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Secretary Community Safety & Legal Affairs Committee Queensland Parliament

Email: CSLAC@parliament.qld.gov.au

Dear Reader

REVIEW OF ASSISTED REPRODUCTIVE TECHNOLOGY BILL 2024

Thank you to the Committee for giving me the opportunity to make a submission. I consent to my submission being published. If asked, I would be honoured to give evidence.

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SUMMARY

I am very happy with the contents of the Bill. I am also very happy with the process steered by the ART review team that has led to the tabling of the Bill.

I propose eight minor changes to the Bill:

• Clause 7(2) be changed to:

"(2) However, an *ART provider* does not include a person who provides an ART service on behalf of an ART provider."

- Clause 20 that the withdrawal of consent be up until only any time before the treatment cycle of the recipient commences, or at any time before the creation of an embryo, whichever is sooner, consistent with paragraphs 5.12 and 6.4 of the National Health and Medical Research Council, *Ethical Guidelines on the use of assisted reproductive technology in clinical practice and research* (2017 updated 2023), and that in respect of the withdrawal of consent for donor embryos this be by the embryo donors (not the gamete providers).
- Clause 25(3), as to due diligence to check that the limit on donations is able to be complied with, that the ART provider is able to inquire of the Registrar whether the name of the prospective donor is on the donor conception information register, and how many donations (whether through an Australian or overseas ART provider or private donation) from that donor are recorded.
- Clause 48- that an Australian ART provider may be able to be supplied information by the Registrar so that the ART provider can comply with its due diligence requirements under cl.25(3), or under a corresponding interstate law or the RTAC *Code of Practice*¹ to limit the number of recipient families from donation.
- There ought to be a provision in the Bill like s.103 of the *Births, Deaths and Marriages Registration Act 2023* (Qld), allowing for reciprocal administrative arrangements with interstate donor registries.
- Clause 40 change the definition of *private donor conception procedure* from:

"means a self-insemination procedure using a donated gamete that was carried out in Queensland"

to:

"means a self-insemination procedure using a donated gamete that was carried out in Queensland (or outside Queensland, if the donor, parent or donor-conceived person resides in or resided in Queensland)."

- Clause 47 amend from:
 - "(1) The parties to a private donor conception procedure may provide the Registrar with all or any relevant information relating to the birth of a donor-conceived person as a result of the procedure.

¹ It could be drafted as its conditions of accreditation, but it should be easier to understand by stating that it is the RTAC *Code of Practice*.

- (2) The parties to a private donor conception procedure are the donor of any gamete used in the procedure and the parents of the donor-conceived person.
- (3) The provision of information of the Registrar requires
 - (a) the written consent of all the parties to the procedure; or
 - (b) if any party has since died the written consent of all the remaining parties to the procedure and evidence of the death of that party.
- (4) Evidence that a party to the procedure has since died is a relevant statutory declaration by the remaining parties or any other evidence authorised by regulation."

to:

- "(1) A party to a private donor conception procedure may provide the Registrar with all or any relevant information relating to the birth of a donor-conceived person as a result of the procedure.
- (2) The parties to a private donor conception procedure are the donor of any gamete used in the procedure and the parents of the donor-conceived person."
- That there be a statutory review in say 3 to 5 years, to measure its effectiveness.

The Bill deals with four areas concerning assisted reproductive treatment in Queensland:

- 1. End of discrimination
- 2. Licensing of IVF clinics
- 3. Posthumous use and retrieval
- 4. Central register and retrospective transparency

1. END OF DISCRIMINATION

Almost 30 years ago, a lesbian sought treatment from Queensland's largest IVF clinic, Queensland Fertility Group, which declined to provide treatment based on guidance from Queensland Health. She challenged that refusal and was successful before the Queensland Anti-Discrimination Tribunal². QFG then sought a review of that decision in the Supreme Court and was successful³. She then appealed, unsuccessfully, to the Court of Appeal⁴.

Immediately after QFG cleared its name of government imposed discriminatory practice, it provided access to single women and lesbians. The then Government failed to defend its own guidelines, which were then ignored by QFG.

After that case was decided, in 2002, the *Anti-Discrimination Act 1991* was amended⁵ by the insertion of s. 45A, which provides:

² JM v. QFG and GK and Queensland [1997] QADR 5.

³ *QFG* & *GK v. JM* [1997] QSC 206.

⁴ *JM v. QFG & GK* [1998] QCA 228.

⁵ Discrimination Law Amendment Act 2002, s.19.

- "(1) Section 46 does not apply to the provision of assisted reproductive technology services if the discrimination is on the basis of relationship status or sexuality.
- (2) In this section:

"assisted reproductive technology services" means:

- (a) services provided in the course of, or for the purpose of, any of the following:
 - *(i) in-vitro fertilisation;*
 - (*ii*) artificial insemination;
 - (iii) gamete, zygote or embryo transfer; or
- (b) any other services provided for the purpose of assisting in artificial fertilisation."

In 2013, the Sex Discrimination Act 1984 (Cth) was amended, relevantly in s. 22 to read:

"It is unlawful for a person who, whether for payment or not, provides goods or services, or makes facilities available, to discriminate against another person on the ground of the other person's sex, sexual orientation, gender identity, intersex status, marital or relationship status, pregnancy or potential pregnancy, or breastfeeding:

- (a) by refusing to provide the other person with those goods or services or to make those facilities available to the other person;
- (b) in the terms or conditions on which the first-mentioned person provides the other person with those goods or services or makes those facilities available to the other person; or
- (c) in the manner in which the first-mentioned person provides the other person with those goods or services or makes those facilities available to the other person."

Those amendments to s.22 to include the attributes of sexual orientation, gender identity, intersex status and relationship status arose primarily because of concerns raised in the United Nations Human Rights Council about the failure of Australia to protect LGBTQIA+ people and continue to discriminate against them as a group.

As a political compromise, regulations commenced under the *Sex Discrimination Act* to allow the States to bring their laws into line, with an exemption applying in respect of every State (except Western Australia) until 1 August 2016 and, in respect of Western Australia until 1 August 2017.

I first wrote to the then and current Attorney-General Ms D'Ath eight years ago seeking the repeal of this provision, which is repugnant in its terms, and invalid constitutionally.

Australians voted overwhelmingly in 2017 for marriage equality, resulting in amendments to the *Marriage Act 1961* (Cth) that year.

It is clear that s.45A runs contrary to s.22 of the *Sex Discrimination Act*, and is therefore, by virtue of s.109 of the *Commonwealth Constitution*, invalid. By contrast to s.45A, the *Surrogacy Act 2010* (Qld) does not discriminate on who can be parents (single or couple) nor about who is a surrogate (single or couple).

Human rights recognised under the *Human Rights Act 2019* (Qld) include recognition and equality before the law⁶, not to arbitrarily interfere with a person's privacy, family or home⁷, and that families are the fundamental group unit of society and are entitled to be protected by society and the State⁸. International human rights jurisprudence has recognised a right to ART as being part of the rights to non-discrimination, privacy and family⁹.

Discrimination in recent years based on sexuality or relationship status, aside from Queensland, has existed in this area in the Australian Capital Territory, South Australia, the Northern Territory and Western Australia.

Australian Capital Territory

The *Parentage Act 2004* (ACT) does not discriminate on the basis of relationship status¹⁰ concerning surrogacy arrangements but requires that a couple undertake surrogacy and that the surrogate be part of a couple¹¹. The *Parentage (Surrogacy) Amendment Bill 2023* (ACT) proposes to remove those requirements, so that an individual can undertake surrogacy, and a surrogate can be single¹². That Bill was passed by the Legislative Assembly yesterday, and is to commence on the day after notification, therefore likely by the end of this week.

South Australia

South Australia discriminated on the basis of sexuality and against singles in the availability of surrogacy. It ceased discriminating against same-sex couples with surrogacy in 2017 and ceased discrimination against single intended parents with surrogacy with the commencement of the *Surrogacy Act 2019* (SA).

