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Dear Reader

### **REGULATION OF ASSISTED REPRODUCTIVE TECHNOLOGY SERVICES -**SUBMISSION

I welcome the opportunity, albeit very tightly proscribed, in which to make a submission as to the proposed regulation of ART services in Queensland.

### **RESPONSES TO QUESTIONS IN THE CONSULTATION PAPER**

# **1.** If ART legislation is introduced in Queensland, what should the Act's guiding principles be?

### **Response:**

The paramount concern should be that of the best interests of any resultant child. The words of s.4A ART Act 1988 (SA) are apt:

"The welfare of any child to be born as a consequence of the provision of assisted reproductive treatment in accordance with this Act must be treated as being of paramount importance, and accepted as a fundamental principle, in respect of the operation of this Act."

Subject to that paramount concern, then a reworking of the objects of s.3 of the ART Act 2007 (NSW) and, as relevant, s.6(2)(d) of the Surrogacy Act 2010 (Qld) and s.7(1)(a) of the Surrogacy Act 2019 (SA), are appropriate:

"Subject to the paramount concern, the objects of this Act are:

(a) to prevent the commercialisation of human reproduction, and

(b) to protect the interests and human rights of the following persons:

(i) a person born as a result of assisted reproductive treatment, and

(*ii*) a person providing a gamete for use in assisted reproductive treatment or for research in connection with assisted reproductive treatment, and

(iii) a person undergoing assisted reproductive treatment, and(c) the autonomy of consenting adults in their private lives should be respected."

# 2. How can the Act ensure that the health and wellbeing of people accessing ART and donor-conceived people are at its centre?

### **Response:**

Aside from particular measures in the Act, by setting out a clear state in the objects and guiding principles of the Act, such as suggested above.

The references to human rights include the following human rights identified in the *Human Rights Act 2019* (Qld), set out in **Table 1**.

#### Table 1: Some of the human rights that are implicated

Section of the Human Rights Act 2019	Human right	
15	Recognition and equality before the law	
26	Protection of families and children	
28	Cultural rights- Aboriginal peoples and Torres Strait Islander peoples	
37	Right to health services	

Under the common law, the right or freedom to reproduce, or not to reproduce, has been recognised in Australia<sup>1</sup>. The right to reproduce, and by it the right to access assisted reproductive services, has been recognised as a fundamental human right internationally<sup>2</sup>.

### Question 3: How could an ART Act support the culture, values and beliefs of all Queenslanders?

**Response:** See responses to questions 1 and 2 above.

# Question 4: What are the benefits and/or risks of introducing ART legislation in Queensland?

Response: An overly restrictive method of regulation, inconsistent with the framework of the Ethical Guidelines and interstate regulation will likely increase cost, and decrease potential innovation by clinics, leaving consumers with less access to services.

A mandatory requirement for serious incident in IVF units to be reported to State authorities and RTAC in a timely manner should lead to an increase in quality outcomes in IVF units.

<sup>&</sup>lt;sup>1</sup> *Re Jane* [1988] FamCA 57; *F and F* [1989] FamCA 41.

<sup>&</sup>lt;sup>2</sup> For example, Murillo v Costa Rica, Inter-American Court of Human Rights (2012)

# Question 5: Is there a need for Queensland to provide criteria for ART eligibility in legislation?

**Response:** No. That should be a clinical decision between patient and treating physician. In 2012, a Queensland Attorney-General proposed that gays, lesbians and single people who underwent surrogacy would be committing a criminal offence- based on their sexuality or relationship status. I am proud that I helped defeat such a discriminatory proposal. Such a proposal would have run counter to the subsequent amendments to s.22 Sex Discrimination Act 1984 (Cth).

S.45A *Anti-discrimination Act 1991* (Qld) purports to allow discrimination in this field. I comment about that below. I say *purports*, as it is likely that the section is invalid.

In the words of one of my clients: "Governments aren't God. They shouldn't say who can and who cannot be parents."

Many intended parents come to Queensland IVF clinics from interstate and overseas. They should still be welcome.

# Question 6: Should counselling before receiving ART treatment be mandatory in Queensland?

**Response:** No, other than when donors are involved, or for surrogacy (in which case counselling is mandated under the *Surrogacy Act 2010* (Qld). Counselling ought to be offered for those undertaking ART, as is required currently under the *Ethical Guidelines* and interstate. Those suffering infertility should not be compelled to also undertake counselling before they can access treatment. Their trauma at being unable to reproduce should not be compounded by systems abuse.

If Queensland mandates counselling for all ART, some patients will decide to undertake treatment interstate, where such counselling is not required.

### Question 7: Should counselling before being involved in donor conception practices be mandatory in Queensland?

Response: Yes, as currently required under the *Ethical Guidelines* and the *Surrogacy Act 2010* (Qld).

### Question 8: Are there any other things that should be required before a person accesses ART treatment or participates in a donor conception program?

Response: Yes. The identity of the person should be established, such as driver's licence, to minimise fraud. The minimum data should be maintained by the clinic following the establishment of identity, given obligations under the *Privacy Act*, and recent data breaches (where more than the minimum was kept), as seen with Optus, Medibank and Latitude Finance, among others.

### Question 9: Are there any concerns with Queensland adoption similar requirements to other jurisdictions about how gametes and embryos may be used?

Response: The various restrictions on use appear sensible; and largely consistent with requirements under the *Ethical Guidelines* (except the last two points, which are additional to the *Ethical Guidelines*.

I have addressed gender selection separately below. However, as South Australia has demonstrated successfully, these items are not essential in any Act for the State to regulate the IVF industry. Rather than duplicate the *Ethical Guidelines*, the State can rely on these various matters remaining in the *Ethical Guidelines*, but have overall control of the industry by clinics having to be registered.

# Question 10: Should the family limit in Queensland be regulated by family or by person? What should that limit be?

**Response:** By family, as occurs in NSW or Victoria. The cap should be 10. I discuss this topic at length below.

# Question 11: What should the storage time limit be for gametes and embryos? What other requirements should be included in relation to storage?

