

SUBMISSION TO THE INQUIRY INTO DONOR CONCEPTION PRACTICES IN QUEENSLAND

Prepared by:

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Dr. Sonia Allan OAM CF PhD

Dear Committee Secretary

RE: Inquiry into Donor Conception Practices in Queensland

I thank you for the opportunity to make a submission to your inquiry into donor conception practices in Queensland.

I have examined donor-conception issues closely since 2003, when I was first asked to work on a reference for the Victorian Law Reform Commission on access to assisted reproductive technologies. Since then I have built expertise in the area of the ethical, social, legal and human rights issues raised by donor-conception—I have participated in numerous government inquiries across Australia regarding such issues, and have written extensively on issues related to access to information by donor-conceived people (see further Appendix 1); in 2011, I was appointed as a Churchill Fellow to conduct a study of information release systems around the world, and to bring such information back to Australia; I recommended the model for information release that has recently been adopted in Victoria; in 2016 I led the review of the South Australian *Assisted Reproductive Treatment Act 1988* (SA), with one of the terms of references being to consider a provision for a donor register in South Australia, and in 2018 I led the review of the Western Australian *Human Reproductive Technology Act 1991* (WA) and the *Surrogacy Act 2010* (WA). This year I have been working with South Australia on the establishment of their donor conception register.¹

Most importantly, as a consequence of nearly two decades of working in the area, I have come to know donor conceived people, donors of gametes and embryos, and recipient parents

¹ The outcomes of that work are expected later in the year.

from across Australia and beyond, and have significant knowledge of *all parties seeking the ability to exchange information*. In 2019, I also co-organised a group of donor-conceived people, drawn from representatives from all over the world, to [present in the United Nations for the 30th Anniversary of the Convention on the Rights of the Child](#).

My submission will address the following issues concerning the recording and release of information to donor-conceived people and their donor siblings:

1. The history of donor conception in Australia.
2. The current state of law and guidelines governing the recording and release of information about donors to donor-conceived persons across Australia.
3. The Senate Committee Inquiry, 2010 – which called for the establishment of a national register, or in the alternative for the States to act ‘as a matter of priority’ to address issues related to donor conception – and the need for Queensland to do so.
4. The issue of retrospective release of information about genetic parents (donors of gametes/embryos) to donor-conceived persons, including the need to separate the issue of *information release* from issues of *legal parenthood*, and *contact*.
5. Examination of the where information might be held and how such information might be released
6. Other relevant matters.

In considering the above issues, I note it is my submission/request that the Committee recommend that:

- A. All information about genetic parents (donors of gametes/embryos) and donor-conceived persons should be held at a Central Register, maintained by the register of Births, Deaths and Marriages.
- B. The recording of information upon that register should include all available information about genetic parents (donors of gametes/embryos) *regardless of when such donations took place*, including the opportunity for past donors and those who ‘donated’ outside of the clinic system to voluntarily add their names to the register upon providing evidence of a known donor arrangement.
- C. A prohibition should be enacted to prevent intentional destruction of all donor conception records.

- D. A system should be put into place that allows for the release of identifying and non-identifying information about genetic parents (donors of gametes/embryos) to donor-conceived people, but that also enables people who donated prior to September 2004² to express contact preferences and advance notice of requests for identifying information in order to balance the 'privacy interests' of the respective parties involved. This would allow for the release of identifying information about donors, while protecting the intimate sphere of a person's daily life by allowing the person who donated to control whether and if so, how contact may occur.
- E. Management of releasing information to donor-conceived people about their genetic parents (donors of gametes/embryos) should be done sensitively with intermediary support services and counselling made available to those who need such services in relation to both information release and contact (such services should not be mandatory, but should be available when a person chooses to use them);
- F. Donor-conceived people should be **notified** of their status, via their birth certificate, as without knowledge that they are donor-conceived, they may not then make a choice about whether they wish to access such information.

I note that my submission closely aligns to the recommendations and submissions I have made in other states and territories, as it applies equally to Queensland.

Again, I thank you for the opportunity to express my thoughts, and do hope they are helpful to your inquiry.

Kind regards,



Sonia Allan

² (Since when consent to release of identifying information was required by the National Health and Medical Research Council).

A. Introduction

History of Donor Conception in Australia

The use of donor sperm to achieve pregnancy has reportedly existed for centuries. However, since the early 1950s its existence became better known and from the 1970s its use greatly increased. Technological advances further increased the occurrence of donor conception in Australia with the first in-vitro fertilisation ('IVF') procedure in Australia occurring in 1979, and the first IVF baby born in June 1980. Since then numerous assisted reproductive technologies (ART) and practices have been developed (including gamete intra-fallopian transfer ('GIFT'), zygote intra-fallopian transfer ('ZIFT'), intracytoplasmic single sperm injection ('ICSI'), and surrogacy). All of these latter technologies may involve the use of donor oocytes, embryos or sperm, and take place within the clinic system with ART specialists, counsellors and other professional staff involved in the process of a person or persons using ART to attempt to conceive a child.

Private arrangements among certain parties have also existed throughout the history of donor conception. This is often referred to as 'known' donations and involves a man agreeing to donate his sperm to a woman or female couple. In these instances, the woman may inseminate herself outside of the clinic system, or sexual intercourse may occur for the purposes of conceiving a child. The latter would fall outside of what is referred to as ART.

The use of ART in Australia continues to increase—for example, in 2019 it was reported that there had been 16,310 live births resulting from the use of ART,³ compared to 12,637 born to women following ART treatment in 2013,⁴ and 10,522 babies born as a result of ART in 2006.⁵ While the majority of treatments involve the use of fresh or frozen non-donor gametes (eggs and sperm), there were 829 egg/embryo donation births in Australia/New Zealand, and 395 babies born to women who had DI treatment in Australia in 2019;⁶ 462 egg/embryo donation births in

³ JE Newman, RC Pau, GM Chambers, *Assisted reproductive technology in Australia and New Zealand 2019* (2021) Sydney: National Perinatal Epidemiology and Statistics Unit, the University of New South Wales, Sydney.

⁴ Alan Macaldowie, Evelyn Lee, and Georgina M Chambers, *Assisted reproduction technology in Australia and New Zealand 2013* (2015).

⁵ YA Wang, JH Dean, T Badgery-Parker & EA Sullivan, *Assisted reproduction technology in Australia and New Zealand 2006*, (2008). Assisted reproduction technology series no. 12. AIHW cat. no. PER 43. Sydney: AIHW National Perinatal Statistics Unit.

⁶ Newman et al, above n 3.

Australia/New Zealand, and 308 babies born to women who had DI treatment in Australia in 2013;⁷ and 354 live births following embryo transfers which involved oocytes/embryo donation and 278 live deliveries of children who were conceived using donor insemination in 2006. These figures do not include DI cycles undertaken in hospitals or private clinics that are not fertility clinics. They also do not include the situation in which ‘known donors’ are used.

Given the recorded figures, if at an estimate there has been an average of 600 births per year since the early 70s in which donor gametes/embryos were used to conceive, this would amount to approximately 30,000 donor conceived individuals living in Australia born through the clinic system. Donor support groups estimate the figure to be closer to 60,000 if one includes those individuals that were conceived with the assistance of a GP or outside of the clinic system. There are a portion of such individuals who were, and continue to be, conceived and born in Queensland.