Section 9 of the Assisted Reproductive Treatment Act 1988 (SA) sets out conditions of registration. Section 9(1)(ba) says that a condition of registration:

"Subject to subsection (1a), a condition prohibiting the person from refusing to provide assisted reproductive treatment to another on the basis only of the other's sexual orientation or gender identity, marital status or religious beliefs".

Section 9(1a) provides:

"Section 9(1)(ba) does not apply to a registered objector but, in that case, it is instead a condition of the registered objector's registration that the registered objector take steps to refer the person seeking assisted reproductive treatment to another person who is registered under this Part."

Section 8(2)(ba) and (3) provide:

"The Register must include, in relation to each person on the Register—

(ba) if the person notifies the Minister that the person has a religious objection to the provision of assisted reproductive treatment to another on the basis of the other's sexual orientation or gender identity, or marital status—that fact; and

⁶ S.19.

⁷ S.25.

⁸ S.26(1).

⁹ Murillo v. Costa Rica (2012), Inter-American Court of Human Rights; Dickson v. United Kingdom (2007) ECtHR Application No. 44362/04.

¹⁰ *Parentage Act 2004* (ACT), ss. 24, 26(3)(b).

¹¹ Parentage Act 2004 (ACT), ss. 23, 24, 26(1)(b).

¹² Parentage (Surrogacy) Amendment Bill 2023 (ACT), cl. 8.

(3) A person referred to in subsection (2)(ba) may, for the purposes of this or any other *Act, be referred to as a registered objector.*"

Northern Territory

Section 4(8) of the *Anti-Discrimination Act 1992* (NT) allowed for discrimination in artificial fertilisation procedures. I was part of the Northern Territory Government's joint surrogacy working group, which led to the enactment of the *Surrogacy Act 2022* (NT). I pointed out this discriminatory provision. I was told that it would be no doubt addressed when there was to be a review of the *Anti-Discrimination Act 1992* (NT). I took the view that the discrimination should end immediately and not wait for the review. I was delighted that the Government agreed. That provision was repealed with the commencement of the *Surrogacy Act 2022* (NT)¹³.

Western Australia

The *Surrogacy Act 2008* (WA) discriminates against single men and male couples¹⁴. It is likely that it also discriminates against, in some circumstances, transgender, intersex or non-binary people. The McGowan Government sought to remove this discrimination in 2018, but the Bill was not enacted. The Western Australian Government has announced that there will be a Bill to replace the *Human Reproductive Technology Act 1992* (WA) and the *Surrogacy Act 2008* (WA) soon, when it is expected that this discrimination will be removed, but that has not yet occurred.

A State law providing restriction as to availability of assisted reproductive treatment which falls foul of s.22 of the *Sex Discrimination Act 1984* (Cth) is invalid, as was seen in South Australia¹⁵, in Victoria¹⁶, and again more recently in Victoria¹⁷. S.22 has not been tested relating to LGBTQIA+ issues, but it is likely to be valid¹⁸.

In its review of the Anti-Discrimination Act 1991, Building Belonging, the Human Rights Commission noted that Queensland Fertility Group "actively advertises to and provides services for same-sex couples and single parents"¹⁹. The review considered that:

- There is no justification to retain the assisted reproductive technology services provision because it:
 - \circ is redundant.
 - does not meet currently community standards.
 - may be invalid under the Constitution.
 - may be incompatible with the *Human Rights Act*.

Recommendation 44 states:

"The Act should repeal the Assisted Reproductive Technology provision which allows discrimination on the basis of sexuality or relationship status in the area of goods and services."

¹³ Surrogacy Act 2022 (NT), section 61.

¹⁴ Surrogacy Act 2008 (WA), s. 19(2).

¹⁵ Pearce v South Australian Health Commission (1996) 66 SASR 486; [1996] SASC 6233; [1996] SASC 5801.

¹⁶ McBain v Victoria [2000] FCA 1009.

¹⁷ *EHT18 v Melbourne IVF* [2018] FCA 1421.

¹⁸ Toonen v. Australia, Communication No. 488/1992, U.N. Doc CCPR/C/50/D/488/1992 (1994).

¹⁹ p.398.

The Government accepted that recommendation.

I was keen that this Bill repealed s.45A, as I conveyed to the ART review team. I am delighted that the repeal of section 45A is proposed in clause 155.

In practice, I am not seeing discrimination occur. The second largest IVF clinic in Queensland, City Fertility, has for some years also operated as Rainbow Fertility, specifically marketed towards LGBTQIA+ patients. As a matter of course, Queensland IVF clinics provide services to LGBTQIA+ patients.

In addition to their obligations under section 22 of the *Sex Discrimination Act*, Queensland IVF clinics are required to comply, as part of their accreditation with the Fertility Society of Australia and New Zealand with the National Health and Medical Research Council, *Ethical Guidelines on the use of assisted reproductive technology in clinical practice and research (2017, updated 2023)*. Guiding Principle 7 provides:

"Processes and policies for determining an individual's or a couple's eligibility to access ART services must be just, equitable, transparent and respectful of human dignity and the natural human rights of all persons, including the right to not be unlawfully or unreasonably discriminated against."

This then goes on to explain:

"In determining an individual's or a couple's eligibility to access ART services, there must be no unlawful or unreasonable discrimination, for example, on the basis of:

- race, religion, sex, sexual orientation, relationship status, gender identity or inter-sex status or social status, disability or age
- *the reason(s) for seeking assisted conception*
- refusal to participate in research. The right of an individual or a couple to accept or reject specific procedures or treatment should be respected. However, where the choice of an individual or a couple is in conflict with the current clinical evidence of practice, it is likely to have an adverse effect on the person who would be born, or as demonstrable adverse social impacts (e.g. the transfer of multiple embryos at the one time), then it is appropriate that these factors are taken into account in decision-making regarding the procedure. There are circumstances where it is reasonable for a clinician to delay treatment or decline to treat an individual or couple.
- Conscientious Objection

A member of staff or a student who expresses a conscientious objection to the treatment of an individual patient or to an ART procedure is not obliged to be involved in that treatment or procedure, so long as the objection does not contravene relevant anti-discrimination laws and does not compromise the clinical care of the patient (e.g. the patient is referred to someone without a conscientious objection and is willing to accept their care). The clinic must allow a member of staff or a student who expresses a lawful conscientious objection to withdraw from involvement and ensure that the member of staff or student is not disadvantaged because of their lawful conscientious objection."

2. LICENSING OF IVF CLINICS

Under a Commonwealth Act, every IVF clinic in Australia must be accredited with the Fertility Society of Australia and New Zealand²⁰. That Act allows for the operation of State laws²¹. The *Research Involving Human Embryos and Prohibition of Human Cloning for Reproduction Act 2003* (Qld) has been declared to be a corresponding State law for the purposes of the Commonwealth Act²². In addition to the requirement under the Commonwealth Act, every IVF clinic in Queensland must be accredited under the Queensland Act with the Fertility Society of Australia and New Zealand²³. Each IVF unit must enter into a deed with the Fertility Society of Australia and New Zealand²³. Each IVF unit must enter into a deed with the Fertility Society of Australia and New Zealand. Among other requirements of that deed are to comply with the *Code of Practice*. The *Code of Practice* requires, among other things, compliance with the law and compliance with the *Ethical Guidelines*. The *Ethical Guidelines* are, in effect, licensing requirements imported into the *Code of Practice*²⁴. They are not law, but if not complied with, the accreditation of the IVF unit is at risk. Given the capital that is invested by clinics, the risk of loss of accreditation and therefore the loss of the business and millions of dollars invested with the business is potentially considerable.

The *Ethical Guidelines*, in the words of the NHMRC²⁵:

"(P)rovide an overarching framework for the conduct of ART in both clinical practice and research and, when read in conjunction with federal and state or territory legislation, create a robust framework for the conduct of ART in Australia."

I would agree with that assessment.