**Response:** As South Australia has demonstrated, this does not have to be in the Act. If there is to be a period in the Act, the period should be the longest one possible. It is a most unpleasant conversation to have with clients to tell them that their genetic material cannot now be used due to an arbitrary rule in a statute.

### Question 12: Are there any other requirements that should be included in legislation?

**Response:** There should be separate offences for destruction of falsification of ART records, or making false or misleading representations to clinics for the purposes of the Act, or by clinics to the Government for the purposes of the Act- as seen in ss. 61A and 62 of the *ART Act 2007* (NSW).

Fertility fraud has occurred in Australia, such as Megan Jane Hooper in Western Australia who forged her husband's signature in order to use the stored embryo so that she could become pregnant<sup>3</sup>. Having a specific offence should deter the instances of fertility fraud.

There have been documented cases around the world of IVF doctors using their own sperm to create embryos. In addition to this being a specific offence, as proposed, there also ought to be a legislated cause of action by those directly affected by that fraud (the recipients and the donor conceived person), with the time limit to run from when the person became aware of the fraud. In the words of a researcher<sup>4</sup>:

"Former patients of these physicians speak of feeling violated and assaulted, their personal dignity and bodily integrity trampled, their family plans routed, and their trust broken."

As that researcher stated<sup>5</sup>:

"Perhaps the most fundamental and important interest that doctor-conceived children have is being able to impose accountability on physicians who engage in illicit insemination...

Doctor-conceived children have strong interests that should be legally protected through criminal charges and civil liability for fertility fraud. After all, law is charged with

 <sup>&</sup>lt;sup>3</sup> <u>https://www.watoday.com.au/national/western-australia/woman-admits-fraud-to-get-estranged-husbands-frozen-embryo-20140307-34bu8.html</u>; cf. *Daegar & Daegar (No 4)* [2023] FedCFamC1F 837 at [186]-[188].
<sup>4</sup> https://www.repository.law.indiana.edu/cgi/viewcontent.cgi?article=3903&context=facpub.

<sup>&</sup>lt;sup>5</sup> At p.182-183.

protecting the vulnerable and giving them an opportunity to obtain answers and accountability. There are other ways in which doctors can owe legal duties to individual soutside a physician-patient relationship, particularly when the physician's violation of medical standards of care causes foreseeable harms. Patients undergo insemination for one reason: to conceive a child. It would be cruel and irrational to deny that a physician performing an insemination could not foresee how this conduct could harm any resulting children. At a minimum, potential harms include unexpected and traumatic disclosures of doctor-conceived status, disrupted personal identities, severely damaged trust in medical professionals, destabilized family relationships, and increased possibilities of consanguineous relationships within a particular geographic area."

To destroy ART records could have the most profound negative effects on a donor conceived person. Parliament needs to state that to do so is an offence.

# 13. Are the existing provisions for posthumous retrieval of tissue in the Transplantation and Anatomy Act 1979 adequate? Should there be specific provision regarding posthumous retrieval of gametes in any new ART legislation?

**Response:** Yes; No. This issue is discussed at length below.

#### 14. How should the posthumous use of a person's gametes be regulated?

Response: As per the *Ethical Guidelines*. I discuss the current thorough process below.

### **15.** Should any new ART legislation provide for the ante-mortem retrieval of gametes from an unresponsive person?

**Response:** Yes, by amendment of the Transplantation and Anatomy Act 1979. I discuss this issue below.

#### 16. Do you think a state-based licensing system is needed? Why or why not?

**Response:** It is a matter for the Government and Parliament. I discuss this issue below.

### 17. Are there any particular features of registration or licensing schemes in other jurisdictions that Queensland should adopt or avoid?

Response: Discussed below.

#### 18. What do you anticipate will be the impact on ART providers of a new licensing system?

**Response:** In order to comply, there will be an increase in costs, both as a one off and ongoing measure.

### 19. Are there particular information requirements you think should or should not be included in the Act? Why?

**Response:** Responded to question 12 above.

#### CURRENT LANDSCAPE

Queensland does not have a specific ART Act. It is in that regard unlike New South Wales, Victoria, South Australia and Western Australia which do. The Northern Territory does not have an ART Act. However, the only IVF clinic in the Northern Territory has an agreement with the Northern Territory Government in which, in return for receipt of subsidies to enable patients to attend at the clinic, medical practitioners must, so far as possible, comply with South Australian registration requirements. Tasmania does not have an ART Act.

The ACT does not have an ART Act. Nevertheless, there is currently a Bill before the Legislative Assembly to regulate ART services in the ACT.

The proposed moves in Queensland and the ACT will likely mean that before the end of the year, for a population of 27 million, Australia will move from having five systems of regulation of ART services (NSW plus SA, plus Vic, plus WA, plus (ACT, NT, Qld, Tasmania)) to seven (ACT, plus NSW, plus QLD, plus SA, plus Victoria, plus WA) plus (NT, TAS).

The Queensland Government has made it plain that topics not to be covered as part of the current review are:

- 1. Donor conception register.
- 2. Affordability and accessibility of ART services.
- 3. Surrogacy.
- 4. National regulation and national and donor conception register.
- 5. Research.
- 6. Regulation of donor websites, groups, apps and other informal arrangements.

It is for the Government to determine whether to put a Bill to Parliament regulating ART in Queensland, and for Parliament to determine whether or not to enact that Bill.

Having said that, I do not accept the premise of this statement on page 6 of your paper concerning RTAC accreditation of IVF units:

"RTAC accreditation is required to obtain Medicare rebates for ART services and medications for any patient attending an ART service.

*Compliance with these documents* [ RTAC Code of Practice and NHMRC Ethical Guidelines] *is an accreditation requirement, not a legal requirement, and there are no robust enforcement mechanisms in place.*"

The point of accreditation is not in order to obtain Medicare rebates (although that is an effect). The point is to comply with both Commonwealth and Queensland law.

