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28/04/2022

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**RE: Inquiry into matters relating to donor conception information**

To Whom it May Concern,

First, I would like to thank the Queensland Parliament for their consideration of donor-conceived Queenslanders' rights to access genetic information about their donors, and thus, about themselves. I, Caitlin Macmillan, have conducted, and continue to conduct research on the implications of donor conception on members of the donor conception community and take this opportunity to share the importance of legislation that supports donor-conceived people, including information access equality, as demonstrated in the academic and grey literature. I support legislation that promotes information access to donor-conceived people, and their descendants, irrespective of conception method, data, and location.

## Overview

The current lack of legislation relating to donor conception in Queensland fails to acknowledge the prevalence of the practice, and the challenges that some donor-conceived people face. Donor conception, and legislation relating to donor conception, effects a large number of people. There is also a cohort of people not yet aware of their donor conception status, who are yet to navigate the complex Queensland framework for information, and who do not yet have a voice.

## Upholding the United Nations' Rights of the Child

Legislation would facilitate, and retrospective abolishment of donor anonymity would go some way to fulfil, the United Nations Convention on the Rights of the Child, specifically articles 7 and 8. The current Queensland framework is unable to fulfil these Rights.

## History

Donor conception has a long history spanning generations and as such, legislation has an intergenerational and far-reaching effect. The practice has been successfully used since at least 1884 (Gregoire & Mayer, 1965) and physicians and non-medical professionals (e.g., psychologists) offering donor conception services since 1915 (Bartholomew, 1958; Barton et al., 1945; Davis, 2017; Gregoire & Mayer, 1965; Hühner, 1938). The industry has been shroud in secrecy; the first conception was a secret, kept even from the impregnated woman, and clinics were run in sercrect. The rogue and secretive practices set the scene for a culture detached from accountability.

Legislation would finally recognise the wider implications of donor conception, particularly on the person born as a result, and promote a transparent donor conception culture that supports the offspring, their rights, and their needs.

## Prevalence

The prevalence of donor conception, and thus donor-conceived people, has increased exponentially. In Australia, there is an estimated 20,000 to 60,000 donor-conceived people (Allan, 2010; Horler, 2015; Purtill, 2016), but the historical lack of record keeping and low disclosure makes it impossible to confirm. Current records suggests 1,045 donor-conceived people were born in Australia in 2020 (Newman et al., 2021). This estimate however does not account for recipient parent' use of unregulated donor conception methods, such as travelling overseas, recruiting private donors, or purchasing gametes online and conducting home inseminations. Further in Australia, unreported pregnancies after donor treatment have been inadvertently discovered (Marriner, 2016).

Once an invisible, hidden population, donor-conceived adults are beginning to identify themselves in large numbers. This is due to non-disclosing parents choosing to disclosure, and donor-conceived people learning their conception history independent of their parents. Common methods include Direct-to-Consumer DNA testing, reading parents' documents or a journal that revealed donor conception, figuring it out based on lay understanding of genetics, or being told by a non-parent (Crawshaw, 2018; Harper et al., 2016; Macmillan et al., 2021). The prevalence of donor-conceived people being told their conception history by someone other than a parent is unsurprising given the high prevalence of recipient parents disclosed to others without disclosing to their child; studies have found this to be 50 to 85% of parents (Braverman et al., 1998; Cook et al., 1995; Golombok et al., 1999; Leiblum & Aviv, 1997).

## Limitations of the current Framework

For donor-conceived Queenslanders who discovered their conception independent of their parents, current frameworks based on NHMRC guidelines, does not afford them the same opportunities to information as their donor-conceived peers. Donor-conceived people who discovered their conception history independent of their parents may not be comfortable sharing their discovery with parents (Daniels, 2020), or their parents may be unavailable (estranged or deceased), or unwilling to facilitate information access (i.e., provide the name of the clinic used) so that donor-conceived people can progress their journey in accessing information, should they want to. Reliance on parents being available and forthcoming with information places a burden on older donor-conceived people whose chances of having a parent pass away, unavoidably increases. A central registry with information allows donor-conceived people to navigate and take ownership of their journey and the information that is made available and removes parent-based restrictions. An example of discrimination within the Framework against donor-conceived people whose mother is unavailable or unwilling to facilitate information access can be demonstrated in Queensland Fertility Group's policies (2018) in which for a donor-conceived person to access information they required their mother's written permission. In the event that her permission could not be obtained, neither could information.