Nevertheless, the ability of the Fertility Society to take action against an IVF clinic is limited to undertaking audits, and making a determination that the clinic is non-compliant, which would result in loss of accreditation. The Fertility Society does not have the legislated powers to do more. The Fertility Society, in imposing requirements on clinics, cannot act as a cartel²⁶ under the *Competition and Consumer Act 2010* (Cth).

The Fertility Society is conscious of its social licence and those of IVF clinics throughout Australia, and the thicket of inconsistent legislation governing the industry, particularly between Australian States. The Fertility Society has commissioned former Health Minister Professor Greg Hunt and Dr Rachel Swift, an embryologist and public health expert, to undertake a comprehensive review of governance and standards within the IVF industry across Australia and New Zealand. This review will culminate in the development of a detailed 10-year roadmap aimed at establishing uniform national legislation for ART and IVF providers in Australia, while continuing to align with New Zealand's principles of the *Human Assisted Reproductive Technology Act 2004*.

 ²⁰ Research Involving Human Embryos Act 2002 (Cth), s. 10(2)(d), s. 8 definition of accredited ART Centre.
 ²¹ S. 42.

²² Declaration by Greg Hunt, Minister for Health, 26 September 2018.

²³ Research Involving Human Embryos and Prohibition of Human Cloning for Reproduction Act 2003 (Qld), ss. 23 and 21 – meaning of accredited ART centre; Research Involving Human Embryos and Prohibition of Human Cloning for Reproduction Regulation 2015 (Qld), reg. 2.

²⁴ Where the *Ethical Guidelines* have been imported into the Fertility Society of Australia and New Zealand's Code of Practice: *Clark v Macourt* [2013] HCA 56 at [121].

²⁵ Ethical Guidelines, p.11.

²⁶ Some years ago, the American Society for Reproductive Medicine specified rules to IVF clinics in the United States as to a cap to be paid to egg donors. A subsequent court case brought by disgruntled would be egg donors who alleged that the ASRM acted as a cartel resulted in a settlement, which included dropping the cap.

The review and strategic plan are focused on enhancing accessibility to safe and effective fertility treatments for families across Australia and New Zealand. While Australia and New Zealand already boast one of the world's safest and most successful IVF sectors²⁷, factors such as the increasing median age for women giving birth and advancements in technologies like genetic carrier screening through the Australian publicly funded Mackenzie's Mission program are expected to significantly increase the number of children born by ART and IVF over the next decade.

Since 2004, there has been a requirement under the *Ethical Guidelines* for open identity donation, in other words that when the child becomes an adult, the child can find out the identity of the donor. Since that time, there has also been a requirement on a cap of the number of recipient families. That cap has commonly been seen to be 10 families.

A consistent concern by consumers is the cost of IVF. A concern I have about having a licensing regime in Queensland is that, with the commencement of licensing in Queensland, there will be eight different licensing regimes for a country of 27 million (not much bigger than the population of one city, Shanghai). Most Queensland IVF clinics operate across State borders²⁸. Each additional inconsistency that arises across Australian State borders means extra compliance costs for most Queensland IVF clinics, which higher costs invariably are then sooner or later passed on to consumers.

I hope that there will, instead of there being eight different variations in regulation of IVF clinics nationwide, be one system – either with national laws or at least nationally consistent laws. However, I am not seeing any push by any Government for that outcome. As the Fertility Society has identified, a national IVF industry exists, which should be subject to nationally consistent rules, so that the current complexity is reduced, and the cost to consumers is reduced.

Queensland will join the licensing of IVF clinics that exists in New South Wales, South Australia, Victoria and Western Australia, and is soon likely to exist in the Australian Capital Territory, when the relevant provisions of the *Assisted Reproductive Technology Act 2024* (ACT) commence.

If this Bill is enacted, Tasmania alone will only require compliance with the *Ethical Guidelines*. The Northern Territory, in theory, requires only compliance with the *Ethical Guidelines*. The Northern Territory does not have an ART Act. There is only one IVF clinic in the Northern Territory. It has a contract with the Northern Territory Government that, in exchange for that Government providing travel subsidies for patients, the clinicians will, so far as possible, comply with South Australian licensing conditions.

The Government has taken the policy position that regulation will be undertaken by Queensland Health and not by a separate statutory body. In my view, that is the right call. Separate statutory bodies only exist in Victoria (Victorian Assisted Reproductive Treatment Authority – VARTA) and in Western Australia (Reproductive Technology Council – RTC). In each of those States, there has been considerable criticism about the effectiveness of those organisations, to such an extent that the Victorian Government has undertaken a review with the intention of abolishing

²⁷ By way of examples, the third IVF conceived baby, Candice Reed was born in Australia in 1980; the first baby conceived from a donated egg was born in Australia in 1983; Australian and New Zealand IVF clinics have been trailblazers worldwide in pioneering single embryo transfers, contributing to among the lowest maternal mortality rates internationally and minimising risks to newborns; Australia is pioneering (after the UK) mitochondrial donation, to prevent this awful disease being transmitted to children; transparency through publication of IVF clinics' data- and therefore being able to measure outcomes in an objective manner both through the Australian and New Zealand Assisted Reproductive Database (ANZARD) and by most clinics with <u>www.yourivfsuccess.com.au</u>.
²⁸ Of the 24 Queensland IVF units, only two do not operate as part of a group across State borders: CARE Fertility, at Greenslopes, and Coastal IVF, at Maroochydore.

VARTA and taking its powers largely inhouse, and in Western Australia the Government has undertaken now two reviews, the effect of which has been, in practice, to strip away some of the work undertaken by the RTC, and with the intent of if and when any Bill is enacted, to replace the RTC with a more responsive structure.

SPECIFIC PROVISIONS

Clause 7: meaning of *ART provider*

It will be an offence to provide an ART service unless the person is a licensed ART provider: cl.12. Any ART service must be provided by, or under the supervision of a medical practitioner: cl.13. What is an ART service is defined in cl. 6.

What is an ART provider is defined in cl.7:

"(1) An ART provider is a person who provides an ART service.

(2) However, an **ART provider** does not include a person who provides an ART service on behalf of a licensed ART provider under a contract of employment or a contract for services."

My submission is that: "under a contract of employment or a contract for services" be deleted.

The intent of the provision is that anyone who provides an ART service on behalf of a licensed ART provider will fit under the coverage or umbrella of the licensee. There is not the requirement (and nor should there be), that every fertility doctor, fertility nurse and embryologist must be a licensed ART service, and therefore have RTAC accreditation²⁹, as well as the State licence. Instead, the IVF clinic will be the licensed ART provider, and those who provide the service on its behalf fit under its umbrella. The clause is copied from the ACT Act³⁰. Each of New South Wales, South Australia, Victoria and Western Australia have approached this issue slightly differently in form, but the intent is the same- the IVF clinic is registered or licensed, and those who do the work for it fit under its umbrella, so that those which have RTAC accreditation are the ones who also have State registration or licensing.

A fertility specialist has raised concerns with me that cl.7(2) might have the unintentional effect of stopping all IVF in Queensland, because the fertility specialists will not come, in my language, under the umbrella.

I do not profess to be an expert on financial arrangements between fertility specialists and their clinics. However, from my practice as a family lawyer, I have seen that it is common for medical specialists to have service companies, which in turn are trustees of family trusts. Those service companies provide facilities and employ staff. Some doctors also have separate companies for the derivation of income. Sometimes these entities under the control of doctors enter into partnerships, limited partnerships, service agreements, licensing agreements or joint ventures with others.

My point is that the medical practitioner who undertakes the work on behalf of the IVF clinic, for example, who retrieves an egg from a patient for the use in IVF, and is therefore providing an ART service under cl. 6 *"obtaining a gamete from a gamete provider for use in an ART procedure"* may not be employed by the IVF clinic or may not be under a contract for services

²⁹ Cl.57(1)(a).