Although there is not a specific ART Act in Queensland, it is not the case that the operation of IVF clinics in Queensland are a free-for-all. Every IVF clinic in Australia must be accredited by the Fertility Society of Australia and New Zealand under the *Research Involving Human Embryos Act 2002* (Cth) and matching State and ACT legislation, in the case of Queensland, the *Research Involving Human Embryos and Prohibition of Human Cloning for Reproduction Act 2003* and the *Research Involving Human Embryos and Prohibition of Human Cloning for Reproduction for Reproduction Regulation 2015*.

Commercial donation is prohibited under the *Prohibition of Human Cloning for Reproduction Act 2002* (Cth) and the *Research Involving Human Embryos and Prohibition of Human Cloning*  for Reproduction Act 2003 and the Research Involving Human Embryos and Prohibition of Human Cloning for Reproduction Regulation 2015.

In addition, commercial egg, sperm and embryo donation and advertising is either prohibited or regulated under the *Transplantation and Anatomy Act 1979* (Qld) and *Transplantation and Anatomy Regulation 2017* (Qld).

In order to become accredited by the Reproductive Technology Accreditation Committee (RTAC) of the Fertility Society of Australia and New Zealand, an IVF clinic must:

- 1. be subject to a quality assurance scheme.
- 2. comply with the RTAC Code of Practice.

Three elements of that *Code of Practice* are vital:

1. A requirement to be subjected to audits on behalf of RTAC. That auditing process is thorough and has, since 2021, involved cross-checking of information.

Many of the recent concerns raised about the quality of IVF in Queensland concern donations that occurred prior to 2004 when the current requirement for clear caps on the number of donations and the removal of anonymity in due course for donors at the election of the child upon the child turning 18, has been a mandated requirement. Transparency by the Government about when the conduct of IVF clinics complained about occurred would be appreciated. Conduct complained about in 2022, for example, concerning events that occurred before 2004 would if upheld shine the light on practices by IVF clinics (and their regulation) before 2004, but are unlikely to reflect current practice.

- 2. That data from the clinic is supplied to the Fertility Society of Australia and New Zealand and then published. Publication is by the University of New South Wales of the Australia and New Zealand Assisted Reproductive database.
- 3. Compliance with the *Ethical Guidelines*.

The *Ethical Guidelines* are not law. Nor is the *Code of Practice*. However:

- It is in effect a criminal offence under both Commonwealth and Queensland law to operate an IVF clinic without RTAC accreditation.
- In order to maintain that accreditation, IVF clinics must comply with the *Code of Practice*.
- The *Ethical Guidelines* have been incorporated into the *Code of Practice*<sup>6</sup>.

Therefore, in effect the *Ethical Guidelines* are licence conditions. Failure by an IVF unit to comply with the *Ethical Guidelines* imperils the existence of the unit, because of the potential withdrawal of accreditation. The single most valuable asset of any IVF clinic is its goodwill and accreditation. Remove the accreditation and millions of dollars of the owners' capital disappears.

There has been a view expressed by some that the *Ethical Guidelines* are merely that, guidelines, and are not mandatory to be complied with, nor are they enforceable. That view is wrong as a

<sup>&</sup>lt;sup>6</sup> Per Clark v Macourt [2013] HCA 56 per Keane J at [121].

matter of law. The effect, as Justice Keane stated, is that the *Ethical Guidelines* have been incorporated into the *Code of Practice*. If there is a breach of the *Ethical Guidelines* or the *Code of Practice*, then the clinic places its accreditation at risk. An IVF unit is either compliant, and therefore maintains accreditation, or non-compliant, and has accreditation removed.

Consistent with ANZARD data, it would appear that Queensland clinics are of a very high quality.

Most IVF units in Queensland are owned by funds, or in one case is a public company, as seen in **Table 1**. These clinics operate conservatively, given the monetary risks involved if accreditation is withdrawn. No one wishes to answer to others (fund owners, disclosure to the share market) about why the organisation did not comply, and the resultant loss of capital.

IVF clinic	Parent company	Fund owned or public company
Queensland Fertility Group	Virtus Health	Fund
The Fertility Centre	Virtus Health	Fund
Monash IVF	Monash IVF	Publicly listed company
Cairns Fertility Centre	Monash IVF	Publicly listed compnay
Fertility Solutions	Monash IVF	Publicly listed company
City Fertility	City Fertility	Part fund owned
Genea Fertility	Genea Fertility	Fund
Adora Fertility	Adora Fertility	Fund
Life Fertility	Life Fertility	Doctor owned
Coastal IVF	Coastal IVF	Doctor owned
Care Fertility	Care Fertility	Doctor owned

Table 1 Ownership of Queensland IVF clinics

IVF clinics in Queensland already have onerous regulatory requirements<sup>7</sup>.

I note that, whilst there have been concerns raised as part of the investigation undertaken by the Office of Health Ombudsman into assisted reproductive services in Queensland, about the process of audits undertaken by RTAC of IVF units in Queensland, no officer from the Office of Health Ombudsman has yet attended upon such an audit.

<sup>&</sup>lt;sup>7</sup> ACCC v IVF Finance Pty Ltd (No 2) [2021] FCA 1295 per O'Bryan J at [15] – assertion by ACCC.

Whatever concerns Australians may have about the quality of IVF services in Australia, ANZARD is significant. It is the oldest assisted reproductive database in the world. By publishing data, it brings transparency to IVF clinics in Queensland.

ANZARD data demonstrates, for example, that the quality of IVF services in Australia and New Zealand is of a world standard. This is seen, for example, by the twinning rate, which is the lowest in the world.

Australian and New Zealand clinics through the *Code of Practice* and professional organisations have long advocated for single embryo transfers to occur. Unlike other parts of the world, where double or triple (or more) embryo transfers are common, the practice in Australia and New Zealand is to have single embryo transfers. Australian and New Zealand clinics "lead the way" globally<sup>8</sup>. Single embryo transfers are best practice worldwide because they reduce risk, both for the woman carrying the child and for any baby which is born. Children who are born as twins or other multiples have higher complications. Births involving twins or other multiples are complicated and risky.

