Dear Associate Professor Allan,

Submission Re: Review of the Operation and Effectiveness *Western Australian Human Reproductive Technology Act 1991 (HRT Act)* and the *Surrogacy Act 2008.*

We thank you for this opportunity to make a submission to this legislative review.

This document contains the opinions and comments from a selection of the Western Australian RTC approved, ANZICA Fertility Counsellors. Please note that throughout this document the reference to "the counsellors" represents only those counsellors named at the end of this document.

We have organised this document according to the "*Terms of Reference*" that were provided to guide submissions for this review. The end of our submission includes other comments not stipulated in the terms of reference but applicable to the Acts in question.

Review of the HRT Act:

1) *Research and experimentation on gametes, eggs in the process of fertilisation and embryos. In particular consider the current disparity between the HRT Act and relevant Commonwealth legislation and need to adopt nationally consistent legislation regarding excess assisted reproductive technology (ART) embryo research and prohibited practices.*

The counsellor's support the need to adopt nationally consistent legislation in regard to embryo research and prohibited practices.

2) *Genetic testing of embryos, saviour siblings, mitochondrial donation and gene editing technology.*

- We recommend mandatory counselling (implications and/or support) before genetic testing commences and mandatory genetic counselling / consultation prior to genetic testing.
- The counsellors also support a recommendation for Medicare rebates for this testing, in some cases. We appreciate that this is a matter for the Australian Government rather than a change to the legislation under review.
- We recommend that clinics do not need to seek the approval of the RTC to undertake PGD or PGS as it is a medical decision undertaken after careful evaluation by the Fertility Specialist and the patient.
- We recommend that clinics are required to provide screening for Spinal Muscular Atrophy (SMA) as well as Cystic Fibrosis (CF).
- The counsellors also support a recommendation for Medicare rebates for this testing, in some cases. We appreciate that this is a matter for the Australian Government rather than a change to the legislation under review.
- We recommend that clinics are required to provide carrier screening of couples/donors for Spinal Muscular Atrophy (SMA) as well as Cystic Fibrosis (CF). In addition, clinics are required to offer/discuss carrier screening to maximize the detection of at-risk couples for a pregnancy affected by inherited conditions as currently testing is now available for >175 conditions.

3) *Posthumous collection, storage and use of gametes and embryos, including the consent required, conditions for use, and any impact on other legislation such as the Human Tissue and Transplant Act 1982, Artificial Conception Act 1985, Births Deaths and Marriages Registration Act 1998, Administration Act 1903 and Family Provision Act 1972.*

- The counsellors recommend that nationally consistent legislation regarding posthumous collection, storage and use of gametes and embryos be adopted. We believe that the sector currently suffers from a lack of consistent legislation and service delivery across states. Consistent legislation across states would provide patients with clarity regarding their treatment options.
- We recommend a mandatory addition to clinic consent forms requiring patients to explicitly indicate their wishes for posthumous use of their gametes and embryos.
- Consistency with recent RTAC guidelines is recommended.

4) *Rights to storage of gametes and embryos including -*
- *Rights upon separation or divorce, or the death or the physical or mental incapacity of an individual, or one or both members of a couple.*
- *Rights of third parties such as subsequent spouses, and the rights of other relatives.*

The counsellors recommend that patients' wishes regarding these matters be recorded on the consent before treatment commences.

5) *The storage of gametes, eggs in the process of fertilisations and embryos (including the duration of storage and procedures for extension of storage periods).*

Counsellors agree with the current guidelines.

6) *The Chief Executive Officer's (CEO) power to issue directions, the power to make a Code of Practice, regulations and guidelines, and the scope and effect of the existing directions and regulations under the HRT Act.*

No comment

7) *The effectiveness of powers of enforcement and disciplinary provisions under the HRT Act and the adequacy of offences and penalties.*

No comment

8) *Whether there should be a process of review or appeal of decisions made (by the Reproductive Technology Council (Council)) under the HRT Act.*

We support a process of review or appeal of decisions made by the RTC. Further, we recommend that an independent review body, such as the State Administrative Tribunal, would be consistent with the review processes defined in other state legislation.

9) *The impact on the HRT Act of relevant Commonwealth and State legislation, and aspects of legislation of other jurisdictions which could be incorporated into the HRT Act.*

The counsellors support the adoption of nationally consistent legislation regarding access to assisted reproductive treatment for all, regardless of marital status, sexual orientation and gender identity.

The effectiveness of the current licensing regimen, including fee structure, reporting requirements, powers of inspection and powers of obtaining information.

