak body for donor conceived people in Australia.
- **Provide** DCA's Queensland-based member, Sophie Turner, with the opportunity to present to the Committee on this submission.

## 2. Issues relating to access to donor conception information

DCA provides the following comments for the Committee's consideration.

### 2.1. Rights of donor-conceived persons, including to know their genetic origins

Rights of donor conceived people internationally have historically been overlooked, or de-prioritized, in favour of the objectives (and misattributed 'rights') of fertility clinics and recipient parents. The most fundamental of these rights is the right to know their genetic origins. DCA believes the right of donor conceived people to know their genetic origins is not only about a donor conceived person's ability to access to basic information regarding genetic parents and other family members, but also about enabling donor-conceived people to connect with their genetic family members and their genetic heritage more directly.

New Zealand's establishment of both a voluntary register (for records relating to conceptions before the introduction of the HART Act) and mandatory register (for those after the Act's introduction) were important positive steps in improving the rights of donor conceived New Zealanders; however, both registers have limitations relating to effectively linking donor conceived people to their genetic origins.

DCA also notes that rights of donor conceived people also include the right to be described in terms supported by donor conceived people. This includes ensuring language in policy and legislation is people-centered and avoids positioning a donor conceived person in dehumanising (e.g., "product of donor conception" or "offspring") or infantilizing terms ("donor baby", or "donor child").

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

Donor conceived people should have access to as much information regarding their genetic parent via donor conception as feasibly possible – at a minimum, that is all information that has been recorded regarding their conception and information that allows donor conceived people to connect with genetic parents and family members.

The choice by a donor to donate, even under supposed 'conditions' of anonymity, or recipient parents' choice to conceive using a donor, should not supersede the rights of donor conceived people to information. Donors and recipient parents have choices (even if it appears limited) whereas donor conceived people are afforded no such choices. The rights of donor conceived people to information must therefore be central to all decisions, to address this lack of choice.

The Queensland Government must ensure donor conceived people's rights to know their genetic origins remains at the forefront of policy and legislation development in relation to donor conception. This focus will ensure mandatory data collection and reporting requirements and processes provide future donor conceived people with the basic information they need regarding their genetic parents and

siblings (including but not limited to medical histories) as well as means of connecting donor conceived people directly to genetic parents and siblings.

### **2.3. Access to historical clinical records and implications of retrospectivity**

The same principles outlined in section 2.2 apply - Donor conceived people should have access to as much information regarding their genetic parent via donor conception as feasibly possible – at a minimum, that is all information that has been recorded regarding their conception and information that allows donor conceived people to connect with genetic parents and family members. The choice by a donor to donate, even under supposed ‘conditions’ of anonymity, or recipient parents’ choice to conceive using a donor, should not supersede the rights of donor conceived people to information. Donors and recipient parents have choices (even if it appears limited) whereas donor conceived people are afforded no such choices. The rights of donor conceived people to information must therefore be central to all decisions, to address this lack of choice.

Unfortunately, it is well known that many clinics in New Zealand, Queensland, and Australia lack historical clinical records because of willful destruction, loss through negligence, or never having created them in the first case. New Zealand’s HART Act, which introduced mandatory reporting requirements to a government register, should be applauded for its prevention of these practices continuing for as long as they have in Queensland and Australia.

In the sad but common case where no information exists regarding a donor, clinics must proactively identify and provide available clinical records relating to a donor conceived person’s conception even if they seem inconsequential.

As outlined in section 2.2, the Queensland Government must ensure donor conceived people’s rights to know their genetic origins remains at the forefront of policy and legislation development in relation to donor conception. This focus will also ensure retrospective data collection and reporting requirements and processes provide current donor conceived people with information regarding their conception that could support donor conceived people to connect directly to genetic parents and siblings. This would include avenues for new information to be collected and reported (not only from donor conceived people, but also from donors, siblings of donor conceived people, and clinics) that may support donor conceived people to eventually access information regarding their genetic parent/s and heritage.

Examples of information that is of use to donor conceived people, even where identifying information about a donor is not available, may include the number of donors used by a clinic by year, the number of live births, the number of siblings per recipient parent, the numbers of live births by donor etc. Clinics and the Queensland Government also have a responsibility to encourage donors to retrospectively provide information that may have been lost, destroyed, or never recorded.

### **2.4. Access to support and counselling for donor-conceived persons and donors**

Support and counselling should be available to donor conceived people when they are embarking on either attempting to uncover their genetic origins or ahead of meeting a genetic parent, parents, or siblings. Similar support and counselling should also be made available for donors and their families, and recipient parents and their families. Fertility clinics, who make significant profit from donor conception,

should be responsible for providing ongoing funding for counselling and specialist support services delivered independently of clinics but under the oversight of the Queensland Government.

Significant improvements are also required to the support and counselling currently provided to prospective recipients – DCA’s observations of practices in New Zealand fertility clinics and reports from prospective recipient parents indicate that support provided to prospective recipient parents is often insufficient in terms of time and quality, including but not limited to failing to promote the rights of donor conceived people or actively encouraging recipient parents to seek out views and experiences of donor conceived people.