³⁰ S.11.

with the IVF clinic. The medical practitioner's entity might have that contract for services, or it might have a partnership, limited partnership, licensing agreement or joint venture with the clinic.

In my view, the essence of the sub-clause is that the work that is done is done on behalf of a licensed ART provider. It unnecessarily complicates matters by requiring the person who is performing an ART service to say that they must be *"under a contract of employment or a contract for services"* with the IVF clinic. Those words are unnecessary, add confusion, and therefore can and should be deleted from the text.

Clause 17: consent to export

One may think, upon reading clause 17, that without the written consent of a gamete provider, there cannot be, for example, export of the gametes from Queensland. This section is modelled in large part upon similar provisions of the *Assisted Reproductive Technology Act 2007* $(NSW)^{31}$. There have been a series of cases in the Supreme Court of New South Wales³² in which those provisions have been considered where widows have enabled the posthumous retrieval of sperm from their late husbands.

On the face of the New South Wales Act, the widows are unable to use that sperm because the gamete provider (their late husband) did not provide written consent to use, or supply or export³³. Instead, the Supreme Court of New South Wales has ruled consistently that the widows own the sperm and that it is not owned by the clinics. Therefore, any penalty that applies to an ART provider does not apply to the widow. Therefore, although I consider it unlikely, in light of the provisions concerning posthumous retrieval and use (discussed below) that widows will be seeking to export their late husbands' sperm, if they were to seek to do so, in my view they would not be prevented from doing so as clauses 16 and 17 apply to the clinics and not to the widows.

Clause 18(3): no discrimination as to donation

I am delighted to see that in 18(3) the gamete provider cannot limit the use of the donated gamete or donated embryo on the basis of a protected attribute under the *Anti-Discrimination Act 1991*.

This contrasts with section 17(2) of the New South Wales Act:

"A gamete provider's consent may address such matters as the uses that may be made of the gamete (or an embryo created using the gamete) and whether the gamete or embryo may be stored, exported from this State or supplied to another ART provider."

The New South Wales Minister in the Second Reading Speech about clause 17 of the ART Bill said:

"Clause 17 of the Bill allows a gamete donor to place conditions on their consent, including condition that directs their gametes can only be used by a particular person or a particular classification of people.

For example, people of particular cultural or ethnic background may only consent to the use of their gametes by people from a similar background.

³¹ S.21 to 23, and in respect of export, s.22.

³² For example, *Re Edwards* [2011] NSWSC 478.

³³ Assisted Reproductive Technology Act 2007 (NSW), ss.21, 22, 23.

The ability for donors to place conditions on the use of their gametes is especially important because any child born as a result of that donation will be able to identify their genetic parents and may wish to contact or meet them.

It is believed to be in the best interests of the child for the genetic parent to have given consent to the circumstances surrounding the child's birth and upbringing.

To put this in another way, it will not be in the child's best interests to discover later in life that their genetic parent has a fundamental objection to the existence or the social and cultural circumstances in which they were raised."

While those are noble sentiments, if that approach had been followed in the Bill, it would likely ensure that Queensland IVF clinics would be in breach of the *Sex Discrimination Act 1994* and the *Racial Discrimination Act 1975* (Cth), among others. The Bill takes a far better approach, both ensuring that there is not discrimination, nor breach of Commonwealth law.

Clause 20: withdrawal or variation of consent

This clause, modelled on a provision in the NSW Act^{34} , causes me some concern. That concern was raised with me by Queensland ANZICA³⁵ members when I ran a webinar about the Bill. Clause 20(1) provides:

"The consent of a gamete provider under this division may be modified or withdrawn at any time until -

- (a) for a donated gamete, other than a gamete that becomes a donated gamete only after being used to create an embryo – the gamete is placed in a person's body or an embryo is created from the gamete; or
- *(b) for a gamete used to create a donated gamete the embryo is implanted in a person's body; or*
- (c) in any other case the gamete, or an embryo created from a gamete, is placed or implanted in a person's body."

This is a major change from the current requirements under the *Ethical Guidelines*, which is that consent can be withdrawn until the commencement of the treatment cycle, not until immediately before treatment.

Paragraphs 5.11 and 5.12 of the *Ethical Guidelines* provide:

"Responsibility for Gametes

5.11 Ensure that all parties are aware of who is responsible for decision-making about the use, storage and discard of donated gametes

Recipients of donated gametes need to know who is responsible for the gametes and resulting embryos used in their treatment. At the same time, the right of the gamete donor to withdraw their consent for donation also needs to be protected (see paragraph 5.12).

³⁴ S.17.

³⁵ Australia & New Zealand Infertility Counsellors Association.

- 5.11.1 Clinics must maintain clear procedures for the transfer of responsibility for gametes and the resulting embryos at each stage.
 - When the gamete donor has not specified a recipient for their gametes (unknown donation), the clinic has responsibility for decision-making about the allocation, storage and discard of the gametes, subject to any directions or limitations expressed in the consent of the donor. Once allocated, the responsibility for decision-making is transferred to the recipient (see paragraph 6.2).
 - When the gamete donor has specified a recipient for their gametes (known donation), and consent for treatment has been given by the recipient, the recipient has responsibility for decision-making about the use, storage and discard of the gametes or resulting embryos, subject to any directions or limitations expressed in the consent of the donor (see paragraph 6.2).
 - The clinic is responsible for maintaining the appropriate storage of donated gametes (see Chapter 7).

Withdrawal of consent for donation

- 5.12 Recognise the right of an individual to withdraw or vary their consent
 - 5.12.1 A gamete donor can withdraw or vary consent for donation at any time before the treatment cycle of the recipient commences, or at any time before the creation of an embryo, whichever is sooner."

Paragraph 6.2 provides:

"Responsibility for donated embryos

6.2 Ensure that all parties are aware of who is responsible for decision-making about the use, storage and discard of donated embryos

Recipients of donated embryos need to know who is responsible for decision-making about the embryos used in their treatment. At the same time, the rights of the embryo donor(s) to place limitations on the use, storage and discard of the donated embryos and to withdraw their consent for donation also need to be protected (see paragraphs 4.6.1 and 6.4). Clinics must have clear procedures for the transfer of responsibility for embryos at each stage.

- The embryo donors are responsible for decision-making about the use, storage and discard of an embryo whilst it is in storage awaiting donation to an identified individual or couple (known donation), or to another individual or couple (unknown donation).
- The clinic is responsible for maintaining the appropriate storage of an embryo, as outlined in Chapter 7.
- In circumstances involving unknown donation, the clinic is also responsible for the allocation of an embryo to an individual or couple.

- Once a recipient individual or couple has accepted a donated embryo, they are responsible for decision-making about its use, storage and discard, including decisions about the reallocation of an embryo (see paragraph 6.1.3), subject to any directions or limitations expressed in the consent of the donor(s) or imposed by law.
- When an embryo is reallocated to a subsequent individual or couple, and they have accepted an embryo, that individual or couple is responsible for decision-making about its use, storage and discard, including decisions about the reallocation of embryos (see paragraph 6.1.3), subject to any directions or limitations expressed in the consent of the embryo donor(s) or imposed by law."

Paragraph 6.4 of the *Ethical Guidelines* provides:

"Withdrawal of consent for donation

- 6.4 Recognise the right of individuals or couples to withdraw or vary their consent
 - 6.4.1 The embryo donor(s) can withdraw or vary consent for donation (or reallocation) at any time before the treatment cycle of the recipient commences."

Donated gamete is defined in clause 9(1):

- "(a) A gamete donated by a gamete provider for use by someone other than
 - *(i) the gamete provider; or*
 - (ii) any spouse of the gamete provider; or
- (b) A gamete used to create a donated embryo, whether or not
 - *(i) the gamete was originally obtained from the gamete provider as a donated gamete; or*
 - (ii) the embryo was originally created for use as a donated embryo."

Donated embryo is defined in clause 9(2):

"Is an embryo donated after its creation for use by someone other than –

- (a) a gamete provider from whom a gamete used to create the embryo was obtained; or
- (b) any spouse of the gamete provider."