All of Queensland's IVF clinics, bar two, are participants in yourivfsuccess.com.au, an initiative of the federal government. Their data is easily publicly available. The available data shows, for example, a commitment by the clinics to single embryo transfers. This available data helps inform consumers about the quality of the clinic they might choose. Life Fertility alone does not publish its data. Genea Fertility is a new clinic in Brisbane, and is not yet in a position to publish data.

We should be proud that our IVF clinics have adopted world-best practice in minimising risk to patients.

While systems can be put in place to minimise things going wrong in the lab, such as Quality Assurance protocols, compliance with the *Code of Practice* and **Ethical Guidelines**, and even legislation, as is proposed, ultimately none of these can stop human errors being made. All that they can hope to do is to minimise the number and type of human errors.

### MINIMISING DIFFERENCES

The proposed changes in Queensland, if enacted, will result (and if the ACT changes are enacted) in seven different models of regulation for an industry in a country of 27 million.

The constant refrain from consumers is as to the cost of IVF in Australia. Notwithstanding subsidies from the Commonwealth by way of Medicare, this refrain has been never ending. Undertaking IVF is extraordinarily expensive. It is out of reach for some.

Most of Australia's IVF clinics operate across State borders. The difference in the form of regulation from State to State, the greater the compliance costs of each IVF clinic. That cost inevitably will be passed onto consumers.

Therefore, I ask that wherever possible, that Queensland does not reinvent the wheel as to the form of regulation, but as much as possible, is able to copy regulation of some from interstate so that there is a known quantity for the IVF clinics as to the form of regulation, and the cost of compliance is able to be kept down.

<sup>&</sup>lt;sup>8</sup> <u>https://www.focusonreproduction.eu/article/ESHRE-News-ESHRE-2021-freeze-all</u> .

I also ask that any legislation need not be long to achieve its aims. It can be short, like the *Assisted Reproductive Treatment Act 1988* (SA) and *Assisted Reproductive Treatment Regulations 2010* (SA), but remain effective. All of the regulatory models (NSW, SA, Victoria, WA and as proposed in ACT) rely on the existence of RTAC, the *Code of Practice* and the *Ethical Guidelines*, and seek to add some more. South Australia keeps its version mercifully short. By contrast, Victoria and Western Australia have extensive regulation.

The key to all the regulation is simple. The keys to the lock are that a clinic must have State registration in addition to RTAC accreditation. That key, however it is expressed, is in the ability of the State to suspend or revoke that registration. Whether expressed in short form, as seen in s.10 *ART Act 1988* (SA) or in a longer version, such as s.57 *ART Act 2007* (NSW)- the effect is the same, which is to give the clear message to IVF units that if they act outside the accepted norms, then their ability to operate may be at risk.

### **REMOVAL OF DISCRIMINATION**

The Government has said that affordability and accessibility of ART services is not an issue to be covered.

Nevertheless, this is an apt time for the repeal of s. 45A of the *Anti-discrimination Act 1991* (Qld), which provides that the general requirement not to discriminate does not apply to the provision of assisted reproductive technology services if the discrimination is on the basis of relationship status or sexuality.

The Human Rights Commission, writing in *Building Belonging: Review of Queensland's Antidiscrimination Act 1991* (July 2022) said of s.45A:

- There is no justification to retain the provision because it:
  - o is redundant
  - o does not meet current community standards
  - *maybe invalid under the constitution*
  - o maybe incompatible with the Human Rights Act.

The Commission recommended:

"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."<sup>9</sup>

The Government has accepted that recommendation.

S.45A is in conflict with s.22 Sex Discrimination Act 1984 (Cth), which prohibits discrimination on the basis of the other person's sex, sexual orientation, gender identity, intersex status or

<sup>&</sup>lt;sup>9</sup> Queensland Human Rights Commission, Building Belonging: Review of Queensland's Antidiscrimination Act 1991, July 2022 at p.400.

marital or relationship status, among others. On the face of it, s.45A is not valid, by virtue of s.109 *Commonwealth Constitution*<sup>10</sup>.

Previous disputes between State laws restricting access to ART and s.22 *Sex Discrimination Act* have all ended in favour of the latter prevailing.

There is no need to wait for an overall review of the *Anti-discrimination Act 1991* to be drafted to remove this exemption. I first raised the repeal of this section with the Government about 5 or 6 years ago. There is no obvious reason for it to remain. I note that when the Northern Territory enacted its *Surrogacy Act 2022* (NT), the equivalent provision to s.45A in its *Anti-discrimination Act 1992* (NT), s.4(8) was repealed. That government did not wait for the then pending review of its *Anti-Discrimination Act* to take effect.

The Human Rights Commission said of s.45A:

"We received 18 submissions on this topic, and all said that the provision should be removed, because:

- assisted reproductive services, like other health services, should be available to anyone who needs them regardless of their relationship status or sexual orientation.
- The exemption implies that single parents are non-heterosexual couples are not worthy of assistance to become parents and perhaps should not become parents at all, which is contrary to all research in this area, and inconsistent with the introduction of marriage equality.
- Fertility service providers in Queensland do not exclude people based on their sexuality or relationship status and some target their services to the LGBTQ+ community, which shows that the law is not reflecting practice."

My husband and I are parents of our daughter through the assistance of a surrogate in Queensland, the making of a parentage order in Queensland and the help of two IVF clinics in Queensland. We were not discriminated against.

After our daughter was born, a story ran in a national newspaper about us. A prominent social commentator then posted on her social media feed "*With one magic wave of a gavel, this little girl has been forever denied her mother*". There was then a torrent of homophobic abuse by others about us having become parents.

There is a simple, quick and moral imperative that as part of this proposed Bill, that there be a repeal of section 45A of the *Anti-discrimination Act 1991*, to make it plain that Queenslanders are supportive of non-discriminatory access to assisted reproductive services.

### HOW NOT TO REGULATE ASSISTED REPRODUCTIVE SERVICES

There was no suggestion in the briefing that there be a separate statutory authority to regulate assisted reproductive services in Queensland.