No comment

10) *Management of information / the Reproductive Technology Registers, including:*
- *Confidentiality of information*
- *Use of data for research*

- *Use of data for purposes of national data collection and;*
- *Access to information about donation, genetic parentage and donor conception,*
- *The Voluntary Register (donor-assisted conception).*

- The current model of RTC data collection required of counsellors is confusing, time-consuming and lacks relevancy. We recommend that it be reviewed as a matter of urgency.
- We strongly support the current model for mandatory counselling prior to donor linkage. However, we recommend that counselling be provided at no cost to the individuals seeking information from the Voluntary Donor Register or Donor Register. The current model of requiring donors to pay for their counselling is a barrier to connection being established with the recipient and /or the children born as a result of the donation, and works against the best interest of donor offspring and their right to access identifying donor information.
- De-identified data should be available for research.

11) *The effectiveness of the operation of the Council and committees of the Council*

The function, membership and roles of the RTC and its committees, including the Counselling Committee, are not clear. It is not clear how committee members are selected and renumerated, and what their responsibilities are, both in relation to the RTC and approved counsellors. We support greater transparency regarding membership, function and role of RTC and RTC committees, and improved communication between these bodies and others in the sector.

12) *The need for the continuation of the functions conferred, on the Council and on the CEO respectively by the HRT Act.*

The counsellors recommend that the RTC take on a greater role in education and guidance, for both consumers and professionals, in relation to all assisted reproductive technology matters. VARTA is an example of a successful model.

We recommend that the RTC take a more active role in the provision of information /guidance to people about the potential risks involved in seeking overseas treatment, especially involving gamete donation and surrogacy, so they can make informed decisions, not only in relation to their treatment options, but also in relation treatment implications and the “best interests of the child”.

We recommend that different models of donor linking and donor registry management be explored, and that the RTC take a more proactive role in promoting donor linking and enabling appropriate services to be established to support donor linking. We are supportive of the ANZICA donor linking guidelines.

The Review of the Surrogacy Act 2008

1) *Interaction with the HRT Act;*

No comment.

2) *The need for provision as to the administration of the Surrogacy Act and any functions to be conferred on the Minister, Council, CEO and assisting staff/persons, respectively by this Act;*

No comment.

3) *The effectiveness of the current regime, reporting requirements, powers of inspection and investigation, powers of obtaining information;*

We recommend that the RTC develop a resource function, providing guidelines and advice for intending parents and surrogates. This might include provision of information as to the disadvantages of international commercial surrogacy and how intending parents can access altruistic surrogacy in Australia, and information regarding clinical psychologists and lawyers who are knowledgeable about the RTC's processes and requirements.

4) *The effectiveness of powers of enforcement and disciplinary provisions under the Surrogacy Act, the adequacy of offences, penalties and timeframe for bringing proceedings;*

No comment

5) *The impact on the Surrogacy Act of relevant Commonwealth and State legislation and aspects of legislation of other jurisdictions, which could be incorporated into the Act, including consideration of harmonisation of domestic surrogacy legislation;*

We strongly support the harmonisation of legislation throughout Australia with regards to access to surrogacy. The counsellors support the adoption of nationally consistent legislation regarding access to surrogacy for all, regardless of marital status, sexual orientation and gender identity.

6) *The need for continued prohibition on commercial surrogacy;*

The counsellors are fully supportive of this position, and recommend that the RTC actively promotes the benefits (present and future) of altruistic surrogacy.

We suggest that the RTC clarify "reasonable expenses" and provide information about realistic clinic, medical, psychological assessment and legal fees so that prospective patients can make informed decisions as to where they would pursue surrogacy. This information is likely to deter some from entering, unnecessarily, into international surrogacy arrangements.

7) *International commercial surrogacy arrangements;*

The counsellors do not support international surrogacy arrangements; however we acknowledge the growing number of children born to surrogates from overseas, and the likely future need to assist children born from such arrangements.

8) *International trade in gametes and embryos; including importing international gametes*

The counsellors support a continued ban on the international trade of gametes and embryos, given that it is commercially based and there are long term implications regarding the lack of access to identifying information about the donors. There are concerns re family limits and counselling of prospective donors, as well as access to identifying information.

We recommend the development of an information sheet be available to persons considering travelling overseas for this purpose, detailing the options and realistic costs of domestic gamete and embryo donation, and identifying the shortcomings of international third-party conception.

The issue of reasonable compensation for egg donation is an important one. An ASRM Ethics Committee opinion (2016) (ASRM position paper on Financial Compensation of Oocyte donors, 2016) reported that men typically are compensated approximately $100 for a sperm donation. It has been estimated that egg donation involves 55 clinic contact / treatment hours. Thus, it is important that an amount of money that would be considered reasonable compensation rather than inducement be determined, so that egg donors are not disadvantaged.

We recommend that the RTC develop guidelines for intending parents as to the choices available, and identify advantages and disadvantages in order to guide the many intending parents who are considering travelling overseas for gametes and embryos as well as guidance around limitations to the RTC approving the importation/exportation of gametes, before they are created.