The NHMRC guidelines recognise the importance of information access, but are unable to support donor-conceived people, their families, or the clinics. NHMRC provides no instruction and there is no consensus on what information should be collected by clinics, how long it should be kept for, how it should be stored, or who it can be access by and how. This makes it difficult for clinics who must negotiate donor-conceived peoples' rights to information, within current and/or historical policies and practices, that may have superficially promised of anonymity and/or lacked record keeping or maintenance, and who have prioritised the mother, their patient. Further, the current framework cannot assist people conceived at a clinic that has since closed or been sold, in which case the 'owner' of the records may not be the clinic. In the event a clinic is no longer operating, donor-conceived people's ability to access information is rendered almost, if not, impossible. This is highly probable considering as of June 2002, according to Wendy Edmond, former Minister for Health Queensland, no donor conception procedures were conducted in public hospitals. Thus, records were privately managed at the discretion of the clinic or treating clinician. Based on submissions made to the interstate enquiries on the matter, there are suspicions that retired physicians have resorted to storing files on their private property. However, there is no evidence to confirm or deny these claims.

## Benefits of a register and retrospectively abolishing anonymity on current donor conception practices and disclosure

Donor-conceived people (and parents acting on their child's behalf) who have attempted to access information without the availability of registries describe a difficult and sometimes traumatic experience that is rife with inconsistency (Adams & Lorbach, 2012). The outcome of information seeking can vary depending on when a clinic is contacted and who takes the call. That can mean being told there are no records, only to learn upon another attempt that there are, or receiving some non-identifying after one enquiry, only to receive incompatible information at another (Adams & Lorbach, 2012).

Donor-conceived people, especially those who discover their conception later in life, or who only become interested in information later in life, need to be able to access records after a considerable amount of time. So too subsequent generations. Many recipient parents underwent treatment when paper records were kept, which are vulnerable to degradation and destruction. A centralised register will offer immortalisation. Without it, additional cases of record deterioration (as has been reported for some Prince Henry's records) or destruction (as confirmed as occurring at the Royal North Shore Hospital after an internal investigation) may transpire.

Current legislation will offer central, accessible and sustainable storage of information and record protection that the current Queensland Framework cannot. Legislation offers policy and practice standardisation with accountability and consequence for non-compliance.

## The benefits of a registry and retrospective abolishment of anonymity on current practices and disclosure

Parents who use unregulated methods of donor conception are difficult to include in registries. However, the development of a registry may entice prospective into using local donors through regulated clinics, as opposed to resorting to unregulated methods. Regulated methods operating alongside a national registry will afford their children and future generations easy access to genetic information, and potentially genetic relatives. In theory, it should also facilitate disclosure since a common reason given by non-disclosing parents is the inability to provide genetic information (Cook et al., 1995). Research suggests that parents are motivated to provide, or facilitate access to, information to support their child's identity development and satisfy their curiosity (Freeman et al., 2009)

## What does the Australian literature say?

A registry aligns with the interests of many donor-conceived adults represented in academic literature. In an investigation of 69 donor-conceived Australian adults, all born when infinite donor anonymity was assumed, and surveyed prior to Victorian legislation removing anonymity, 88% were motivated to seek information about their donor. Notably, this was not synonymous with wanting contact; 71% were interested in contacting their donor. The most common reasons for each were consistent: wanting medical information, to address gaps in identity, and curiosity. All of which are pertinent to health and wellbeing and will be discussed below. Results align other study findings that included Australian donor-conceived people in their multinational samples (Hewitt, 2002; Jadva et al., 2010; Mahlstedt et al., 2010; Marquardt et al., 2010).

### *The need for medical history*

The ability to access a registry to access genetic information is important for donor-conceived people and future descendants. Removing any anonymity assumptions would allow up to date medical information and two-way relay, some that donors have expressed support for (Rao, 2018; Victorian Assisted Redproductive Treatment Authority, 2017). The implications of not having access to genetic information can be fatal, as shown in the widely reported story of Narelle Grech, a donor-conceived Australian, who died of early onset bowel cancer. Her doctors reported in the media that her cancer was genetic, and her death likely avoidable had her genetic history been available to prompt early screening. This is not a one-off scenario (e.g., Lambert, 2009), and can also have tragic consequences for donor-conceived people's descendants (e.g., Motluk, 2021).