The effect of clause 20(1)(a) is that unlike the current procedure when the withdrawal of consent is not effective once the treatment cycle has begun, the withdrawal of consent can occur at any time until immediately before the gamete is placed in a person's body. ANZICA counsellors raised with me a concern about this, namely, that a patient could commence their treatment cycle today and in effect, have to wait the best part of a month not knowing whether the withdrawal could occur before treatment is affected, in the meantime taking hormones to enable them to assist them in becoming pregnant. It would be better, consistent with the *Ethical Guidelines*, that the withdrawal of consent cannot take effect after the treatment cycle has begun – so that the

recipient can have some certainty, as part of a balancing of the interests of the gamete provider and the recipients.

The effect of clause 20(1)(b) for a donated embryo is that consent can be withdrawn at any time before that embryo is implanted. Again, withdrawal of consent should be allowed, consistent with the *Ethical Guidelines*, up to the commencement of the treatment cycle.

The Bill, rather than giving embryo donors the ability to withdraw consent for treatment, gives that power to the gamete providers. I do not understand why the gamete providers have that power for on-donation of embryos when it should be the embryo donors, and there should be certainty for all parties involved to know who has the power to withdraw consent.

Clause 21: verification of identity of gamete provider

This reflects current practice and is a sensible method.

Clause 25: limit on number of donor-related Australian families

I support this number. It is a balancing act to work out the limit of the number of recipient families so as to avoid consanguinity, and to make gametes available.

There has been, in the absence of statute, widely been seen to be a 10 family limit since 2011. RTAC in *Technical Bulletin 3 Donor Issues*, April 2011 (which remains current) said, in response to the Senate Inquiry Report:

"The Senate Inquiry Report reported that some units were confused about the RTAC Code of Practice and NHMRC guidelines relating to the maximum number of offspring for a donor ...

Where State legislation does not apply, the following are advised:

• A maximum of ten donor families per sperm donor. This is based on the highest limit in the existing State legislation (Victoria) the number of families per donor includes all families wherever the donor sperm is used, not just the number of families for one unit, and one city, or in one country. This interpretation is based on the definition in existing State legislation."

That ten family limit has applied, in effect, nationwide other than in New South Wales³⁶ and Western Australia, each of which have a five family women limit, the latter being worldwide³⁷. That 5 or 10 family limit may mislead. In practice, it is a four or nine family limit, because it is always assumed (whether or not the donor has any children) that the donor will have children. Much of our donor sperm is imported from the United States and must comply with Australian requirements³⁸. The lower cap has an impact. I have been advised by one donor coordinator of a New South Wales clinic that they have a waiting list of 300 families waiting allocation of donor sperm.

Western Australia has compounded this issue by the extraordinary barriers those who wish to undertake surrogacy there must go through. That State discriminates, as I said, about who has access. Other barriers include the very low availability of donors, due to the five family limit

³⁶ S.27.

³⁷ Human Reproductive Technology Directions 2021 (WA), cl. 8.1.

³⁸ Ethical Guidelines, [5.5]; and be altruistic: Prohibition of Human Cloning for Reproduction Act 2002 (Cth), s.21; Research Involving Human Embryos and Prohibition of Human Cloning for Reproduction Act 2003 (Qld), s. 17; Transplantation and Anatomy Act 1979 (Qld), ss.40, 44A; Criminal Code, s.12.

worldwide, and the requirement that the donor must be known, and a party to the surrogacy arrangement³⁹. It is no surprise, with all these factors, that as best as I can estimate it that for every child born in Western Australia through surrogacy⁴⁰, about 20 are born overseas⁴¹.

The lower the limit, the less accessible donor gametes are, the more likely that intended parents will undertake private donations or go overseas. During the pandemic there was a marked decrease in available sperm for donation. This was because there was a surge in demand⁴² and fewer American men were donating⁴³, with the result that there was less sperm available to be imported. I saw a marked increase in clients undertaking private sperm donation, which number decreased at the end of the pandemic, with the availability of donor sperm through clinics.

The ten family limit in clause 25 does not apply overseas, and nor should it - because Queensland should not be seeking to legislate as to overseas practices - where a Queensland law cannot be enforced.

The definition of *donor-related Australian families* in section 25(2) allows for the possibility of there being ten families to which donations can be made, rather than nine. I know a few gay men who have been sperm donors who were more than happy to be sperm donors but never wanted to have children themselves. Under the current requirement, they can only donate to nine others. The effect of this change means that they can donate to ten, as they never intend to have any children.

The Bill does not deal with how lesbian couples might be accommodated. It used to be the practice of the IVF industry that each woman would be counted as a separate recipient. Therefore, when the cap was reached, if a lesbian couple wanted to have one child each (but being members of the same family) with the same sperm donor, so that their respective genetic children were genetic siblings, a problem could arise for the second woman. This has been identified in both New South Wales and Victoria⁴⁴ as counting the second woman, in effect, as being under the cap. This is treated differently in the Bill in that, consistent with current practice of the IVF industry in Queensland, both women are considered to be members of the same family. If they separate, then there may be an issue with the cap. That issue if the couple separate has been identified in section 27 of the *Assisted Reproductive Technology Act 2007* (NSW) – but the cap in New South Wales is five women, not 10 families as proposed in this Bill.

I see it as less pressing here than in New South Wales to have that accommodation. It is not an issue that has been raised with me about one member of a Queensland lesbian couple not being able to use sperm from that donor because the cap has been reached. If the Committee were concerned about this issue, then there could be a replication of section 27(1A) of the New South Wales Act:

"This section does not prevent the provision of ART treatment using a donated gamete to a woman if --

³⁹ Surrogacy Act 2008 (WA), s.17(b)(iii).

⁴⁰ In every year, save 2023, one child a year was born through surrogacy in Western Australia: source Reproductive Technology Council of Western Australia, annual reports. I am told by a colleague that three children were born in the first half of 2023, a record.

⁴¹ In most years more than 200 children are born overseas to Australian intended parents through surrogacy. Source: Department of Home Affairs, Applications for Australian citizenship by descent for children born overseas through surrogacy: 2008-2023, obtained by me under Freedom of Information. I have then calculated this on a per capita basis, WA having about 10% of the national population.

⁴² <u>https://www.abc.net.au/news/2021-07-16/covid-19-pandemic-fuelled-ivf-baby-boom-creating-sperm-drought/100293140</u>.

⁴³ https://www.nytimes.com/2021/01/08/business/sperm-donors-facebook-groups.html .

⁴⁴ Assisted Reproductive Treatment Act 2008 (Vic.), s.29.

- (a) the woman or the spouse of the woman is the parent of a child born as a result of *ART* treatment using a donated gamete from the same donor, or
- (b) the woman belongs to a class of women prescribed by the regulations for the purposes of this section."

I note that the relevant regulations in New South Wales do not so prescribe.

Clause 25(5) & (6) of the Bill provides:

- "(5) For this section, a *family* comprises a parent, their spouse (if any) and their children.
- (6) To remove any doubt, it is declared that—
 - (a) if a person has a former spouse—the person, the former spouse and the children of both the person and the former spouse comprise a separate family; and
 - (b) if a person has more than 1 spouse—the person, any other spouse and the children of the person and the other spouse comprise a separate family."

It is important, by reasons of equity, access to donor gametes, and national consistency that the limit be ten, not five.

The Assisted Reproductive Technology Act 2024 (ACT) has a cap⁴⁵ of either:

- Five or more families in the ACT.
- Ten or more families in Australia.

That smaller number within the ACT makes sense, given that it only takes - in good traffic – about 30 minutes to drive across the ACT, and that the population of the ACT is only 400,000.