Secrecy Surrounding Donor Conception

For many donor-conceived people both identifying and non-identifying information about their genetic parents (and genetically related siblings⁸) remains unknown, due to the secrecy that has surrounded donor conception. For heterosexual couples, such secrecy often was (and may continue to be) closely linked to family angst about infertility. In the past, recipient parents were told they should not seek information about the donor, while donors were told they should not seek information about the recipient parents or the resultant child. In the case of heterosexual couples, it has also been reported that it was often easier for parents simply not to tell the resultant child they were donor conceived either because of their shame about their own battles with infertility, their fears of being rejected by the resultant child, or because despite their desire to tell their child, they were frustrated by having no way of imparting further information about the donor.

While the secrecy does not appear to have been ill intended—that is, all involved may have believed that what they were doing was best for the donor-conceived person—as donor-conceived people reached adulthood, or had families of their own, it became increasingly apparent that secrecy, and being denied access to information about genetic heritage, has had a significant negative impact upon many.

⁷ Macaldowie, above n 4.

⁸ Be such siblings born to other families who have used donor conception, or within the donor’s own family.

Into the present, despite the growing acceptance of ART and donor-conception as a way to assist people to build their family, many continue to be frustrated by lack of access to information about the genetic parent ('donor') and/or 'genetic siblings' of the donor-conceived person born as a result. That is, despite a desire to be open, in most jurisdictions in Australia, access to information has been difficult to say the least. There has therefore been a move towards encouraging disclosure and away from secrecy amongst all families that access ART. The need for information is further discussed below.

B. The importance of exchanging information for donor-conceived people, recipient parents, and donors

There are numerous arguments that support the call for access to information by donor-conceived people about their donors.⁹ These arguments are being voiced more often as the number of affected individuals who are demanding access to information about their genetic relations increases. We should also anticipate that there are numerous individuals who are yet to reach adulthood who may in the future call for information about their donors.

The following reiterates arguments drawn from a number of the papers I have authored and refer you to in Appendix 1.

Development of Identity and Sense of Self

Donor-conceived people report that in circumstances where the mode of conception has been kept secret from them, on discovering their status and that they are not genetically related to their parent(s), they have experienced a sense of "lost identity" and a corresponding desire to know more about their genetic parent (the 'donor').¹⁰ This has been referred to as "genealogical bewilderment".¹¹ It is important here to note that we can no longer accept arguments that assume

⁹ For detailed discussion of the issues and arguments, I refer the committee to the reports and articles listed in Appendix 1.

¹⁰ S.Allan, *Donor Conception and the Search for Information: From Secrecy and Anonymity to Openness?* Routledge, Oxford (2017); A. Turner and A. Coyle, "What Does it Mean to be Donor Offspring? The Identity Experience of Adults Conceived by Donor Insemination and the Implications for Counselling and Therapy" (2000) 15(9) *Human Reproduction* 2041; Jadva V, Freeman T, Kramer W and Golombok S, "Experiences of Offspring Searching for and Contacting their Donor Siblings and Donor" (2010) 20 *Reproductive BioMedicine Online* 523 at 524.

¹¹ Turner and Coyle, n 10; E. Wellisch, "Children without Genealogy: A Problem with Adoption" (1952) 13(1) *Mental Health* 41; H. Sants, "Genealogical Bewilderment in Children with Substitute Parents" (1964) 37(2) *British Journal of*

that because donor-conceived people were ‘wanted’ by their parent(s), and the donor was only acting to ‘help’ those parent(s) conceive, that a donor-conceived person has no interest or rights to access information about their biological heritage. This is particularly so as a person’s development of identity is viewed as fundamental to a sense of self.¹²

Further, the curiosity about their donor and the propensity for donor-conceived people to search for information is not related to the desire to escape negative family issues; rather, most donor-conceived people report positive relationships with their parents.¹³ On the other hand, such feelings coexist with a strong desire to know about one’s donor and frustration at being denied information.¹⁴

Note: While not all donor-conceived people may feel a sense of ‘lost identity’ or ‘genealogical bewilderment’ that some, or any, such people do, is reason enough to address the issue of being denied information and support in seeking it. Further, one does not have to have suffered harm, or even have negative emotions related to their mode of conception, to have a desire to understand and know about their genetic heritage and relations.

Medical History

There is great importance for having access to information concerning a genetic parent’s medical history (for example, whether or not there is a familial history of heart disease, diabetes, cancer, mental health issues, and/or other heritable diseases).¹⁵ Donor-conceived people who are denied access to familial medical histories are placed at increased risk as a result of not having access to information about their genetic heritage. This becomes very significant as people age. For example, a donor who donated in the 1970s or 1980s, when donor-conception was shrouded in

Medical Psychology 133. Such bewilderment may be particularly acute for some people who discover later in life that they were donor-conceived.

¹² Sonia Allan, ‘Access to Information about Donors by Donor-Conceived People: A Human Rights Analysis’, *Journal of Law and Medicine* (March, 2013); Richard Chisholm, ‘Information rights and donor conception: Lessons from adoption?’ (2012) 19(4) *Journal of Law and Medicine* 722; Eric Blyth, Marily Crawshaw, Lucy Frith and Caroline Jones, ‘Donor-conceived people’s views and experiences of their genetic origins: A critical analysis of the research evidence’ (2012) 19(4) *Journal of Law and Medicine* 769; Naomi Cahn, ‘Legal parent versus biological parent: The impact of disclosure’ (2012) 19(4) *Journal of Law and Medicine* 790.

¹³ PP Mahlstedt, K LaBounty and WT Kennedy, “The Views of Adult Offspring of Sperm Donation. Essential Feedback for the Development of Ethical Guidelines within the Practice of Assisted Reproductive Technology in the United States” (2010) 93(7) *Fertility and Sterility* 2236.

¹⁴ Turner and Coyle, n 8; Dennison M, “Revealing Your Sources: The Case for Non-anonymous Gamete Donation” (2008) 21(1) *Journal of Law and Health* 1 at 13.

¹⁵ Centers for Disease Control and Prevention (CDC), “Awareness of Family Health History as a Risk Factor for Disease” (2004) 53(44) *Morb Mortal Wkly Rep* 1044.

secrecy, may not until more recently have become aware that they are a carrier of certain diseases. Similarly, a donor-conceived person may become aware of a heritable condition but has no way presently to notify their genetic parent(s) (the 'donor') or genetic siblings conceived using gametes or embryos donated by the same person. This may have ramifications not just for the person unaware of such information but for generations to come. (On the other hand, the release of medical information raises issues about health privacy and confidentiality which are generally protected in Australia – clear legislation permitting the release of information about the donor is therefore needed).

Risk and Fear of forming Consanguineous Relationships

Some donor-conceived people report the fear of unknowingly forming relationships with siblings or possibly their unknown genetic parent.¹⁶ While the actual probability of such an occurrence is unknown (as the actual number of donor-conceived people is unknown), such a risk may be significant within Australia, given the small population and the significant number of donor-conceived people in existence. It is noted that forming such relations may have legal ramifications – see for example, the *Marriage Act 1961* (Cth) which provides that marriages between an individual and their parent, and an individual and their half-sibling are unlawful.¹⁷ Further, such relationships may result in children being born to couples who are related, giving rise to an increased risk of genetic or chromosomal difficulties in those children¹⁸

However, note that it is not just actual risk that need be considered. The fear, angst, and psychological impact of not knowing who one is related to has been described by many donor-conceived people. There have been instances of donor-conceived siblings going to school with each other, living in close vicinity to each other, and even being friends, without knowing they were first-degree relatives. Some have described how this has impacted them when forming relationships, or even just how it impacts them in day-to-day life. The psychological impact in this regard, cannot be discounted.