If there is any suggestion that there be a separate statutory authority, I would ask clearly that there not be. In neither New South Wales or South Australia is there a separate statutory

<sup>&</sup>lt;sup>10</sup> *Pearce v SA Health Commission* (1996) 66 SASR 486; *McBain v Victoria* [2000] FCA 1009; *EHT18 v Melbourne IVF* [2018] FCA 1421.

authority: in each of those States, assisted reproductive services are regulated by the relevant Minister or Department.

However, there have been separate statutory authorities in each of Victoria – the Victorian Assisted Reproductive Treatment Authority (VARTA) and in Western Australia, the Reproductive Technology Council (RTC).

VARTA has been identified in the last couple of years as being dysfunctional. The Allan Government stated last year that it would be seeking to legislate to abolish VARTA, and to bring its functions directly within the Department of Health. This proposal is consistent that the acting CEO is an officer of the Department.

The same can be said about the RTC. The Allen Inquiry in Western Australia set out numerous criticisms of the RTC, and recommended that it be abolished. A Bill has not yet been presented by the Western Australian Government to that effect (although it has been drafted), but that Government has already taken steps so that in effect the regulation of assisted reproductive services in Western Australia is now being undertaking by the Department of Health, and not by the RTC.

It would appear only a question of time, after that scathing criticism, for the RTC to be abolished.

### FAMILY LIMITS

The *Ethical Guidelines* currently talk about a reasonable number. The effect in practice, arising from *RTAC Technical Bulletin No. 3 (2011)*, is that the cap that is used by Queensland IVF clinics is a family limit of 10. That limit, in effect, is nine, because the donor's family or potential family is deducted from the total.

That limit is, in effect, a national cap. That cap has taken effect in the ACT, Northern Territory, Queensland, South Australia and Tasmania by virtue of the Ethical Guidelines and Technical Bulletin No. 3. That is also the cap in Victoria under s. 29 of the *ART Act 2008* (Vic). NSW has a cap of 5 women, and WA has a cap of 5 women worldwide. In each of those, therefore, there is an effective cap of 4 families, i.e., one for the donor and 4 other women.

With the rise of lesbian couples seeking to become parents, at first those couples were treated as separate families, i.e. each woman was counted as one of the women for the purposes of the cap. More recently, the practice of Queensland clinics has been to treat those women as a family unit and therefore within the cap – even if they were to subsequently separate.

This issue has been addressed carefully in my view under section 27 of the *Assisted Reproductive Technology Act 2007* (NSW) where New South Wales (and in a similar way, Victoria) has identified that both women should be included under the cap.

The concern that I have about section 27 is that it carries a limit of five women. My concern about that is that the most significant amount of sperm that is provided to intended parents in Queensland through IVF clinics is imported, primarily from the United States. Feedback from clinicians in Western Australia and in New South Wales is that often it is uneconomic for overseas sperm banks to provide sperm to those jurisdictions within Australia with that limit. This then limits the ability of intended parents in each of those States to the full choice of donor, and in some cases has led to the intended parents undertaking their IVF journey interstate (such as Queensland) or overseas.

I strongly support that there be a cap. In my view the cap should be set at 10 women, with the allowance made in both the NSW and Victorian Acts about who is a family. In part, I suggest the limit of 10 so that there is national consistency (with the exceptions of NSW and WA).

However, I have grave concerns that if the cap is set at less than 10 families, then many intended parents will be unable to access donor sperm in Queensland other than through riskier, informal arrangements – where no cap is apparent. The pressure to undertake known sperm donation will increase.

I note that the Government is not proposing to regulate donor websites, groups, apps or other informal arrangements. The risks to recipients and to the resultant children from those arrangements as to no cap are significantly greater than they are through clinics. For example:

- An American sperm donor who came to Australia and used the pseudonym Joe Donor is supposed to have provided sperm that resulted in the conception of 100 children<sup>11</sup>.
- In 2020, Alan Phan, 40, from Brisbane who had been a sperm donor through IVF clinics and then ceased being a donor because he had reached the cap, continued on a private basis, resulting in the conception of 23 children in one year<sup>12</sup>. The remaining sperm stored from Mr Phan or embryos created from that sperm, was destroyed by clinics once the story came to light, as the clinics concerned would have breached their requirements as to the cap under the *Ethical Guidelines*.
- Australia's oldest sperm donor, aged 72, had fathered 21 children that he knew about, but had been banned from clinics due to his age and the cap. John Lindsay Mayger has continued to donate, no matter the risks<sup>13</sup>.
- Adam Hooper runs a Facebook group as to sperm donation. He was reported in 2022, after having fathered more than 20 donor-conceived children, as being in Queensland<sup>14</sup> and then in New Zealand<sup>15</sup> providing free specimens to women hoping to have a baby as part of his baby making tour.
- Media reports from 2022 was that a sperm donor, who had been banned from donating through IVF clinics as he had hit the cap, continued to do so, using four aliases, resulting in more than 60 children being conceived<sup>16</sup>.

No person ought to wake up and discover that they have 60 or 100 donor siblings.

If the cap is set too low, then the legitimate desires of intended parents to become parents when there is not available sperm, is to then go and find known donors.

I note that in clause 40 of the Assisted Reproductive Technology Bill 2023 (ACT) there is a proposed cap of:

 $^{16}\,\underline{https://www.dailymail.co.uk/news/article-11764815/Sperm-donor-fathers-60-children-using-fake-names.html}\,.$ 

<sup>&</sup>lt;sup>11</sup> <u>https://www.9news.com.au/national/60-minutes-joe-donor-sperm-ivf-pregnancy-children/bb45b667-9494-4684-8295-64945eb8f3b8</u>.

<sup>&</sup>lt;sup>12</sup> <u>https://www.kidspot.com.au/birth/conception/ivf/australias-most-prolific-sperm-donor-has-fathered-23-children-in-a-year/news-story/4d163b3b0e64c8aeda1a96d25daf35b2</u>.