In addition to these requirements in clause 25, clinics are still required to comply (so far as the provision is not inconsistent), with paragraph 5.3 of the *Ethical Guidelines*:

"Limit the number of families created from a single donor

- 5.3.1 Clinics must take all reasonable steps to minimise the number of families created through donated gamete treatment programs.
- 5.3.2 Gametes from a single donor must be used to create only a limited number of families. In the absence of specific state or territory legislation, clinics must take account of the following factors when deciding on an appropriate number of families to be created:
 - the number of persons already born from the donor's gametes
 - the risk of a person born from donor gametes inadvertently having a sexual relationship with a close genetic relative (with particular reference to the population and ethnic group in which the donation will be used)

- any limitations on the number of families expressed as part of the consent of the donor
- whether the donor has already donated gametes at another clinic.
- 5.3.3 In the absence of a national registry for gamete donation, to encourage disclosure of multiple donations at multiple clinics, potential gamete donors should be reminded of the importance of limiting the number of families created from a single donor. Prior to donation, clinics must:
 - ask potential donors whether they have donated at other clinics
 - obtain consent from potential donors to contact other clinics about any previous donations."

An ART provider, in undertaking due diligence in cl. 25(3), is required to search its records, ask the donor, and if it believes that the donor may have supplied through another Australian ART provider, by asking them. There appears to be no ability for the ART provider to ask the Registrar about an Australian donor to see if the donor has donated before, either through an ART provider in Australia or overseas or privately.

Nor in cl. 48 is there any ability of the Registrar to supply information to an ART provider (whether from Queensland or interstate) about whether an individual has donated before (through an Australian or overseas ART provider or privately). I have suggested "with its due diligence requirements under cl.25(3), or under a corresponding interstate law or the RTAC Code or Practice to limit the number of recipient families from donation", so that the ability to obtain this information, in order to ensure compliance with family limits, is not limited to Queensland clinics. I have said "RTAC Code of Practice" in case there is no corresponding interstate law. Neither Tasmania nor the Northern Territory, for example, have a corresponding interstate law.

Given the prevalence of private donations, there ought to be the ability of an ART provider to find out from the Registrar if the donor has donated before, which is why I have suggested the changes to clauses 25(3) and 48 in the summary.

Clause 61: mandatory notification of events

One cannot legislate for stupid. Human errors can be minimised, and have been minimised, by the existing audit and transparency requirements that comes from RTAC accreditation. Every Queensland IVF must provide its data to the Fertility Society, where it is published by the Australian and New Zealand Assisted Reproductive Database⁴⁶, the longest running such clinics database in the world. Most Oueensland have also signed up to www.yourivfsuccess.com.au, to provide consumers with transparency. These measures in my view are already equal to or superior to those found anywhere in the world.

The requirement for licensing, plus inspectors, and mandatory reporting, including of adverse events within 7 days, will in my view reinforce a focus on transparency and accountability, and in so doing reduce errors being made.

⁴⁶ <u>https://www.unsw.edu.au/research/npesu/clinical-registries/anz-assisted-reproduction-database</u> .

3. POSTHUMOUS RETRIEVAL AND USE

I am delighted as to these provisions, which are contained in Division 5 *Retrieval and Use of Gametes from Deceased or Unresponsive Persons*. It has been an honour to act for widows to enable them to become mothers.

Posthumous Retrieval

Posthumous use arises from one of two sources – either the person has provided their gametes to an IVF clinic prior to their death, or the gametes are retrieved posthumously. The former might occur when IVF was attempted or the person concerned provides their gametes by way of fertility preservation after a cancer diagnosis, for example⁴⁷. With the former, the deceased may have (and now commonly with Queensland IVF clinics will have) been given the opportunity to consent to posthumous use.

Problems arise primarily where retrieval is sought after the person dies and then the surviving partner, typically the widow⁴⁸, seeks to use.

There is a belief that retrieval occurs only after a court order from the Supreme Court⁴⁹. The reality is that most retrievals occur using existing procedures under the *Transplantation and Anatomy Act 1979* (Qld), legislation which is designed to deal with organ donation.

Posthumous *retrieval* is able to occur everywhere in Australia. This is governed under broadly similar State and Territory laws, commonly called *Human Tissue Act* (as in New South Wales, for example) or *Transplantation and Anatomy Act* (as in Queensland, for example). However, posthumous *use* is not possible in Western Australia, and is only possible in South Australia, Victoria and New South Wales if the deceased had provided written consent to the use. In posthumous retrieval cases, that means it is impossible for the bereaved, typically the widow, to be able to use the gametes for reproduction in Western Australia, South Australia, Victoria and New South Wales.

Those widows (because they are overwhelmingly widows) then export their sperm from those States to clinics in either the ACT or Queensland. ACT and Queensland IVF clinics have been able to undertake posthumous use, provided the requirements of the *Ethical Guidelines* have been met.

An effect as to how the *Assisted Reproductive Technology Act 2024* (ACT) has been drafted, as compared to how the Bill has been drafted, will likely lead to an increase of the number of posthumous use cases from interstate to occur in Queensland, as compared to the ACT. The ACT Act⁵⁰ requires either the consent of the deceased to posthumous use or a Supreme Court order. The Bill does not require a Supreme Court order.

Some years ago, a man was in a coma. The assessment by doctors was that he would not recover. He was brain dead. The fertility doctor, assisting the grieving soon to be widow, wished to undertake retrieval. His assessment was that if they had to wait until the man was declared dead, then in all likelihood, what might be viable sperm today would not be viable sperm then. The view that I took, as did the hospital lawyer, was that there was no lawful basis to remove the sperm, which would have been an assault. Any order under the *Guardianship and*

⁴⁷ As seen in *Bazley v Monash Wesley IVF Pty Ltd* [2010] QSC 118.

⁴⁸ I have been told of one case in Queensland when a widower was able to retrieve eggs posthumously. Men have died prematurely from accident (such as car, skateboard, surfboard, at work), drug overdose, suicide, and heart attack or stroke.

⁴⁹ As seen in *Re Cresswell* [2018] QSC 142, for example.

⁵⁰ S.36.

Administration Act 2000 had to be in the best interests of the patient (which it would not be). The Supreme Court in making an order under its *parens patriae* jurisdiction had to do so in the best interests of the patient, which would not be the case.

The result was as predicted. When the man died, there was no viable sperm.

I asked in 2023 that there be a review so that there could be the ability to retrieve gametes when the patient was unresponsive. Only one State allows this currently, Victoria.

The checks and balances under the *Human Tissue Act 1982* (Vic)⁵¹ are more restrictive and less practical than those contained in this Bill. In my view, the work of the ART review team should be commended for a more flexible approach, which hopefully will mean that there will not be a repeat of what was visited upon that grieving widow.

In another case, I was contacted by a new widow, whose husband had died in a regional city. She wanted to retrieve the sperm. The phone call was on a Friday morning. During the course of the day, it became apparent that due to a lack of doctors who were available who had the necessary training to undertake the retrieval, the doctor would need to come from another regional city. There needed to be three people available for a retrieval – namely, the relevant person from the hospital or morgue, a fertility specialist or urologist who has experience in retrieving gametes posthumously, and an embryologist from an IVF clinic to ensure that the sperm or eggs are able to be stored and preserved quickly. We were not able, due to the tyranny of distance and it being a Friday to coordinate the body, the doctor and the scientist.

During the course of the review that led to this Bill, I had my most recent posthumous retrieval. A man was injured at work on Wednesday, resulting in him being hospitalised, in a coma and brain dead. His widow wished to retrieve his sperm for use in reproduction. I then acted for the widow. I was notified of her seeking my help on Thursday morning. There were then a series of phone calls by my office on the Thursday attempting to line up my client, the hospital, the coroner and fertility specialists. Retrieval could only occur after the man had died. Matters were complicated because on the Friday evening and over the weekend fertility specialists were attending a conference. Matters were also complicated because the man was a registered organ donor, which my office knew nothing about until shortly before the attempt to undertake the retrieval occurred, and the man had been declared dead.

The man was declared dead after-hours on a Friday. Somehow, we were lucky that he died in Brisbane and that we were able to locate a fertility specialist and scientist. Retrieval occurred at about 8pm on the Friday.