¹⁶ Senate Legal and Constitutional Affairs References Committee, Submission 156 (M Crawshaw) p 7.

¹⁷ *Marriages Act 1961* (Cth), s 23(1)(b), makes marriages involving “prohibited relationships” void. Section 23(2)(a)-(b) states that “marriages between an individual and their parent and an individual and their sibling, including half siblings” are “prohibited relationships”.

¹⁸ RL Bennett RL, AG Motulsky, A Bittles et al, “Genetic Counseling and Screening of Consanguineous Couples and Their Offspring: Recommendations of the National Society of Genetic Counselors” (2002) 11(2) *Journal of Genetic Counseling* 97. The authors, in recognising the risk associated with forming consanguineous relationships, recommend genetic counselling and screening for consanguineous couples and their offspring. Donor conceived people who are unaware of their relatedness to others would not have the opportunity to undergo such counselling/screening.

Equality

Laws and guidelines, across Australia, and within jurisdictions, result in donor-conceived people being treated differently depending upon *where* a donor-conceived person was born and *when* the gamete/embryo donation took place.

That donor-conceived people are not granted automatic entitlement to information about their genetic parentage has led to some stating that they are being discriminated against. Such claims often also look to the law long since having recognised the need for information about genetic heritage in for other people:

- a) adoptees (which has involved the laws being enacted to permit retrospective release of information to adoptees about their birth parents),¹⁹
- b) people whose paternity is at issue (where the law allows for orders to be made for DNA testing to establish paternity),
- c) indigenous people, including—but not limited to--the stolen generation, and their interests and rights to know their cultural and biological heritage.

The Impact on Families

Denying access to information about the donor (genetic parent) also impacts upon recipient parents. Parents of donor-conceived people are prevented from being able to provide their children with information from a young age, that many actually wish to impart.

Some recipient parents report wanting to be able to be open and honest with their children, but at a complete loss when they cannot tell their child anything other than that they were donor-conceived – noting it is natural in response to such disclosure for a child to then ask questions about who the donor was.

For some families, the lack of information may lead them to decide to keep the method of conception a secret. This in turn can also add to the stigma parents feel about having had to access donor-conception in the first place.

¹⁹ Note the analogy between adoptees and donor conceived people relates to the search for information, and not necessarily the personal experience of being adopted or donor conceived. While there are similarities, there are also significant differences. This is particularly important in recognizing that ‘after-adoption’ services may not be best placed to ‘counsel’ donor conceived people, because the issues faced by them may be significantly different to those faced by other clientele.

For other families, it may be that secrecy about donor conception is not an issue. They tell their children about how they were conceived but are again at a loss when asked for further information.

Being able to tell the children that they may access identifying and non-identifying information (at whatever age the law deems suitable) may assist all of these families in having open conversations with their child(ren).

Donors

It is not necessarily the case that past donors wish to remain anonymous.²⁰ The Donor Conception Support Group quoted a former sperm donor in their submission to the 2010 Senate Committee Inquiry into the issue:

I was a sperm donor during 1997-1998. [M]y donations were during the period when [d]onors had to sign away any future contact. This was a condition of participation and I only wanted to help people – but at the back of my mind was the hope that the rules would change to allow the resultant children to trace their donor fathers, if they wished to do so.²¹

Similarly, the Victorian Assisted Reproductive Treatment Authority (VARTA) stated that the belief that secrecy was paramount to protect all parties to the arrangement was based on myths:

[T]hat donors would not want to be contacted, that parents would not want to know more about their donor, and that donor-conceived people would not want information about their donor if they really loved their parents.²²

VARTA stated that “donors do not forget they have donated and often wonder about the people they helped to create. Who are they? Are they healthy? Are they happy? Are they loved?”²³

Lifting the veil of secrecy and shame that has surrounded donor conception

As access to assisted reproduction has expanded, and our country celebrates and recognises many different family formations, so too should it facilitate the access of those families to information. This is vital, as such information is at risk of being lost or destroyed, for example, as clinics or doctors’ surgeries close.

²⁰ Senate Legal and Constitutional Affairs References Committee, Submission 73 (Rainbow Families Council) p 2; Submission 122 (Donor Conception Support Group) p 139.

²¹ Senate Legal and Constitutional Affairs References Committee, Submission 122 (Donor Conception Support Group) p 74.

²² Victorian Assisted Reproductive Treatment Authority.

²³ Victorian Assisted Reproductive Treatment Authority.

C. Australian state and territory laws

Legal parentage of children where donor conception has been used

It is important to note that every jurisdiction in Australia has legislation the object of which is to provide legal certainty regarding the status of children and their parents.²⁴ Such legislation was introduced in all jurisdictions in the 1970s to address the stigmatisation of children born to women who were not married and to remove notions of ‘illegitimacy’. Legal recognition of parents gives rise to a set of rights and responsibilities (or obligations) under the law that serve to protect and maintain children. These generally include that a legal parent may make decisions about medical treatment for the child; appoint a testamentary guardian for the child; bring about legal proceedings on behalf of the child; make decisions or meet legal obligations concerning schooling or employment for children under 17 years of age; be entitled to be party to child protection hearings; or be entitled to be present if the child is being questioned by police. In addition, the child may lay claim to the co-parent’s estate if adequate provision in a will has not been made or the co-parent dies intestate (without a will).²⁵

In all jurisdictions it is generally provided that a woman giving birth to a child is that child’s legal parent. When, with the consent of her husband, a married woman had undergone artificial insemination using donor sperm, the husband is presumed to be the father of the resulting child and the donor is presumed not to be the father. When the procedure involves an ovum or embryo transfer (whether or not the woman’s ovum or the husband’s sperm was used) the woman’s husband is presumed to be the father. Following numerous inquiries and law reform reports across Australia,²⁶ all Australian jurisdictions also presume the same-sex partner of a birth mother who

²⁴ *Artificial Conception Act 1985 (WA)*; *Family Relationships Act 1975(SA)*; *Parentage Act 2004 (ACT)*; *Status of Children Act 1996 (NSW)*; *Status of Children Act (NT)*; *Status of Children Act 1974 (Tas)*; *Status of Children Act 1978*; and *Status of Children Act 1974 (Vic)*.

²⁵ For detailed discussion of the impacts upon children in these circumstances see Queensland Government, *Review of the Legal Status of Children Being Cared for by Same-Sex Parents* (August 2009); Victorian Law Reform Commission, *Assisted Reproductive Technology and Adoption* (March 2007); John Tobin, *The Convention on the Rights of the Child: The Rights and Best Interests of Children Conceived Through Assisted Reproduction* (2004) viii (Occasional Paper Commissioned by Victorian Law Reform Commission).

²⁶ Queensland Government, *Review of the Legal Status of Children Being Cared for by Same-Sex Parents* (August 2009); Human Rights and Equal Opportunity Commission, *Same-sex: Same Entitlement* (May 2007); Victorian LRC, *Assisted Reproductive Technology and Adoption* (March 2007); New South Wales Law Reform Commission, *Relationships* (June 2006); and Tasmanian Law Reform Institute, *Adoption by Same-Sex Couples* (May 2003)..

has used ART to conceive is a legal parent of a child born.²⁷ In all the above instances is presumed not to be a legal parent of the child and *has 'no rights and incurs no liabilities' in respect of the child* (unless for example a sperm donor later becomes the husband of the child's birth mother). This is important to note as sometimes there is fear that release of information to donor-conceived people will give rise to legal rights and responsibilities by the donor—it must be noted that it will not.