<sup>&</sup>lt;sup>1313</sup> <u>https://www.dailymail.co.uk/news/article-9087093/Meet-Australias-oldest-sperm-donor-fathered-50-kids.html</u>

<sup>&</sup>lt;sup>14</sup> <u>https://www.kidspot.com.au/news/serial-sperm-donor-adam-hooper-going-on-babymaking-tour-of-gueensland/news-story/b7465a4c01a2b3451e73f7072defedff</u>.

 $<sup>^{15} \</sup>underline{https://www.dailymail.co.uk/news/article-11764815/Sperm-donor-fathers-60-children-using-fake-names.html}\,.$ 

- (a) Five or more families include a child born as a result of ART treatment provided in the ACT using a donated gamete or embryo of the donor, or
- (b) 10 or more families include a child born as a result of ART treatment provided in Australia using a donated gamete or embryo of the donor.

It takes little imagination to work out why the ACT might have suggested a cap of five within the ACT but 10 nationwide. The ACT is a small place, with a population of about 400,000 people. By contrast, Queensland's geography is huge with a much larger and diverse population. Someone who has been a donor to a clinic in Cairns poses much less risk if that gamete is used by a clinic on the Gold Coast, for example – than if the same gametes were donated to a clinic in the ACT to be used city wide there.

In addition to the *Ethical Guidelines* obligations about a cap, IVF specialists are very much aware of American Society for Reproductive Medicine ethical opinions to limit the number of donations in a given population, to reduce the risk of consanguinity.

In 2020-2021 as a result of the pandemic, there was a shortage of donor sperm being exported from the United States, including that being supplied to Queensland clinics. During that period, I saw a remarkable increase in the number of clients both in Queensland and interstate who were seeking to become parents with known sperm donors. The common refrain that I heard during that period was that for many of them, there was a lack of or a lack of variety of sperm donors through their local IVF clinic. Whilst in some cases the donor was a friend or family member (of the non-biological mother), the driving force for most of the intended parents was the inability of choice or availability of sperm through their local IVF clinic.

Parliament should not be taking steps that in effect prevents intended parents having that choice by choosing a number that is too low.

### CLEAR DEFINITION OF WHAT IS AN ART SERVICE

There should be a very clear definition of what is an *ART service*. There is a simple definition, for example, contained in section 5 of the *Assisted Reproductive Treatment Act 1998* (SA). By contrast, the definition contained in the New South Wales Act is complex. There have been a number of posthumous cases in the New South Wales Supreme Court where there has been a dispute about whether a transport service will be considered to be an ART service. For example, in *Chapman v South Eastern Sydney Local Health District* [2018] NSWSC 1231, counsel for the Attorney-General submitted that a transport service was an ART provider. I note the statements in the judgment at [81]-[[85].

No Queensland resident should have to have a court case to determine some certainty about who is an ART provider. A clear statutory definition should avoid that litigation.

### **GENDER SELECTION**

I note that there is consideration that there should be a ban on gender selection in Queensland for non-medical purposes. In doing so, it is said, that Queensland will merely be, in effect, copying the approach taken by the NHMRC *Ethical Guidelines*.

Western Australia and Victoria prohibit gender selection. New South Wales and South Australia do not. I have not seen any reports anywhere that suggest that gender selection is happening to any degree in Queensland other than for medical purposes.

I would caution the Government against legislating on this point and to leave it in the hands of the NHMRC, which has a thorough community and expert focus.

As made plain in the NHMRC *Ethical Guidelines*, there are concerns stated about sex selection for non-medical purposes and despite the Australian Health Ethic Committee's "majority view that there may be some circumstances where there is no ethical barrier to the use of sex selection for non-medical purposes, paragraph 8.14 (sex selection for non-medical purposes are not currently supported) applies until such time that either public debate occurs and/or State and Territory legislation addresses the practice."

It may well be that public debate occurs (which has not done to date) and that consideration may be given to allowing sex selection for non-medical purposes.

In my view, there ought not be a value judgment made about this in a tightly circumscribed setting without significant community consultation – which there has not been for this process.

### POSTHUMOUS USE FOR REPRODUCTION

Posthumous use is banned in Western Australia. Posthumous use is restricted in each of New South Wales, South Australia and Victoria to a requirement that the deceased consented in writing to the use of their gametes or embryos made from those gametes posthumously.

This restriction in practice has led to a barrier to widows being able to be able to use their late husbands' sperm in those States. Widows<sup>17</sup> instead have exported that sperm to either the ACT or Queensland in order to facilitate treatment. Treatment has been possible in each of the ACT or Queensland by virtue of there not being that restrictive legislation, provided that there has been compliance with the NHMRC *Ethical Guidelines*.

Posthumous use commences first with consideration as to whether there are gametes or embryos that is stored. From experience, this is much less common, although seen in a reported case in Queensland in *Bazley v Monash IVF* [2010] QSC 118.

The much more common scenario is that the man has died suddenly (and I am aware of one case of a woman dying with her eggs being retrieved), usually leaving the widow in shock and needing to make a decision as to whether or not to retrieve the sperm. There has been a small number of reported cases where widows have obtained orders from the Supreme Court in order to enable them to retrieve the sperm, such as in *Re Cresswell* [2018] QSC 142.

However, as the court in that case and in other cases has commented, it is doubtful whether the Supreme Court has jurisdiction to order retrieval. But in any case, there is already a mechanism for retrieval posthumously under the *Transplantation and Anatomy Act 1979* (Qld).

In my view, the safeguards that are in place under that Act are thorough and the process works well.

The timeframe for retrieval of the sperm according to doctors varies anywhere between four hours and 24-48 hours. Evidently, the earlier the sperm is retrieved, the higher the chances that it is able to be used.

A process by which a court application is required to authorise retrieval will greatly increase costs for grieving widows at the most vulnerable point of their lives, without in my view adding

<sup>&</sup>lt;sup>17</sup> I refer to widows. Consistent with the actuarial life tables, the people who die prematurely typically are men. Their surviving spouses are typically women.

significant safeguards that are not already contained under those of the *Transplantation and* Anatomy Act 1979 (Qld).