The proposed changes as to retrieval make the process easier and less burdensome on widows. By enabling retrieval from someone who is unresponsive, this should mean that rather than trying to put together a team to collect at 8 p.m. on a Friday, it could be done on a Friday morning during office hours.

Posthumous Use

Clause 31 in large part replicates the checks and balances as to posthumous use in the *Ethical Guidelines*. In the absence of a court order, a Queensland clinic wants to know some basic steps before it engages in posthumous use:

1. If the retrieval occurred interstate, was it lawful? This in turn requires a lawyer's letter setting out what law has been complied with (or not).

⁵¹ Ss. 24A to 24F, especially s.24D.

- 2. If the gametes are stored interstate, is export from interstate lawful? Again, this is covered in the lawyer's letter.
- 3. Have the requirements of the *Ethical Guidelines* been met? Currently, those requirements are (if there has not been any objection by the deceased to posthumous use), contained in paragraphs 8.22 and 8.23 of the *Ethical Guidelines*:
 - "8.22 Respect the wishes of the person for whom the gametes or embryos were stored

Regardless of the relevant individual's position on the posthumous use of their stored gametes or embryos, there may be a legal impediment to such use in some states or territories and a court order may first be required.

- 8.22.1 Where permitted by law, clinics may facilitate the posthumous use of stored gametes or embryos to achieve pregnancy, if:
 - the deceased person left clearly expressed directions consenting to such use following their death (see paragraph 4.6.4)
 - the request to do so has come from the spouse or partner of the deceased person, and not from any other relative
 - the gametes are intended for use by the surviving spouse or partner
 - *the conditions of paragraph 8.23 are satisfied.*
- 8.22.2 Where the deceased person has left clearly expressed directions that object to the posthumous use of their stored gametes or embryos, clinics must respect this objection and not facilitate the posthumous use of the stored gametes or embryos to achieve pregnancy.
- 8.22.3 Where the deceased person has not left clearly expressed directions regarding the posthumous use of their stored gametes or embryos, where permitted by law, clinics may facilitate the posthumous use of stored gametes or embryos to achieve pregnancy, if:
 - the request to do so has come from the spouse or partner of the deceased or dying person, and not from any other relative
 - the gametes are intended for use by the surviving spouse or partner for the purposes of reproduction
 - there is some evidence that the dying or deceased person would have supported the posthumous use of their gametes by the surviving partner, or at the very least, there is no evidence that the deceased or dying person had previously expressed that they do not wish this to occur
 - the surviving spouse or partner provides valid consent (see paragraph 4.5)

- the conditions of paragraph 8.23 are satisfied.
- 8.23 Allow sufficient time before attempting conception and/or pregnancy
 - 8.23.1 Given the enduring consequences of the decision, clinics should not attempt conception or a pregnancy using stored gametes or embryos unless:
 - sufficient time has passed so that grief and related emotions do not interfere with decision-making
 - in addition to the requirements outlined in paragraph 4.1, the surviving prospective parent (the spouse or partner) is provided with sufficient information to facilitate an accurate understanding of the potential social, psychological and health implications of the proposed activity for the person who may be born
 - the surviving prospective parent (the spouse or partner) has undergone appropriate counselling (see paragraph 4.3)
 - an independent body has reviewed the circumstances and supports the proposed use."

Independent body is defined in the Ethical Guidelines as:

"An institution, group or person involved in decision- or policy-making who is able to provide an 'independent' or 'disinterested' opinion or advice.

May include a clinical ethics committee, a regulatory body or board, a tribunal or a magistrate, a Human Research Ethics Committee, a counsellor, or another relevant expert. The appropriateness of the body will be determined by the particular circumstances, and may be prescribed by legislation."

In my view, the Bill rightly does not provide a barrier to widows requiring them to obtain an order of the Supreme Court. Instead, in clause 31, it requires the approval of an independent review body. That independent review body is to be specified by regulation. It is likely to be either someone such as an independent ethics committee of the relevant clinic or an independent fertility counsellor or an independent lawyer, consistent with current practice.

Clause 31(3) replicates paragraph 8.23 of the *Ethical Guidelines*, save that there is no time limit specified in clause 33(3).

The current requirement "sufficient time has passed so that grief and related emotions do not interfere with decision making" is vague. There have been views expressed that this might be a period of 12 months. It varies. For some widows, it is a period of six months, for some it is a period of two years. It depends on their circumstances. The ART review unit took the view that there should not be a prescribed time. One could well imagine that an IVF clinic would be reluctant to provide treatment and an independent review body would be reluctant to authorise use, unless there a period of sufficient time passed before treatment commenced.

4. CENTRAL REGISTER AND RETROSPECTIVE TRANSPARENCY

I support these provisions. In my submission and evidence to this Committee in 2022, I said that it was a human right to know one's genetic origins, and that anonymity is dead. With the rise of databases such as Ancestry.com and 23andme.com anonymity is over.

The rise of technology has been relentless, as we all know. In the meantime, another tool has become prominent, that of picture scraping. Most of us have pictures of ourselves on social media. Tools using picture scraping, such as Google reverse image search, mean that the possibility of remaining anonymous for those who share images on social media is now next to impossible. Most of us are able to be located and identified.

In my view, the proposed provisions have been well drafted. I fully support those provisions which put, first and foremost, the interests of donor-conceived people.

I am supportive of retrospective transparency, pioneered worldwide in Victoria in 2017, and was accepted in South Australia earlier this year (after earlier being rejected) in its *Assisted Reproductive Treatment (Posthumous Use of Material and Donor Conception Register)* Amendment Act 2024 (SA), which is yet to commence, and in the ACT in the Assisted Reproductive Technology Act 2024 (ACT) – which provisions are yet to commence.

The concern that I expressed in 2022 to this Committee is that while a central register run by the Registrar of Births Deaths and Marriages would be a great improvement on individual registers run by individual IVF clinics, there is still no national register. I said that in the absence of a national register, the various central registries should act like one when searches were undertaken. I am not seeing anything by which there would be cooperation amongst the various States and the ACT (if this Bill is enacted, then Queensland, ACT, New South Wales, South Australia, Victoria and Western Australia). I hope that they do.

Not being coordinated means that there is a continued likelihood of people falling between the cracks, and there is an increase in cost:

- to donor-conceived individuals and their parents,
- to clinics (which gets passed on ultimately to patients), and
- to recipients who discover, too late, that the genetic material stored on their behalf cannot be used.

Reciprocal administrative arrangements

In the absence of a national donor register, there ought to be the ability of the State and ACT donor registries to act in co-operation, if possible. This requires Parliamentary authorisation.

There ought to be a provision in this Bill which is equivalent to s.103 of the *Births, Deaths and Marriages Registration Act 2023* (Qld), which allows reciprocal administrative arrangements with other registries interstate.

To make it easier for donor-conceived people to find out where they have come from, and to ensure the ability to comply with family limits, there ought to be the ability of the Registrar to have reciprocal administrative arrangements with the other State or ACT central registries, so that they can, as far as possible, act as a one stop shop. Even if the other jurisdictions do not so legislate, Queensland should give a clear message that it is prepared to engage in co-operative federalism, and that by having such a provision, it is seeking to uphold the rights of donorconceived people- both those who have been born, and those to be born.

Clause 47: private donations

I am deeply concerned about aspects of private donation. I have acted in a number of private donations where the donor is evidently known to the intended parent or parents and there is a written agreement plus assistance from a fertility counsellor and preferably assistance from an IVF clinic. However, it is apparent that there are many private donations that occur where those types of safeguards are not present. I was delighted to see that private donor conception procedures will be included in the register, as set out in clause 47. My concern about clause 47 is that there can only be that information provided if *all* the parties consent (unless it can be proved that one of the parties has died). That is not broad enough. I am further concerned that the definition of *private donor conception procedure* in clause 40 is limited only to a procedure that occurs in Queensland.