Regulation of ART and laws regarding information about donors

The recognition of the recipient parent(s) as a legal parent(s) of a donor-conceived person, has unfortunately however, facilitated the secrecy and/or denial of information about donor-conceived people's genetic heritage. This has resulted particularly in circumstances where there has been an absence of recording the donor's details centrally, and a lack of notification regarding donor-conceived status. While recognition of legal parentage is fundamental to family functioning, and the child's well-being, there is thus a call for the end to secrecy and allowing for information release. Unfortunately, in this regard, the law in Australia has not been uniform across jurisdictions.

In addition, while the various jurisdictions today purport to follow ethical codes of conduct in the documentation and retention of identifying information and the medical history of sperm donors, this has not always been the case. The retention of information on donors has traditionally been within the sole discretion of medical clinics and doctors. State and territory legislation specifies a period in which medical records must be retained but, after this period, information on donors may be destroyed. As mentioned above, it has therefore been common for many donor-conceived persons, when informed of their donor-conceived status and curious for information about their donor, to be informed by the clinics, or GP that performed the artificial insemination, that such information has been destroyed. For other donor-conceived persons the information still exists, however they are unable to access it. This is a result of inconsistent legislation regarding access to information across Australia, including a complete lack of such legislation in Queensland.

For donor-conceived children conceived outside of the clinic system (i.e., through known donation'), access to information is completely reliant on the parties to that arrangement maintaining and giving information themselves. That is, unless the known donor was entered onto

²⁷ *Status of Children Act 1996* (NSW), s14(1A); *Status of Children Act 1974* (Vic), s13; *Artificial Conception Act 1985* (WA), s6A; *Status of Children Act* (NT), s5DA; *Parentage Act 2004* (ACT), s11(4); *Status of Children Act 1974* (Tas), 10C(1A); *Status of Children Act* (Qld), s19C-19E.

the birth certificate, his information may not have been recorded anywhere. (Note in Queensland there was a case in 2014 in which a known donor was originally recorded on the birth certificate was removed to enable the same-sex parents to be placed on the birth certificate).²⁸

The dilemma is, in all circumstances (for all families), that the donor's information should be recorded somewhere—and preferably upon a register—to ensure the donor-conceived person may access it if they wish to.

Specific Laws Regarding Information Recording and Release

All states and territories (including those without legislation) refer to the National Health and Medical Research Council (NHMRC) guidelines and recommendations for ethical practice.²⁹ Currently, four Australian states also have legislation that governs access to information concerning donor conception.³⁰ Three states, Victoria, Western Australia and New South Wales maintain donor registers, while South Australia established its donor register in November 2021 and is working currently to determine the operation of that register.³¹

This is illustrated in Table 1, which details state and territory positions, highlights the differences between them regarding access to information and donor registries, and illustrates the complexities of registers where they do exist.

²⁸ See *A & B v C* [2014] QSC 111.

²⁹ NHMRC Ethical Guidelines on the Use of Assisted Reproductive in Clinical Practice and Research 2004 (Revised as at 2007).

³⁰ *Human Reproductive Technology Act 1991* (WA); *Assisted Reproductive Treatment Act 2008* (Vic); *Assisted Reproductive Treatment Act 1988* (SA); *Assisted Reproductive Technology Act 2009* (NSW).

³¹ This work is expected to be finalized this year.

Table One: Access to information: state and territory regulations and registries.

STATE	LEGISLATION/ REGULATIONS/ GUIDELINES	ACCESS TO IDENTIFYING AND NON-IDENTIFYING INFORMATION	VOLUNTARY REGISTER
Western Australia	<i>Human Reproductive Technology Act 1991</i> (WA)	<p>A 1999 report reviewing the Act considered that donor-conceived people should be able to obtain information about their origins, including identifying information.</p> <p>Compulsory Register: Identifying Information</p> <p>People conceived after 2004 may access identifying information when they turn 16 about their donor.</p> <p>People conceived prior to 2004 may access non-identifying information that is held on the register. (Noting that information has only been held on the central register since 1993). Many people will have to approach the clinic involved in their conception and access to information will depend on clinic's record keeping and policies.</p> <p>Recommendations were made in 2019 to provide access to information to all donor-conceived people. The government is currently working on how to proceed.</p>	<p>Voluntary Register³²</p> <p>A voluntary register exists to facilitate the exchange of identifying information. Such information is entered on the Voluntary Register if a person completes a properly signed and witnessed written registration form. Access is based on the mutual consent between donors and donor-conceived persons.</p> <p>Related donor-conceived siblings may also have access to identifying information about each other if they have all consented. This may be done without identifying the donor.</p> <p>The Register is currently operated by 'Jigsaw WA'.</p>

³² NB. Although the WA voluntary register may include details of people involved in donation since ART started in Western Australia (circa the early 1970s) its operations are influenced by whether the donation was made before or after the *Human Reproductive Technology Act 1991* came into operation, on 8 April 1993 as central records have only been stored since April 1993. The only records available before that time are those held by the fertility clinics and medical practitioners that provided such services. Because detailed records were not always kept in the early days of ART the registry notes that it is very difficult to match records for donors and donor offspring where donations were made before the early 1980s.

STATE	LEGISLATION/ REGULATIONS/ GUIDELINES	ACCESS TO IDENTIFYING AND NON-IDENTIFYING INFORMATION	VOLUNTARY REGISTER
Victoria	<i>Assisted Reproductive Treatment Act 1988</i> (SA)	<p>Mandatory Register The law has changed over time. Historically, the date of consent of the donor determined which register information is held on, and therefore access to information varied depending on when gametes were donated. This meant people conceived with gametes donated pre 1988 had no access to identifying information; post 1988 only with donor consent; and post 1998 all donor-conceived people had access.</p> <p>Amendments to the law in 2015 allowed for retrospective release of identifying information <i>with consent</i> of the donor for those conceived with sperm, eggs or embryos donated pre-1998. This gave those conceived with gametes donated pre-1988 people the same rights as those conceived with gametes donated pre-1998—i.e. access to information with consent; but maintained differential treatment to those conceived with donated gametes post 1998 – all of whom can access information.</p> <p>Further amendments to the law in 2016 allowed for full retrospective release of information from 1 March 2017 for all donor-conceived people regardless of consent of the donor, with the option for donors/donor-conceived people, and donor siblings to place contact preferences. Intermediary and support services are provided by VARTA, who administers the register.</p>	<p>Voluntary Registers Voluntary registers were originally set up to enable information exchange by people not governed by the legislation. There were two registers kept when held by the former Infertility Treatment Authority, defined again by changes in legislation: *Post-1988 Voluntary Register *Pre-1988 Voluntary Register.</p> <p>The voluntary register continues under the new regime.</p>
New South Wales	<i>Assisted Reproductive Technology Act 2007</i> (NSW) Assisted	From 1 January 2010 identifying information has been held on a register maintained by the NSW Department of Health. Donor conceived individuals may access this information when they turn 18. Those conceived prior to 1 January 2010 need to contact the clinic in which they were conceived for non-identifying information if such records still exist.	A voluntary register is also to be maintained by the NSW Department of Health. Information will only be disclosed in accordance with the consent of the person who has entered information upon the register.

