

April 7, 2016

A/Prof Sonia Allan  
A.R.T. Act Review  
c/- Policy and Intergovernment Relations Unit  
SA Health  
PO Box 287, Rundle Mall  
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Dear A/Professor Allan

Thank you for your letter of 15<sup>th</sup> February 2016. Our comments on the legislative review are as follows:

### **Access to Assisted Reproductive Treatment**

We would support the recommendations for amendments to the eligibility criteria proposed by the South Australian Law Reform Institute (Page 2, Fact Sheet 5). These recommendations remove the discriminatory aspects of the current eligibility criteria and are as follows:

Recommendations that eligibility criteria for ART treatment be amended to

- Clarify that a person can access ART if, in the person's circumstances, they are unlikely to become pregnant other than by an ART procedure and
- Include the guiding principle that people seeking to undergo ART procedures must not be discriminated against on the basis of their sexual orientation, marital status or religion.

The current discriminatory eligibility criteria have implications for the best interests of children and for people seeking to conceive who are not eligible in SA.

For example:

- With respect to access to fertility preservation, the current legislation discriminates against women because, unlike other states, South Australian women do not have access to an ART procedure to preserve their eggs. This results in a classic Catch 22 scenario – women can only bank their eggs when their fertility is already compromised, thus reducing chance of a positive outcome. Men are able to bank sperm and preserve fertility without legal restraint. This is clearly inequitable. In 2012, the American Society for Reproductive Medicine announced that egg freezing should no longer be considered experimental and it is now a first line fertility treatment. Given that technology for successfully freezing eggs has been developed, this discrimination should be removed.

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- People who are deemed ineligible may choose to embark on private arrangements with donors where there are inadequate health screens and fragile contracts relating to responsibilities and legal parental rights. There are many examples of such arrangements ending up in protracted legal battles around children, surely contrary to the principle of paramountcy in upholding the optimum welfare of a child.
- A same sex couple may decide which partner is to conceive based on medical eligibility in SA, not upon whose wish it is to carry a child, breast feed a child etc. This is surely in no one's best interests.
- In the circumstance of one partner only being eligible in SA but each wishing to bear a child, unless the couple travels interstate for treatment for both, they will have different donors for each child – again adding undesirable complexity for the children involved.

Discriminatory eligibility criteria results in people crossing state borders to access treatment and this is unnecessarily burdensome in a context which is already stressful. South Australia remains in the minority of Australian jurisdictions to have such discriminatory legislation.

#### **Paramountcy of the Welfare of the Child Provision**

This will always be a difficult matter in which to establish clarity particularly in situations where, at the time of seeking ART services, there is no child. However, the principle of children's best interests being privileged above those interests of the other stake holders (prospective parents, clinics, donors etc) should be upheld to the best of our abilities as a community.

The 2010 changes to the Act, whilst strengthening the statement about the importance of this principle, have disbanded some structures that supported the practice. Those structures have not been replaced hence the strong statement is not given any potency. The SA Council for Reproductive Technology, as a body of people informed in these matters, had both consultative and community educational roles which supported best outcomes for children. There is now no structure which performs this function. In our experience the Ethics Health Advisory Council has had no identifiable presence at the clinic level.

It would also be helpful to have an ethics body, with members well versed in the ethical issues confronting clinics, which clinics could approach for rapid guidance around decision making in complex ethical situations. These frequently do have implications for best interests of would be children.

#### **Establishment of a SA central donor conception register**

A centrally held donor conception register – for which there is provision in the Act – has never been implemented. This would provide security for donor conceived



children, again upholding as paramount the best interests of children. This has been supported by Fertility SA since it became a possibility in 2010.

A central register would unequivocally protect donor conceived people's rights to access information about their genetic heritage regardless of the future status of the clinic at which their parents had had treatment.

However it would need to be established, not just as a data base, but also to provide services for donor linking that follow the best practice ANZICA guidelines and to maintain a community education focus on the rights of donor conceived people.

#### Which information should be kept

Previous recommendations have been made on this matter and currently clinics maintain information according to those recommendations – namely the profile of the donor and the cross referenced information about children born from that donation and their parents. In this way the clinics also ensure adherence to the limit the clinic has placed on the number of families created.

As SA complies with the NHMRC Guidelines there is no set prescription for the number of families that can access one donor, just the requirement that clinics should limit the number of families. It is not necessary to change this or to change the reference to “families” (as distinct from “women”). The latter again runs the risk of discriminating against same sex couples and negates their status as one family – the SA Family Relationships Act now recognizes this status by establishing in its recent amendment that both Mothers are on the Birth Certificate as legal parents where a child has been born in the context of an assisted fertilisation procedure.

Fertility SA would support the establishment of both mandatory (post 2010 donor conceptions) and voluntary registers with the provision that only donor conceived people could access their own information unless there were appropriate consents given (eg for linking with biological half siblings). Donors would remain entitled to receive non-identifying information about the outcomes of their donation.

#### **Registration Scheme for ART Clinics**

##### Compliance with NHMRC Guidelines

This is appropriate to consider, however the guidelines are just that – a relatively loosely-held set of best practice principles that, in this Act, via the conditions of registration, have been given the status of law. This has from time to time created difficulty for clinics, particularly where the guidelines are contradictory to each other, or counter to the paramountcy of the welfare of the child. Examples include:

- For embryos created from donor gametes, the guidelines suggest that these embryos are not to be donated on to others. However, clinics are also advised that in the matter of embryo donation, they should respect the wishes of the



donors (which in at least one case we have come across, is to donate the embryos to another family rather than destroy them).

- Cryopreserved embryos may only be retained for 10 years, yet in some circumstances it would make sense to be able to extend that period.

We believe that in all statute there should be provision for exemption and would recommend that the availability of and process for exemptions be stated clearly in ART Act.

#### Gender balancing for families

We would also suggest consideration is given to allow couples undergoing preimplantation genetic screening (PGS) to have access to the sex of the embryo that they may transfer. This is currently prohibited under NHMRC Guidelines, but our observation is that there is a growing demand for this information from patients. We would therefore suggest that any amendment to the legislation in SA should incorporate the ability to adapt to any changes in the NHMRC guidelines.

We welcome the legislative review and thank you for the opportunity to comment on these issues.

On behalf of Fertility SA

Sincerely



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