## **2.5. Whether a register should be established**

DCA strongly supports the establishment of a register (or mechanism) for capturing information relating to donor conception and using this information to proactively connect donor conceived people with their genetic origins. The following considerations have been identified based on DCA member’s lived experiences, and DCA’s consultation with the New Zealand government, fertility clinics, and recipient parents:

- The requirements of such a mechanism would be different for the purposes of retrospective donor conception and future donor conception.
- The mechanism would require careful identification and implementation of supporting products, governance, policies, legislation, and funding.
- The need to include interjurisdictional operability and consultation (including with New Zealand) and consistency regarding governance, policies, and legislation should be explored and pursued to deliver the best results.
- A mechanism must be focused on providing donor conceived people with the right to know their genetic origins – if this objective is not kept front of mind, the government is at risk of simply developing a product that can be announced but does not make a meaningful impact on the lives of donor conceived people.
- The Government, not clinics or other third party, is appropriately positioned to lead the development of such a mechanism provided donor conceived people are meaningfully included in its development, including being represented in governance and decision-making structures regarding the mechanism’ development and operations.
- A well developed and implemented mechanism may make Queensland and Australia a world leader in the rights of donor conceived people.

## **2.6. Benefits, risks and implications on donor conception practices arising from any recommendations**

In addition to the information provided above, DCA also provides the following comments on the matters outlined in the Inquiry for the Committee’s consideration:

- *Views and experiences of donor-conceived people, donors and industry stakeholders of the current framework:* DCA reminds the Committee of the historical and existing imbalance in rights for donor conceived people in favor of donors and industry and the lack of choice donor

conceived people have in their conception. DCA asks the Committee to consider the need to ensure views and experiences of donor conceived people are centered in this discussion.

- *Current governance/regulatory frameworks, including registers established interstate:* The Committee should consider New Zealand's HART Act and its voluntary and mandatory registers as part of its Inquiry. Births, Deaths and Marriages New Zealand (BDM) should also be consulted regarding their lessons from operating the registers. DCA has found BDM to be a professional, empathetic government agency who are willing to share lessons and opportunities relating to the registers they maintain.
- *Options to manage collection, storage, and disclosure of identifying and non-identifying information about donors, donor-conceived persons and relatives:* Refer comments provided in section 2.5. Particularly note that a mechanism must be focused on providing donor conceived people with the right to know their genetic origins – if this objective is not kept front of mind, the government is at risk of simply developing a product that can be announced but does not make a meaningful impact on the lives of donor conceived people.
- *Whether and how to collect and disclose identifying information about donors where a donation was made on the condition of anonymity, including matters relating to consent:* Refer section 2.2 and 2.3. The Committee should also consider whether 'anonymity' is a condition that could ever be ethically agreed, given donor conceived people (who suffer the greatest negative impact from it) are not able to consent to it when the agreement occurs.
- *Whether any model should include information from private donor arrangements.* A mechanism, which would include a range of supporting products, governance, policies, legislation, and funding, should provide functionality for private donor arrangements. Such a mechanism could also feasibly include support and connectivity for other people who have experienced genetic severance, including adoptees.
- *Costs of any proposal including to establish and maintain any register and options for efficiencies, including a user-pays model:* Clinics profit from donor conception and should therefore contribute to the funding for the establishment and ongoing management of a mechanism and the supporting counselling. However, reluctance or avoidance by clinics to contribute should not be used as an excuse by government not to pursue this reform.
- *Whether regulating donor conception practices and assisted reproductive technology should also be considered as part of establishing a donor conception register; and human rights engaged under the Human Rights Act 2019:* regulation of donor conception practices and assisted reproductive technology in Queensland would help prevent practices which currently limit the rights of donor conceived people to access information regarding their genetic origins. For example, the HART Act has made it almost impossible to conceive using imported gametes in New Zealand – this has prevented many of the challenges experienced by donor conceived people conceived in other jurisdictions (including Australia) using imported gametes. These donor conceived people are far less likely to be able to connect with genetic family and the protections (e.g., sibling limits, health of donors etc.) are unable to be effectively enforced by Australian jurisdictions. However, DCA stresses that proper development and implementation of a mechanism can occur ahead of or in parallel to regulation of donor conception practices. The Queensland Government should not let claims by others that full reform is needed be a barrier

to progressing the development of a mechanism, noting work on regulation is still recommended.

### 3. Conclusion

DCA strongly believes that a government sends a powerful signal regarding their compassion and values when they choose to address inequity. A government commitment to improving the rights of donor conceived people in Queensland through the development of a mechanism that provides access to information regarding their genetic origins would send this signal. It may not be easy, there may be further risks and implications to considered, but the work must start with a commitment from the government to try.

DCA wishes to thank the following bodies:

- The Committee for their consideration of submissions, particularly from donor conceived people and related advocacy groups.
- Donor Conceived Australia for their ongoing partnership with DCA and other advocacy groups in the fight to improve the rights of donor conceived people.
- BDM New Zealand for their professionalism and empathy in consultation with DCA. DCA did not consult BDM on the development of this submission and their views are not represented here, however their willingness to meet with DCA, listen to our concerns, and provide us with meaningful pathways for further consultation and issues resolution has been greatly appreciated.

DCA looks forward to the opportunity to present in person to the Committee and answer any questions Committee members may have regarding the opportunity presented by this Inquiry.

Thank you

Sophie Turner (donor conceived person and Queensland resident) on behalf of Donor Conceived Aotearoa