### *The need for identity*

Identity development is a key milestone of human development. It involves integrating information from past, present and future to form a coherent sense of self. For donor-conceived people who are missing information, or uncertain of information, identity development can be disrupted. This can be distressing, and negatively impact adjustment (Burke et al., 2021). A registry offers donor-conceived people the opportunity to obtain information pertinent to their identity, and with additional removal of anonymity, the opportunity to confirm and expand information. Barriers to information access may be contributing to the higher rates of mental health issues that have been found within Australian study samples (Adams 2021, Macmillan 2021), and substance use (Adams 2020), since identity-related challenges in adoptees have also be linked to poor adjustment outcomes (Feast, 2003; Finet et al., 2020; Grotevant et al., 2017; Howe & Feast, 2000; Sants, 1964; Wellisch, 1952). This may also be compounded by the lack of specialised support available to donor-conceived people, which is reflected on below.

### *The need to satisfy curiosity*

The idea that donor-conceived people are curious about their genetic heritage can be viewed as scandalous and met with disdain or criticism (as observed on social media platforms). However, humans are inherently curious and it is what has allowed us to succeed as an innovative species. It’s importance for healthy development, and the long term, negative consequences of its suppression, has been well-established (Piaget & Cook, 1952)

## Donor perspectives

Fertility clinic’s operated under the assumption that anonymity was in the best interests of the all parties involved (parent, donors, donor-conceived people) and was necessary in order to attract donors. These assumptions have been shown to be incorrect (Adams et al., 2016). Nevertheless, infinite anonymity was assumed by all donors, recipient parents, and physicians and the idea of legislation that removes anonymity could make some donors uncomfortable, so too physicians whose assumption or protection of donor anonymity may have meant not maintaining any or some information relating to the treatment. However, it is important to note that some donors, once supportive of anonymity, have changed their mind (Daniels et al., 2005).

In the Victorian 2016 donor conception inquiry, which was highly sensitive to donors’ best interests, and balancing donors’ right to privacy and donor-conceived peoples’ right to information, donor submissions revealed a range of experiences. It was revealed that not all donors were comfortable with anonymity (either at the time of donation and/or currently). In fact, many donors were supportive of legislative change, and open to information release.

This was also been demonstrated in the rate of donor registration to the Victorian voluntary register in which donors outnumbered offspring 3 to 1, despite offspring outnumbering donors within the general population 10, 20, 30, maybe even 40 to 1 (given the prevalence of genetic half siblings in some families). It is highly probable that Queensland donors share a similar attitude.

Notably, the current legislative proposals would not be breaching any implicit or explicit anonymity agreements since offspring did not, and could not, consent to any such arrangements, and no such arrangements can be made on a prospective person's behalf. If clinics implied donor anonymity from future offspring, this practice was misleading and should not be at expense of the donor-conceive person or their descendants.

## Clinic perspectives

Some clinics may be unsupportive of legislation. In the unfortunately event of this, their reasoning should be scrutinised. It is likely that they will need support in navigating how to contribute information to a registry, addressing enquiries relating to the matter, and adjusting their future practices to allow for data collection and storage that conforms to legislative requirements. It is however possible that their concerns (masked or overt) relate to profitability and/or accountability. Clinics have a substantial financial interested in donor conception practices considering they are a for-profit business. In 2022 the Australian fertility industry's value was estimated at $653 million (IBIS World, 2021). This is expected to rise substantially based on the fertility clinic's reporting an exponential increase in new single patient presentations (Koehn, 2022; Tuohy, 2021). Increased service usage however, also underscores the importance of legislation that supports the people who are to be born from the practices.

## Learning from other states

Queensland is in the fortunate position to be conducting this inquiry after Victoria's similar inquiry and legislation enactment, and after other states developed registries for members of the donor conception community. As such building blocks for Queensland legislation, processes and practices are available that have been thoroughly considered through extensive discussion, negotiation, a scrutiny.

It is imperative that donor-conceived Queenslanders be afforded equal rights, and are not disadvantaged for being conceived in Queensland. Further they should not be discriminated against based on their date of conception, or location of donation, noting that registry development in other states has revealed clinics had engaged in cross-border gamete selling or trading. Such legislation would also align donor conception rights with adoption rights. Adoptees, like donor-conceived people lack genetic information, however adopted people have gained retrospective, largely inhibited access to information which identifies their genetic parents.