Our interpretation of the latest NHMRC 2017 guidelines (4.2.8 and 4.2.9) support our position in discussing these matters with patients, especially with the intention of reducing potential harm.

9) *The effectiveness of the operation of the Council and committees of the Council;*

Please refer to our comments above in point 12) under the HRT Act section.

10) *Whether there should be a process of review or appeal of decisions made (by Council) under the Surrogacy Act.*

The counsellors recommend the development of a process of review for decisions made by Council, which will make it unnecessary for unsuccessful applicants to reapply, under most circumstances.

Further Comments Related to the Acts:

1) Presumptions Against Treatment / Criminal Record check: The counsellors acknowledge the discrepancies between states on this matter, and the difficulties encountered within existing models, there needs to be more attention given to an operational definition of the "best interests of the child" and guidelines to clinics /medical directors re how to manage prospective patients about whom they have serious concerns re providing treatment.

2) Counselling: We recommend that clinicians and nurses be advised of the need to offer a counselling session if treatment is terminated. We believe that many patients are missing out on counselling, not only at the end of treatment, but also at other times during treatment.

3) In regard to cases of counselling with known donation of gametes, we recommend that the current wording in the Directions stating the need for "contact" by the counsellor with the parties at the end of cooling off, should be changed to the practice of requiring face to face "counselling" at the end of the cooling off period, as per the requirements at the beginning of the "cooling off" period, unless there are extenuating circumstances (e.g. living interstate), in which alternative electronic communication (e.g. Skype) can take place.

4) We do not support egg sharing.

5) In line with previous comments, we seek a clearer definition of "reasonable expenses" as this relates to gamete and embryo donation and surrogacy.

6) We recommend clinics be mandated to provide explicit information to patients before treatment regarding chances of success (for pregnancy and live birth) relevant to the patient's age and diagnosis and in regard to the particular clinics' treatment outcomes.

7) We do not support the "on donation" of embryos.

8) We support the introduction of Medicare rebates for Surrogacy, PGS and PGD, in most cases. Whilst we recognise that this is a matter for the Australian Government, there may be opportunities for the WA Government to dialogue with their federal counterparts.

9) We support a review of the age/criteria at which women are considered too old to receive treatment using their own gametes.

10) We support the development of resources that would assist prospective patients' decision making and support them in seeking treatment from WA based clinics, rather than travelling overseas (e.g. basic legal contract for surrogacy that can be downloaded free of charge and personalised, saving them significant legal expenses; guidelines on expected and reasonable expenses; case studies showing how gamete donation and surrogacy can be done in Western Australia.

11) The counsellors recommend that lists of suitably trained and qualified lawyers and clinical psychologists be placed on the RTC website to assist those pursuing surrogacy.

12) We support the development of consistent ART legislation, across all Australian states and territories and the development of a national donor register. There are a number of compelling reasons as to why consistent ART legislation and registers, across all Australian states, is preferable to the current state-by-state situation: Australians are highly mobile between states, not only in terms of residency, but also to access donors /surrogates and preferred treatments in clinics in other states, with the intent of avoiding restrictions in their own states; different legislatures confuse patients and often, is experienced as inequitable and discriminatory, depending on which state they reside in; and finally, with respect to donor conceived persons, there are inequities as to the identifying information available to them, depending on the state they are dealing with.

13) We seek clarity on a female partner accessing treatment with the oocytes of her partner.

14) The counsellors support access to surrogacy arrangements for men in homosexual relationships.

15) We consider "reasonable expenses" in relation to surrogates should include the possibility of up to 40 weeks of potential illness, risks to employment, burden on family members, child care or other assistance that may be required by the surrogate or her family. An

amount to cover the potential reimbursement should be held by an independent third party in "Escrow" accounts to avoid the need to negotiate financial matters during a pregnancy.

16) It is the view of the counsellors that the overriding principle of the "best Interests of the child" lacks definition and is very complex to address, when applied in practice. With increasingly complex patient presentations, from psycho-social perspectives, clinicians and counsellors would benefit from access to specialist advice and/or a forum in which to explore the issues. We request that the RTC address the current status of the "best interests of the child" principle or assist with the development of a process for addressing the principle, in practice.

17) We suggest that the RTC manage enquiries from people wanting to import gametes from overseas or interstate and provide advice as to whether it is permissible under the law. RTC could issue a letter to the person advising that their gametes can be imported, or conditions that must be met to do so that the person could then provide to a clinic. This would increase consumer choice and access to service. Information and guidance in the form of case studies would also help consumers make informed decision about the potential risks of using gametes sourced overseas and that they may not be able to import them to WA and the reasons why.

18) We would like a review of the requirement for counsellors to apply for renewal of their approved status every 3 years.

This submission was made jointly by the following ANZICA WA Fertility Counsellors:

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Submitted: 16th March 2018