The current process works. Consent from the Coroner is quickly obtained- and in writing. In *Re Cresswell*, that consent, which was not in writing, was the subject of later criticism. I have seen a dozen or so retrievals occur in Queensland through the statutory process. In all of them the Coroner was involved. In all of them, written consent from the Coroner's office- in Brisbane, Cairns and the Gold Coast, was obtained speedily.

As I set out in my letter to the Minister last year, **attached**, there are significant barriers in Queensland to posthumous use where the person has died outside a centre where there is an IVF clinic. In each of our major cities – Cairns, Townsville, Mackay, Rockhampton, Sunshine Coast, Brisbane, Toowoomba and Gold Coast – there are available IVF clinics. However, there is not always someone in one of those clinics, particularly in regional centres, who is able to retrieve. Only a small number of IVF doctors undertake posthumous retrieval.

Retrieval involves a minimum of three people:

- 1. The officer of the morgue or hospital.
- 2. A doctor with sufficient skills to remove the tissue.
- 3. A scientist present who is able to preserve that tissue.

If any of these are absent, retrieval is not able to be undertaken.

In my view, the process of identification of the senior available next of kin works. So does the inquiry by the authorised officer about whether the deceased had any objection to post-humous use. Typically, the officer (and IVF specialist) not only talk to the senior available next of kin (for example, the spouse) but other close family members (parents) to see whether or not there is support for the retrieval, and whether or not the deceased had objected.

There is in my view no compelling reason to change the process.

Once retrieval has been obtained, then use cannot happen unless there is compliance with the *Ethical Guidelines*. In my view, the *Ethical Guidelines* are a thorough means to regulate the ability to use posthumously. I note that it is proposed in the ACT under clause 36 of the *Assisted Reproductive Technology Bill 2023* (ACT) that if the deceased had not consented to the treatment in writing, then a court order is required from the Supreme Court. Clause 37(2) sets out a list of factors to be taken into account as to whether or not such an order should be made:

- (a) Whether the domestic partner has capacity consent to the provision of the treatment.
- (b) Whether the domestic partner has undergone appropriate counselling.
- (c) The best interests of any children to be born as a result of the treatment, including -
  - (i) Whether the domestic partner has capacity to provide for the child's emotional, intellectual and other needs, and
  - (ii) Whether the child is likely to have safe and stable living arrangements.
- (d) Whether the gamete provider expressly objected to posthumous use of their gametes.

- (e) Whether the gamete provider is likely to have support of posthumous use of their gametes in the provision of ART treatment to their domestic partner.
- (f) Any other matter the court considers appropriate.

It is difficult, as the court alluded to in *Re Cresswell*, to be able to determine what is in the best interests of a child who has not yet been born let alone conceived.

If the proposed ACT model were to be adopted for posthumous use, it will visit upon grieving widows an extra significant cost burden that treats them differently to anyone else who wishes to become a parent.

I presented a paper about posthumous use at the 2022 scientific meeting of the Fertility Society of Australia and New Zealand. There was then a panel discussion. One of those panellists was a doctor from Queensland whose husband had died. She needed to undertake retrieval and then underwent posthumous conception, resulting in the birth of a child.

She described that the current process under the *Ethical Guidelines* as being "*patronising*" and "*unduly burdensome*" in that it treated her differently to anyone else seeking to conceive. After all, she could not conceive straight away, but had to wait, in accordance with *Ethical Guidelines* requirements. She had to undergo counselling- whether she wanted to or not- before she could proceed. She had to have someone independent of her and the clinic authorise the treatment-again whether she liked it or not.

It was a powerful presentation of potential system abuse with the system as it is currently configured, and left many in the audience crying.

If a requirement to impose in addition to the NHMRC *Ethical Guidelines* is that of obtaining a court order, which would also involve tens of thousands of dollars in legal fees and delay in order to obtain court approval, what reaction would there be of widows who are seeking to conceive with their late husbands' sperm? There is the potential, one might suppose, that any trauma visited upon them by the sudden loss of their husbands is reinforced by that process.

It is relatively common, for widows who live interstate such as Western Australia, New South Wales and Victoria, to export their late husbands' sperm to Queensland or the ACT for the purposes of ART. The sperm is unable to be used in those States, but is able to be used in the ACT or Queensland.

Queensland clinics require three steps to be undertaken before the sperm can be used:

- 1. Clarity that the sperm was collected lawfully in the other State. A concern by any Queensland clinic is not merely that the sperm has arrived in Queensland and is able to be used, but that collection was lawful. Typically, this requires a very long letter written at the expense of the client, for the benefit of the IVF clinic, as to all the steps that were taken for collection to demonstrate beyond doubt that the collection and storage of the sperm interstate was lawful. If the clinic is not able to satisfy itself that the collection and storage was lawful, it will refuse treatment. Upon receipt of such a letter, the clinic then makes a decision as to whether or not to obtain its own independent legal advice.
- 2. Clarity that the sperm is lawfully able to be exported from the other State to Queensland. Again, the legal requirements are set out in a lengthy letter on point. Again, the clinic decides whether to obtain its own independent legal advice.

3. The thorough requirements of the NHMRC *Ethical Guidelines* as to posthumous use are met.

The requirements under the *Ethical Guidelines* are set out in paragraphs 8.22 and 8.23. Paragraph 8.22 provides:

"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. [Currently, there is no such impediment in Queensland].

- 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)

[As I commented above, these cases are very much the exception rather than the rule. Men do not expect to die. I have seen young men die from the following (and their widows seek to retrieve their sperm):

- Car accident.
- o Surfing accident.
- A man who travelled to the Gold Coast from interstate who had an accidental drug overdose whilst out partying.
- A man who had a stroke or severe heart attack, even though he was of apparently good health.
- A man who, whilst waiting to collect his fiancée from work, went skateboarding. He did not wear a helmet. The skateboard hit a rock. He fell off and lost consciousness, never to recover.]
- The request to do so has come from the spouse or partner of the deceased person, and not from any other relative.