It has now been over five years since Victorian legislation retrospectively abolished anonymity and reformed their Central Register. Thus, any concerns raised in relation to the Queensland inquiry into donor conception and suggested legislation can be placated given there has been no evidence of any concerns coming to fruition. Notably, donors and parliamentarians expressed concern that donor conceived people would make undue contact. As such, the Victorian legislation included contact vetos for donors who wished to formalise their unwillingness for any contact and these vetos could offer some comfort to concerned donors under Queensland legislation. However, there has been no evidence in Victoria of donor-conceived people contacting donors who have not expressed a mutual desire for contact, with or without a contact veto in place. This is unsurprising given their use within the adopted community, noting that contact vetos have been removed from adoption legislation, deemed unnecessary.

Some members of parliament, or the donor conception community may suggest the establishment of a voluntary registry as opposed to removing anonymity within a central registry. However, while a voluntary register has operated in Victoria for a considerable amount of time. The Victorian voluntary register was described in the Victorian 2016 inquiry as being a successful method for information sharing with consent, however, there were several limitations that have prevented a number of ‘matches’ between applicants, later made possible after 2016 legislative reform since the voluntary register relied on information, such as donor code, that was not always known to applicants, or available to facilitate matching. The comprehensive register overcame limitations of the voluntary register. The voluntary register was also only utilised by men who assumed, or had confirmed, live offspring being born from their donation in Victoria. It would not be utilised by donors who donated in a non-Victorian state, but whose donations were then made available to and used by a Victorian clinic. It would also not be utilised by donors unaware of there being genetic offspring, such as those advised that no offspring were born from their donation (e.g., Victorian Assisted Redproductive Treatment Authority, 2017), or that their donation was used for research purposes only (e.g., Carabott, 2015). In both examples given, the donors were supportive of their identity being made available to genetic offspring.

### The complementary benefits of DNA testing

The use of DNA testing would be a substantial benefit to registries. This is largely due to:

1) Incorrect record keeping leading to incorrect 'matches' between donors and donor-conceived people (e.g., Dow, 2019). DNA testing can be used to confirm genetic relationships.
2) Its ability to match donors and donor-conceived people to match with each other in the even that their records have degraded, been misplaced or destroyed.

Currently there is an informal reliance on international, for-profit Direct-to-Consumer DNA testing in which a person is required to relinquish some control over their personal information. A DNA-supported donor conception register currently operates in the United Kingdom from which future DNA registries can be modelled off.

### Support

There are currently no Queensland-based support services providing specialised support for donor-conceived people, donors, or their families. Accessible support will be required when helping donor-conceived people, donors and family members navigate information, including the potential discovery that a donor has died, or records have being misplaced or destroyed. Fertility clinics are not appropriately placed to provide or oversee this support. Clinic-employed counsellors' expertise lies in supporting people experiencing infertility issues. Some offspring, through their experience of seeking information, may have developed mistrust for clinics, or if they have experienced distress, attributed this to the clinic's policies or practices. To have to further engage with clinics for information access or support could compound distress. Further, there is a possible conflict of interest considering given recipient parents were once clients, and donors once supported by, the clinic.

### Conclusion

Donor-conceived Queenslanders should be afforded equal rights to genetic information. A Queenslander's ability to access accurate and complete information should not be restricted based on the method or timing of their conception, or the location of the donation. The establishment of a registry, and removing any assumptions of donor anonymity, will remove discrimination present within the current Queensland Framework. It will also address the current Framework's shortfalls in upholding the Rights of the Child. A centralised registry will offer an impartial point of access to allow any donor-conceived person to independently access information pertinent to their identity, health, and wellbeing, irrespective of any clinics' practice or policy and parent-offspring relationship situation. Any legislation must acknowledge, balance, and support the interests of all parties involved, including donors, however the rights of the individual born from the practice must be paramount.

There is no justification for continued operation of donor conception without legislation, or Frameworks that discriminate against citizens.

I welcome any contact from the Committee Secretary. I am happy to clarify or expand on any points made in this submission, and to provide additional evidence, or expand on current evidence, presented in this submission.

Sincerely,

Caitlin Macmillan
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