STATE	LEGISLATION/ REGULATIONS/ GUIDELINES	ACCESS TO IDENTIFYING AND NON-IDENTIFYING INFORMATION	VOLUNTARY REGISTER
	Reproductive Technology Regulation 2009	There is <i>no legislative requirement for people wishing to apply for information to undergo counselling</i> , however, the NSW Department of Health 'strongly recommends' people seek counselling before applying for information held on the register.	
South Australia	<p><i>Assisted Reproductive Treatment Act 1988 (SA)</i></p> <p>Assisted Reproductive Treatment Regulations 2010</p>	<p>South Australian legislation requires record keeping.</p> <p>Following the Allan Review in 2016, a donor conception register was established in 2019.</p> <p>The current Act provides that Minister must keep a register of donors of human reproductive material used in assisted reproductive treatment and resulting in the birth of a child (the donor conception register) which must contain (a) the donor's full name and nominated contact address; (b) the full name and nominated contact address of the person to whom assisted reproductive treatment using the donor's human reproductive material was provided; and (c) the full name of any child born as a consequence of such assisted reproductive treatment (if known); and (d) any other information required by the regulations, and other information that the Minister thinks fit.</p> <p>Work is currently underway regarding the operation of the donor conception register in South Australia.</p>	NONE
Tasmania, Northern Territory ACT	NHMRC Ethical Guidelines on the Use of Assisted Reproductive in Clinical Practice	<p>The current guidelines state:</p> <p><i>'Persons born from donated gametes are entitled to know the details of their genetic origins. ...</i></p> <p><i>5.6.1 Clinics must not use donated gametes in reproductive procedures unless the donor</i></p>	NONE

STATE	LEGISLATION/ REGULATIONS/ GUIDELINES	ACCESS TO IDENTIFYING AND NON-IDENTIFYING INFORMATION	VOLUNTARY REGISTER
Queensland	and Research (2007)	<p><i>has consented to the release of their identifying information to the person(s) born as a result of the donation (see paragraphs 4.6.1 and 5.5.1).</i></p> <p><i>5.6.2 Clinics must not mix gametes in a way that allows the genetic origins of the person who would be born to be uncertain. This includes the attempted fertilisation of a human egg by human sperm from more than one donor at a time.</i></p> <p><i>5.6.3 Clinics must:</i></p> <ul style="list-style-type: none"> <i>• encourage gamete recipients to disclose to their children their genetic origins</i> <i>• provide ongoing support to parents, to help them to understand the potential significance of the biological connection and the benefits of early disclosure</i> <i>• assist parents to find effective ways of disclosing to their children their genetic origins</i> <i>• provide persons born from donated gametes with a supportive environment within which to explore the possibility of meeting with the donor(s) and/or siblings (see paragraph 5.9).</i> <p>There is however no evidence that the guidelines are implemented in a uniform way. Further, the lack of oversight of clinics with respect to ensuring identifying information is made available in states/territories where the only guidance is the NHMRC guidelines is problematic. Donor conceived individuals must contact the clinic where they were conceived to see if they hold any information (non-identifying) and whether they will release that information. Where there is no clinic, donor-conceived people are at a loss as to where to go.</p>	

D. The Senate Committee Report

In the February 2011 report on its inquiry into the past and present practices of donor conception in Australia,³³ the Australian Senate Legal and Constitutional Affairs References Committee (the Senate Committee) made 32 recommendations concerning matters relating to donor conception regulation and legislation across federal and State jurisdictions;³⁴ the conduct of clinics and medical services with regard to payment for donors,³⁵ managing data relating to donor conception,³⁶ and provision of appropriate counselling and support services;³⁷ the number of offspring born from each donor with reference to the risk of consanguineous relationships;³⁸ and the rights of donor-conceived persons.³⁹

Significantly, the Senate Committee recommended that jurisdictions which do not already have legislation in place **should, “as a matter of priority”, introduce legislation to regulate donor conception,**⁴⁰ and that the “Australian Government pursue all available policy and political options ... to ensure that nationally consistent legislation relating to donor conception is developed”.⁴¹ In addition, 17 recommendations related to the preservation, recording and release of records concerning identifying and non-identifying information⁴² about donors to donor-conceived

³³ Senate Legal and Constitutional Affairs References Committee, *Donor Conception Practices in Australia* (2011) p 1.

³⁴ Senate Legal and Constitutional Affairs References Committee, pp 103-104, Recommendations 1, 2 and 3.

³⁵ Senate Legal and Constitutional Affairs References Committee, p 107, Recommendation 22.

³⁶ Senate Legal and Constitutional Affairs References Committee, p 105, Recommendation 12.

³⁷ Senate Legal and Constitutional Affairs References Committee, pp 107-108, Recommendations 25-27.

³⁸ Senate Legal and Constitutional Affairs References Committee, p 108, Recommendations 28 and 30.

³⁹ Senate Legal and Constitutional Affairs References Committee, pp 103-104, 107, Recommendations 3, 4 and 19.

⁴⁰ Senate Legal and Constitutional Affairs References Committee, p 103, Recommendation 1.

⁴¹ Senate Legal and Constitutional Affairs References Committee, p 103, Recommendation 2.

⁴² Identifying information would include the donor/donor-conceived person's name, date of birth and address; non-identifying information might include education (level and qualifications); eye colour; hair colour; height; weight; marital status; number of children (if any); sex; year of birth; place of birth; nationality/culture with which the donor identifies; religion (if any); reason for becoming a donor; number of offspring born through other donations; identity of other offspring born through other donations; interests/hobbies/sporting activities; anything else the donor considers central to their personality. (It is difficult to delineate some of the information as identifying or non-identifying as some information in combination might lead to the identification of a person, but alone would be considered non-identifying.)

persons.⁴³ These included a call for the establishment, “as a matter of priority”, of a national register of donors⁴⁴ and that this central register should operate according to principles which provide for donor-conceived persons to be able to access identifying information about their donor.⁴⁵ **In the alternative they called for state based registers underpinned again by uniform legislation. I submit that Queensland needs to act to meet these requirements.**

I note that the recommendations and report left a number of issues open for further debate, including whether the legislation should provide for the retrospective release of identifying and non-identifying information about donors to donor-conceived persons.⁴⁶ Again, I refer the Committee to a list of references in which I have explored these issues in detail provided to you in Appendix 1. However, I here note that it is my position having undertaken nearly two decades of research on the matters, that given that the call for information has been made most loudly by those donor-conceived persons who are already in existence, and who are denied access to information that already exists the issue of retrospectivity must be resolved for them in a positive manner.

E. Retrospective Release of Information: Differentiating between information and contact

In considering the retrospective release of identifying information about a donor-conceived person’s genetic parent (the donor(s) of gametes or embryos), it is necessary to consider that in the

⁴³ Senate Legal and Constitutional Affairs References Committee, pp 103-109, (see Recommendations 3, 5-14, 19-21, 25, 31-32).

⁴⁴ Senate Legal and Constitutional Affairs References Committee, p 104, Recommendation 5.

⁴⁵ Senate Legal and Constitutional Affairs References Committee, pp 104-105, Recommendation 9. Arguably, such a register would also enable donors to receive information about their offspring, and donor-conceived siblings to receive information about each other.

⁴⁶ See Senate Legal and Constitutional Affairs References Committee, p 114 at [7.26]: “In the absence of authoritative evidence about the legal and ethical implications of retrospectively removing donor anonymity, the committee chooses not to make any specific recommendation about retrospectivity.”

past, some donors of gametes or embryos may have done so under the assumption that their information about their identity would not be shared. The question thus becomes whether such information may be released to donor-conceived people.