[Under Queensland law, this would be the spouse – see section 32DA *Acts Interpretation Act 1954* (Qld) and Schedule 1].

- The gametes are intended for use by the surviving spouse or partner.
- The conditions of paragraph 8.23 are satisfied.

[As I said, 8.22.1 is the exception, rather than the rule. Most of those who die will not have left written instructions. Their death was sudden and unexpected].

- 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 extended 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.

[A concern is that if court approval is required, then the evidence might need to be shown that the deceased would have supported the posthumous use. The ability to obtain that evidence might be extremely difficult. A requirement for court approval may act as an insuperable barrier to prevent widows being able to reproduce. It is more common to find that there is no evidence that the deceased had previously expressed an objection to posthumous reproduction.]

- *The surviving spouse or partner provides valid consent (see paragraph 4.5).*
- The conditions of paragraph 8.23 are satisfied."

Paragraph 8.23 provides:

"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

[There is no hard and fast rule to this, which must be dependent on the facts of the individual case. Typically, however, the minimum period is six months, although in an individual case, may be two years following the death.]

• 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.

[Typically, this is undertaken by an independent ANZICA counsellor providing that information and then providing a report about that fertility counselling. The report is provided to the IVF clinic.]

- 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 NHMRC Ethical Guidelines as:

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

May include a clinical ethics committee, a regulatory body or board, 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 make be prescribed by legislation."

In order to comply with *Ethical Guidelines*, the typical process involves:

- (a) The widow attending upon a fertility counsellor for counselling and information.
- (b) The fertility counsellor then writes a report, setting out that the information has been provided and that the widow is a suitable candidate to proceed. These reports vary in length, from 2 pages to greater than 12 pages.
- (c) A statutory declaration is obtained from the widow setting out history, including the desires of the deceased to become a parent, the circumstances in which the deceased died and the intent to undertake reproduction.
- (d) Provision of relevant documents in support, such as IVF attendances (where applicable), death certificate of the deceased, coroner's consent (where applicable), the deceased's will (if there was one) and written consent of the executors or administrator, if they are different to the spouse. *Re Cresswell* tells us that sperm collected and stored before death is part of the estate (as did *Bazley*), but sperm retrieved posthumously is not. The latter is owned by the surviving spouse. However, because NSW Supreme Court decisions refer to the role of the personal representative, obtaining this consent is wise to obtain, so that there is no doubt about the ownership and consent to use.
- (e) Approval is then obtained by the independent body. Posthumous reproduction to my knowledge is practiced by four Queensland clinics (Queensland Fertility Group, City Fertility, Monash IVF and Life Fertility). Only one of those clinics has a Human Research Ethics Committee, Queensland Fertility Group. Approval is undertaken by that committee before the clinical decision is made as to whether or not to proceed. For the other clinics, the independent body is typically a senior fertility counsellor engaged at the

cost of the widow specifically for the purpose of assessing whether or not approval should be given.

- (f) The report by that independent authority, the report by the fertility counsellor, the statutory declaration of the surviving spouse and, commonly, a letter from a lawyer setting out compliance issues, is then provided to the IVF clinic.
- (g) The medical director of the clinic then consults with the treating doctor, and other senior officials within their clinic, such as the scientific director and the counselling director, to assess whether or not it is appropriate for the clinic to proceed.

Assuming that all those steps have occurred, then treatment commences.

### **PRE-MORTEM RETRIVAL**

In my letter to the Health Minister last year, **attached**, I advocated that there be the ability to have pre-mortem retrieval, so that there is no repeat of events that occurred as described in that letter.

I advocated for the copying of the provisions in the *Human Tissue Act 1983* (Vic), which I considered had adequate safeguards. My view remains the same that there ought to be the ability under Queensland law, with the safeguards identified, to allow pre-mortem retrieval.

### **ANYTHING FURTHER**

If I am able to assist in any other way, please ask.

### PERSONAL CAPACITY

I am, with my husband, a father through egg donation, IVF and surrogacy in Queensland. I have also suffered infertility. I knew since the age of 4 that I wanted to become a father. When it was apparent that I had infertility, I had the black hole of depression- not knowing whether I would ever be a parent. Many of my clients have told me of the severe emotional toll of not being able to be parents easily (unlike everyone they know), and the existing burden of enduring umpteen administrative procedures within IVF clinics, to enable treatment, those procedures being to ensure that clinics are compliant with regulatory requirements.

I was admitted as a solicitor in 1987. I have been a Queensland Law Society Accredited Specialist since 1996. I have a number of affiliations, including being a Fellow of the International Academy of Family Lawyers, a Fellow of the Academy of Adoption Assisted Reproduction Attorneys and an international representative on the Artificial Reproductive Technologies Committee of the American Bar Association. I am a board member of the Fertility Society of Australia and New Zealand Ltd.

Since 1988 I have advised in about 1,900 surrogacy journeys for clients throughout Australia and at last count, 37 countries overseas. I have advised clients with sperm, egg, and embryo donor agreements, among others. I have written and presented extensively around the world about fertility law issues in 200+ presentations, including for Hong Kong University, the University of the Western Cape and Monash University, International Bar Association, American Bar Association, both the Academies, International Surrogacy Forum, Fertility Society of Australia and New Zealand, Family Court of Australia, and the Law Societies of Queensland, New South Wales, and South Australia, and the Family Law Practitioners Association of Western Australia.

Between 2017 and 2022 I lectured at the University of New South in Ethics and the Law in Reproductive Medicine, for which I received a teaching prize (2019). In 2020 I received the inaugural Pride in Law Award.

I have acted for donor conceived adults, who do not know where they have come from. Their pain is awful.

I have acted for men who were sperm donors prior to the changes in 2004, who were promised anonymity- who have now discovered, through databanks such as ancestry.com and 23andme.com, that their anonymity is an illusion. They have been found.

I was awarded the 2023 Queensland Law Society President's Medal.

This submission is my personal submission and not that of any of the organisations to which I am connected.

Yours faithfully

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