We are repeating the mistakes of the past. Before 2004, clinics did not have a cap on numbers and had secrecy at the fore. Now the risk is primarily with private donations. For example:

- In 2019 American sperm donor "*Joe Donor*" came to Australia for the purposes of private donation of his sperm. He estimated that he had more than 800 attempted inseminations that resulted in more than 100 children⁵².
- In 2020 Alan Phan from Brisbane, once he already hit the limit with clinics, continued to create children, *"fathering"* 23 children in one year⁵³. After the story broke, sperm donated by him through IVF clinics (and embryos created with that sperm) in several States had to be destroyed, which was deeply upsetting to recipients.
- As of 2020, Australia's oldest sperm donor 72 had *"fathered"* 21 children that he knew about⁵⁴.
- Adam Hooper, who runs a Facebook group with 1,500 claimed members dealing with sperm donation, did a baby making tour of Queensland in 2022 after already having *"fathered"* more than 20 children⁵⁵ and then not to be outdone, did a baby making tour in New Zealand as well⁵⁶.
- Most recently, in 2023, it appears that an Australian man has *"fathered"* up to 60 children, using four aliases⁵⁷. The parents only realised that there was a connection when they went to a community barbecue and noticed the resemblance of their children.

By requiring the consent of the donor, then in circumstances such as the last case, that information could never be placed on the central register. Everything should be done to encourage private donations to be added to the register, and for IVF clinics to be able to access the name of the donor and the number of previous donations (as I discussed above).

⁵² <u>https://www.9news.com.au/national/60-minutes-joe-donor-sperm-ivf-pregnancy-children/bb45b667-9494-4684-8295-64945eb8f3b8</u>.

⁵³ https://www.kidspot.com.au/birth/conception/ivf/australias-most-prolific-sperm-donor-has-fathered-23-childrenin-a-year/news-story/4d163b3b0e64c8aeda1a96d25daf35b2.

⁵⁴ <u>https://www.dailymail.co.uk/news/article-9087093/Meet-Australias-oldest-sperm-donor-fathered-50-kids.html</u> .

⁵⁵ https://www.kidspot.com.au/news/serial-sperm-donor-adam-hooper-going-on-babymaking-tour-of-

queensland/news-story/b7465a4c01a2b3451e73f7072defedff .

⁵⁶ <u>https://www.newstalkzb.co.nz/on-air/heather-du-plessis-allan-drive/audio/adam-hooper-australian-sperm-donor-on-his-nationwide-new-zealand-donation-tour/</u>.

⁵⁷ <u>https://www.dailymail.co.uk/news/article-11764815/Sperm-donor-fathers-60-children-using-fake-names.html</u> .

Given that Australians move around, I have sought that there be a wider definition of *private donation* so that the donation is caught under the Bill. Only the ACT in its 2024 Act and New South Wales under its 2007 Act allow for private donations to be recorded. The net should be cast as widely as possible in my view to ensure:

- as many donor-conceived adults can find out where they came from, rather than narrowly proscribing the requirement that all parties consent and that the private donation occurred within Queensland.
- Information about possible donors is on the register, and therefore available to clinics, to ensure that there is not a breach of the limit.

New South Wales allows any of the parties to provide the information⁵⁸. The ACT enables a parent to provide the information⁵⁹.

If a donor has been a private donor, and that donor is also donating through clinics, then having their information on the central register (and available to ART providers) decreases the chances of a repeat of multiple donations in excess of the limit.

I was asked by the chair of this committee in 2022 about how private donations could be regulated. At the time I thought it was next to impossible to regulate. On reflection, I have worked out a way. In my view, the websites and apps that enable private donation need to be regulated. Despite Australia having nine systems of law, regulating these sites, with political will, can be done relatively easily:

- Commonwealth legislation to regulate the sites. The Commonwealth Parliament would have the power to do so under its communications power. A Commonwealth regulation can specify the relevant State and Territory Departments or prescribe the relevant State and Territory laws that authorise information sharing.
- State legislation can connect with the Commonwealth legislation say the relevant agency being the Queensland Registrar of Births, Deaths and Marriages, and the others agreeing to share information.
- Until there is State legislation in place, the Commonwealth regulations provide that the lead agency be specified as RTAC.

Regulating these websites and apps will be difficult but not impossible. Those who run these sites should be required:

- to obtain the ID of the would-be donors, for example, driver's license or passport.
- a notice to be provided that it is an offence not to tell the truth (and making it an offence not to tell the truth) that they have to click on and confirm that what they are saying is the truth.
- information on the sites that must be navigated passed before they can search for a wouldbe donor or recipient: the uncertainty about whether or not donors are parents, the parties should get thorough medical screening (if the app is not run by an IVF clinic, with a link to the Fertility Society of Australia and New Zealand), obtain legal advice, enter into written

⁵⁸ S. 33A.

⁵⁹ S. 56.

agreements with a known donor and have fertility counselling (with a link to the website for Australian and New Zealand Infertility Counsellors Association)

- would-be donors disclose:
 - the last time they had STI screening and the results.
 - whether they have any of a list of inheritable conditions.
 - whether they have any criminal convictions, and if so, what and when.
 - whether they were or are the subject of any domestic violence order, and if so, when and whether the order is current.
 - the number of women they have donated to. If the cap hits nine, other than their spouse or former spouse, they are not allowed to access the website or app. The number that they have donated to would appear on their profile.
 - the website/app owner or manager would be subject to criminal penalties for failing to comply.
 - the website/app would be required to provide the name and ID of every would-be donor to one coordinating State agency, which would be authorised to share with:
 - an agency in other State and Territory, and
 - the Reproductive Technology Accreditation Committee of the Fertility Society of Australia and New Zealand. RTAC in turn would be authorised to provide that information to accredited IVF clinics.

The purpose of the information sharing, which would require privacy consents, would be to ensure as far as possible that the limit on donation in each State and Territory is not exceeded.

If those measures are put in place, then the current risks, including no limits through private donation, will be reduced considerably. While bedrooms cannot be policed, websites and apps can be. Kids deserve better than finding out that they may have 60 genetic siblings.

About me

I am a father with my husband through known egg donation and surrogacy (both in Queensland). I have also suffered infertility.

The views in this submission are mine alone.

I am a principal of Page Provan Pty Ltd, solicitors, Brisbane. I was admitted as a solicitor in 1987. Since 1996, I have been a Queensland Law Society accredited family law specialist. Since 1988, I have advised in just under 2,000 surrogacy journeys for clients throughout Australia and 37 other countries. Since about 2012, I have acted in sperm, egg and embryo donation cases. Since about 2015, I have acted in posthumous cases. I have acted for men who donated anonymously as sperm donors, but whose offspring (or the parents of whose offspring) have identified them.

I am a Fellow of the International Academy of Family Lawyers and of the Academy of Adoption and Assisted Reproduction Attorneys. Since 2012 I have been an international representative on

the Artificial Reproductive Technologies Committee of the Family Law Section of the American Bar Association. I am a director of the Fertility Society of Australia and New Zealand Limited.

I have given over 200 presentations in this area of law, including at seminars around Australia and around the world, including for the International Bar Association. I have written many articles in this area, two chapters in academic books (the second of which is to be published in August). My second book, *International Assisted Reproductive Technology: a guide for lawyers*, is in pre-production with the American Bar Association. My most recent article⁶⁰ was published today in *Family Court Review* on LGBTIQ+ access to assisted reproductive treatment.

I have received a number of awards, including:

- University of New South Wales teaching award, for Ethics and the Law in Reproductive Medicine (2019)
- inaugural Pride in Law Award (2020)
- Queensland Law Society President's Medal (2023)

Yours faithfully

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Stephen Page 2023 Qld Law Society President's Medal Recipient Page Provan family and fertility lawyers Accredited Specialist Family Law

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⁶⁰ <u>https://onlinelibrary.wiley.com/doi/10.1111/fcre.12806</u>.