I have conducted extensive research on this matter and note that across Australia there is no impediment to the legislature passing legislation to allow for the release of identifying and non-identifying information about donors to donor-conceived people,⁴⁷ regardless of when the donation took place. However, the legal interests and 'rights' to privacy of donors should also be considered. That is, it is important to consider how the legislature may provide for both donor-conceived people to have the information they seek, and for donors of gametes and embryos to be able to make choices about their private sphere of life.⁴⁸

To address the potentially varied interests of the parties involved, I therefore submit that there is a need to differentiate between the legal consideration of providing information about genetic parent(s) to donor-conceived people, and the issue of whether these parties would like to pursue contact with each other. That is, while in some instances people may desire contact with each other and may form positive relationships, accepting that donor-conceived people should be given access to identifying information about their genetic parent(s) does not in itself imply that all people wish to have such contact. The provision of such information also should not necessitate or obligate contact between the parties – which may be seen as an intrusion upon a person's privacy. The law should therefore provide for situations where the parties do not wish to have contact or to form a relationship.

I submit therefore that this may be achieved by way of enabling a **contact preference system**.⁴⁹ The contact preference system enables a person to express whether and if so how they would be willing to have contact with another person, thus enabling them to make decisions about their intimate sphere of daily life or limiting contact to a form stipulated by a person (eg. Via email, letters, with an intermediary present, or otherwise). It still however allows for information release.

⁴⁷ Sonia Allan, 'Psycho-Social, Ethical and Legal Arguments For and Against the Retrospective Release of Information about Donors to Donor-conceived people in Australia' (2011) 19(1) *Journal of Law and Medicine* 354.

⁴⁸ Ibid. See also Sonia Allan, 'Access To Information about Donors by Donor-Conceived People: A Human Rights Analysis', *Journal of Law and Medicine* (March, 2013).

⁴⁹ See for further discussion of the contact veto system: Sonia Allan, 'Access To Information about Donors by Donor-Conceived People: A Human Rights Analysis', *Journal of Law and Medicine* (March, 2013); Sonia Allan, 'Donor Identification 'Kills Gamete Donation'? A Response to Professor Pennings' *Human Reproduction* (advanced access October, 2012); Sonia Allan, 'Psycho-Social, Ethical and Legal Arguments For and Against the Retrospective Release of Information about Donors to Donor-conceived people in Australia' (2011) 19(1) *Journal of Law and Medicine*; Sonia Allan, 'Donor Conception, Secrecy, and the Search for Information' 19(4) *Journal of Law and Medicine*. 631;

In this way, the donor-conceived person's needs are met regarding identity formation, knowledge about their heritage, medical history, identity, and so on, however a relationship with the donor/donor-conceived person may not follow unless all parties agreed.

I note that the idea of a contact preference system is not new. It has existed in relation to the release of information about birth parents in the adoption context since the 1980s in Australia. As detailed in the book I have written on donor conception and seeking access to information, I also note research on what happened when adoption records were opened in several jurisdictions. That is, I refer the inquiry to a study by Wayne E. Carp on whether opening adoption records had an adverse social impact, in which he considered the retroactive application of laws in the U.S., Great Britain and Australia between 1953-2007 and the implementation of a contact veto or preference system.⁵⁰ The study concluded that a vast gap exists between the *fear* that was initially raised by birth parents and adopted adults that their privacy would be invaded and their family disrupted and the reality that few or no offenses are committed where a contact veto system has been operated. It is striking to me to compare that trajectory of arguments that were raised about retrospective release of information in relation to adoptees to the arguments which has occurred in relation to donor conception over the past years. I implore the committee to recognise the effectiveness that a contact preference system would have in allowing for information release, while providing for choices by parties that would maintain their privacy.

I note further that in 2012, the Victorian Law Reform Committee accepted the suggestion that contact preference system would balance the interests of donor-conceived people and donors, and included it as one of its recommendations in its support for retrospective release of information to donor-conceived people. Laws were enacted on 23 February 2016 to implement such a system with full retrospective release of information to all donor-conceived people conceived in that state coming into force in March 2017. The system has worked effectively.

Note also that retrospective access to information for all donor-conceived people was made possible by law in Switzerland in 2001, which set up a register of donor information for all future children but also included provision for children born before that date to be able to access information about donors via clinics on request. However, retrospective access has proven difficult in that jurisdiction because many files held by clinics have been destroyed.

⁵⁰ E. Wayne Carp, 'Does Opening Adoption Records Have an Adverse Social Impact? Some Lessons from the U.S., Great Britain, and Australia, 1953-2007' 30 *ADOPTION QUARTERLY*.

Germany has also recently recognized a right to information by all donor-conceived people, and that this trumps any rights of donors to privacy—albeit again, due to a lack of central register such information may be difficult to obtain. This again supports a better system that ensures central recording of information.

F. Where should information be held? What else is needed?

The recording and release of information relating to donor conception is not a simple matter. A donor's sperm may be used to by several families, and siblings may also wish to share and exchange information. Information may be held on a central register held either independently of, or as part of, the register of births, deaths, and marriages. Wherever the information is held, it is important to note that some additional support in relation to the collection and release of information may be needed for donor-conceived persons, recipient parents, and donors. This may include intermediary services regarding the linking that needs to occur should donors and donor-conceived persons and/or donor-conceived siblings wish to move to contacting each other.

While some states have established central registers held by stand-alone government authorities (VARTA in Victoria); or health departments (NSW; WA; SA) it is important to recognise that all other birth information for people is held at Births, Deaths, and Marriages. South Australia in its most recent work on the donor-conception register has thus been examining how to link information that is held on the donor-conception register to BDM (noting the Department of Health and Wellbeing has carriage of the legislation relevant to the donor register; and the AG's Department has carriage of BDM).

I submit that in Queensland, taking into consideration the opportunity to establish the register under the remit of the appropriate department:

1. all records should be held at the same central register for donor conception regardless of when a person was conceived—and that this might best be placed at the register for Births, Deaths and Marriages;
2. intermediary support services and/or counselling should be available for donor-conceived, recipient parents and donors in relation to the collection and release of such information if they need them (see further below); and

3. 'contact preferences' should be able to be placed at this register by donors who donated prior to 2004 (since when consent to release of information has been required under NHMRC Guidelines).

Notification of donor-conceived status

I further submit that fundamental to access to information is the need for donor-conceived persons to have knowledge of their conception – and this is where the role of the register of Births, Deaths and Marriages is also crucial. That is, as it is the contention of this submission that donor-conceived people have both a need and a right to know information about their genetic heritage it is important to address the issue of disclosure.

While legislative change removing donor anonymity has in itself played a part in facilitating parental disclosure there may be other ways to encourage disclosure. Counselling and education services should be available to parents and families to facilitate this process. In addition, it is suggested that the inquiry should give consideration to how birth registration and certification may serve to identify a child's genetic heritage.

In Victoria, s153(1) of the *Assisted Reproductive Treatment Act 2008* (Vic) provides for the birth certificate of a donor-conceived child to be annotated with the text 'donor conceived' where a 'birth registration statement' specifies that the child was conceived by a donor treatment procedure. Similarly in legislation drafted (but as yet not enacted) in Ireland, it is proposed that when a person reaches 18 years of age and applies for a copy of his or her birth certificate an tArd-Chláraitheoir shall, when issuing a copy of the birth certificate requested, inform the person that further information relating to him or her is available from the Register. The note shall be released only to the child concerned.⁵¹ Information regarding donor-conceived status is now also recorded on the 'base file' to birth registration in Argentina.⁵² Other approaches include:

- recording both the individual's genetic and social parentage on the birth certificate of a donor conceived person
- the issue of a separate certificate to a donor-conceived person alerting them to the possibility of information held on the Register of Information
- placing a code or symbol on the birth certificate of a donor-conceived person, or

⁵¹ Children and Family Relationships Act 2015 Act No. 9 of 2015.

⁵² Código civil y comercial de la nación, Article 563.

- the issue of two certificates to all people – a ‘Certificate of Birth’, identifying an individual's legal parentage and a ‘Certificate of Genetic Heritage’, indicating where an individual's genetic and legal parentage are different.

None of these proposals are without shortcomings⁵³ and some are more problematic than others. While such matters require far more analysis than that which is possible in this submission, I do believe that at a minimum an annotation to the birth certificate should exist because in order to make a choice about accessing information about their donors, donor conceived individuals must know about the method of their conception in the first place. A second integrated birth-certificate should also be possible.

G. Further Considerations:

i. Age that Donor Conceived Individual May Access Information

In several international jurisdictions (Finland, New Zealand, Norway, Switzerland, the UK) eligibility to request disclosure of the donor's identity is conferred when the donor-conceived person reaches the age of eighteen. This age however may be adjusted in some circumstances. For example, in New Zealand a donor conceived person may apply to the Family Court from age sixteen to be treated as an eighteen-year-old, although the court will need to be satisfied that it is in the individual's best interests to receive the information requested. In other jurisdictions the age is lower. For example, in Austria it is fourteen years, and in the Netherlands and Western Australia it is sixteen years. Sweden alone specifies no age at which the information may be requested, requiring instead that the donor-conceived person has ‘achieved sufficient maturity’.⁵⁴

In Western Australia, a donor conceived individual younger than sixteen years may learn her or his donor's identity, providing that the donor consents and the young person's parent(s) consent on the young person's behalf. Similarly in Victoria, a donor conceived individual that has not yet turned eighteen may learn his or her donor's identity providing the donor consents and the request is made via the young person's parent(s). Pursuant to the *Assisted Reproductive Treatment Act 2008* (Vic), parental or guardian consent will not be required if the young person has received

⁵³ For a detailed critique see E. Blyth, L. Frith, C. Jones, J. Speirs, ‘The Role of Birth Certificates in Relation to Access to Biographical and Genetic History in Donor Conception’ (2009) 172 *International Journal of Children's Rights* 207–33.

⁵⁴ United Nations Committee on the Rights of the Child, 1998.

appropriate counselling and the counsellor judges the individual to be 'sufficiently mature' to understand the consequences of seeking the information.

It is recommended here that access to identifying and non-identifying information be available to donor conceived individuals from the age of eighteen, but that access from a younger age should also be possible with the guidance/support of an adult. This may include a counsellor, youth worker, parent, guardian or other responsible adult.

ii. Intermediary Services and/or Counselling

Intermediary Support Services (meaning a specialist service that engages in 'search' 'find' and 'outreach' services relevant to family linking, and/or providing people with information and support concerning the donor conception register, the release of information, and the option to express contact preferences) should be made available to people who are either accessing information or about whom such information relates. Such services may be provided on an as needs basis, but may also be required in some circumstances such as pre- September 2004 donations.

Counselling, which involves the provision of professional assistance and guidance in resolving personal or psychological problems in relation to donor conception, should be available on a needs basis. It should be readily available for recipient parents, donors and donor-conceived people – although I do note that funding of such services needs to be considered and may differ depending on who is accessing counselling, who is providing such counselling, etc. With this in mind, given that this submission recommends total disclosure and access to information it should be available to assist parents in telling their children about how they were conceived, helping the family address any issues they face in relation to donor conception, and for the donor conceived person if required. It should also be made available to donors to support them in recognising that their donation has resulted in the life of another person who may wish to access information about their genetic heritage and dealing with their feelings about donor-conception, access to information and so on.

NOTE: The provision of support services should not be underpinned by a view that donor conception leads to 'unhealthy outcomes' or negative consequences. That is, while donor

conceived people may wish to have information about their donor and their conception, they may therefore not need 'counselling' but rather need 'support' or 'intermediary' services. Similarly, donors may need support in understanding how the information release system works, and how any contact veto system would operate. Expectation management may also be important. Any such 'support' or 'intermediary' services must therefore cater to the individual needs of the parties involved.

iii. Record Keeping

I believe that all records should be (electronically) transferred to the central register and that there should be a prohibition on destroying or tampering with records currently in existence. (See model for this occurring with the government agency that maintains the register in the Netherlands). If all records were transferred to the register, then it would be of no consequence to the maintenance of records in perpetuity if a clinic closed or doctor holding records passes away. (I note that in the Netherlands the transfer of information to the register was compulsory and was the responsibility of the clinics).

Law should be enacted to prohibit destruction of, or tampering with, such records.

iv. Voluntary registration

It must also be noted that for the large number conceived through donor conception before the implementation of ethical guidelines or the legislation in Queensland which encouraged the retention of records and disclosure of donor identity, the only mechanism to achieve such outcomes is to also provide the opportunity to *voluntarily register information* to promote information-sharing between donors, offspring and/or siblings. Voluntary registration of information should also therefore be possible on the register. This should be possible for all past donors, including those in 'known donor' situations if they can evidence the arrangement and that they are not and have not been in a previous intimate relationship with the other biological parent.⁵⁵

⁵⁵ This latter point is made to avoid the situation in which a legal parent seeks to avoid legal rights and responsibilities by declaring themselves a donor.

H. CONCLUSION

The issues faced by donor-conceived persons concerning information about their genetic heritage and any siblings they may have, are of great importance. Inconsistency amongst states and territories with regards to access to such information creates an unjustifiable position in Australia. This submission calls for Queensland to address the issues faced by donor-conceived persons in their state.

This submission calls for compulsory registration of both identifying and non-identifying information for all donor conceptions regardless of when the donation took place. That is, registration of all identifying and non-identifying information held by clinics, hospitals and doctors surgeries about past and present donations.

It is noted that opponents of disclosing identifying donor information argue that donor privacy should be respected. However, the right to privacy does not and should not trump a person's ability to know important information about their genetic heritage. Whilst retrospective release of information is a sensitive matter, it is possible. There is already a precedent set by the release of identifying information in the adoption context, and in Victoria in relation to donor conception.

Records of information relating to the parties to ART should have been created by all IVF clinics in response to directives from the NHMRC and the Fertility Society of Australia.⁵⁶ However, it must also be noted that for the large number conceived through donor conception before the implementation of ethical guidelines or the legislation in Queensland which encouraged the retention of records and disclosure of donor identity, the only mechanism to achieve such outcomes is to also provide the opportunity to *voluntarily register information* to promote information-sharing between genetic parent(s), donor-conceived people and/or siblings. Voluntary registration of information should also therefore be possible on the register.

The Register of Births Deaths and Marriages may play an important role. It may be a preferred site for the register in Queensland. It is also my submission that the Register of Births, Deaths and Marriages should annotate the birth certificate of a donor conceived individual to alert

⁵⁶ Parliament has power to enact legislation with retrospective effect if it chooses, and modern statutes often contain specific provisions allowing for the prospective and retrospective operation of other provisions within the legislation.

them to the fact they are donor conceived. Knowing such notation will be given to the donor-conceived person may encourage parents to disclose.

It is also my submission that Queensland works towards ensuring that intermediary support services and counselling are available to recipient parents, donors and donor-conceived persons in the move towards openness and sharing of information.

In Australia there are thousands (possibly tens of thousands) of individuals who have been donor conceived. Some of those individuals may wish to know about their genetic heritage, as might their children and generations after them, including those conceived and born in Queensland. They deserve the right to choose. It is not acceptable to maintain or protect the secrecy that was involved in some of their conceptions. The law needs to be changed to provide them, and future donor conceived individuals, access to identifying and non-identifying information about their donors and their biological siblings.

I thank you for the opportunity to make this submission and look forward to seeing positive changes to the law occur in Queensland. I would be more than happy to contribute in any way I can to see this happen.

Kind regards,

A handwritten signature in black ink, appearing to read 'SAllan'.

Dr Sonia Allan OAM CF PhD

SUMMARY OF SUBMISSION:

- Queensland must address the issues faced by donor-conceived persons in their state regarding access to information about their donors.
- Compulsory registration of both identifying and non-identifying information for all donor conceptions regardless of when the donation took place should occur (including registration of all identifying and non-identifying information held by clinics, hospitals and doctors surgeries about past donations).
- All records should be held at the same central register for donor conception – I suggest that such a register would be best placed at the register for Births, Deaths, and Marriages.
- Intermediary support services and counselling should be available for donor-conceived, recipient parents and donors in relation to the collection and release of such information on a per needs basis.
- A 'Contact preference system' should be implemented in relation to pre-2004 donations.
- Voluntary registration of donor information should also be possible and encouraged – this should be available to known donors, and donors where records may have been destroyed to place their information on this register.
- Queensland should annotate the birth certificate of a donor conceived individual to alert them to the fact that further information that they may wish to obtain is held on the Central Register; and consider the option of allowing integrated birth certificates if a person wishes one to be issued.
- Access to identifying and non-identifying information should be made available to donor conceived individuals from the age of eighteen and from a younger age should also be possible with the guidance/support of an adult – this may include a counsellor, youth worker, parent, guardian or other responsible adult.

APPENDIX 1: Books, Articles, and Submissions that discuss arguments concerning release of information to donor conceived people about their donors

Books

- Lauren Burns, *Triple Helix: My donor-conceived story*. 2022
- Sarah Dingle, *Brave New Humans: The Dirty Reality of Donor Conception* 2021
- S.Allan, *Donor Conception and the Search for Information: From Secrecy and Anonymity to Openness?* Routledge, Oxford (2017).
- Juliet R. Guichon, Ian Mitchell, Michelle Giroux (eds) *The Right to Know One's Origins* ASP (2012).

Relevant articles by the Submitter:

- Rafał Łukasiewicz, Sonia Allan, 'Donor-matching' in Third-party Reproduction: a Comparative Analysis of Law and Practice in Europe, *International Journal of Law, Policy and the Family*, Volume 36, Issue 1, 2022, ebac006, <https://doi.org/10.1093/lawfam/ebac006>
- Macmillan, C., Allan, S., Johnstone, M. and Stokes, M. (2021), 'The motivations of donor-conceived adults for seeking information about, and contact with, sperm donors', *Reproductive Biomedicine Online*, vol 43, no 1 , pp 149 - 158.
- Sonia Allan, 'Donor Identification: Victoria Gives Rights to All Donor Conceived People' AIF *Family Matters*. (September 2016).
- Sonia Allan, 'Access to Information about Donors by Donor Conceived Individuals: A Human Rights Analysis' (2013) 20 *Journal of Law and Medicine* 655.
- Sonia Allan, 'Deciding on access to donor-conception information' (2012) 37(4) *Alternative Law Journal* 272, 272.
- Sonia Allan, 'Donor Identification Kills Gamete Donation'? A Response to Professor Pennings' (2012) 27(12) *Human Reproduction* 3380.
- Sonia Allan, 'Donor Conception, Secrecy, and the Search for Information' 19(4) *Journal of Law and Medicine* (June 2012).
- Sonia Allan, 'Psycho-Social, Ethical and Legal Arguments For and Against the Retrospective Release of Information about Donors to Donor-conceived persons in Australia' (2011) 19(1) *Journal of Law and Medicine* 354.

Articles Commissioned for Special Edition of Journal of Law and Medicine (June 2012) (Submitter was special Editor)

- Sonia Allan, 'Donor Conception, Secrecy, and the Search for Information' (2012) 19(4) *Journal of Law and Medicine*. 631.
- Damian Adams and Caroline Lorbach, 'Accessing donor conception information in Australia: A call for retrospective access' (2012) 19(4) *Journal of Law and Medicine* 707.
- Richard Chisholm, 'Information rights and donor conception: Lessons from adoption?' (2012) 19(4) *Journal of Law and Medicine* 722.
- John Tobin, 'Donor-conceived people and access to information about their genetic origins: The relevance and role of rights' (2012) 19(4) *Journal of Law and Medicine* 742.

- Anne Reese, 'Keeping mum about dad: "Contracts" to protect gamete donor anonymity' (2012) 19(4) *Journal of Law and Medicine* 758.
- Eric Blyth, Marily Crawshaw, Lucy Frith and Caroline Jones, 'Donor-conceived people's views and experiences of their genetic origins: A critical analysis of the research evidence' (2012) 19(4) *Journal of Law and Medicine* 769.
- Naomi Cahn, 'Legal parent versus biological parent: The impact of disclosure' (2012) 19(4) *Journal of Law and Medicine* 790.

Government Reports:

- Senate Legal and Constitutional Affairs References Committee, *Donor Conception Practices in Australia* (2011)
- Victorian Law Reform Committee, *Inquiry into Access by Donor-conceived People to Information about the Donors* (March 2012).

Reports written by Submitter

- Sonia Allan, *The Review of the Western Australian Human Reproductive Technology Act 1991 and the Surrogacy Act 2008 (Part 1)* (Jan 2019)
- Sonia Allan, *The Review of the Western Australian Human Reproductive Technology Act 1991 and the Surrogacy Act 2008 (Part 2)* (Jan 2019)
- Sonia Allan, *Report: South Australian Review of the Assisted Reproductive Treatment Act 1988* (2017). Report prepared for the Minister of Health South Australia regarding legislative review of Act.
- Sonia Allan, *A Cross-Jurisdictional Study of Regulatory Requirements and Practice Regarding the Recording of Donor Information and its Release to Donor Conceived People*, 2012. Report prepared for the Winston Churchill Memorial Trust.

Videos

Australian Story – regarding Lauren Burns and other donor conceived people here:

- <https://www.abc.net.au/austory/searching-for-c11---part-1/5777004>
- <https://www.abc.net.au/austory/searching-for-c11---part-two/5776986>
- [https://www.abc.net.au/austory/in-the-name-of-the-child-lauren-burns-\(update\)/13628868](https://www.abc.net.au/austory/in-the-name-of-the-child-lauren-burns-(update)/13628868)

Insight – where donor-conceived people talk about how knowing a name is important to them (with differing views):

- <https://www.sbs.com.au/ondemand/watch/52724803732>

Presentation in the United Nations for the 30th Anniversary of the Convention on the Rights of the Child:

- <https://www.youtube.com/watch?v=GEP3ZGPFdeQ>