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CRICOS Provider No. 00123M

Thursday 28 April 2016

A/Professor Sonia Allan
A.R.T. Act Review,
C/- Policy and Intergovernment
Relations Unit, SA Health,
PO Box 287, Rundle Mall,
ADELAIDE SA 5000

Submission to the Review of the *Assisted Reproductive Treatment Act 1988*

Dear Sonia,

The Robinson Research Institute is pleased to offer the following submission to the review of the the *Assisted Reproductive Treatment Act 1988*, in response to your letter, dated 15 February 2016.

Research at the Robinson Research Institute generates new knowledge on the impact of Assisted Reproductive Technologies for children and parents. Specifically, our research advances understanding on (1) the impact of conception by ART for the life-long health and susceptibility to disease in children, and (2) the nature of treatment options that may have value for infertile couples. Our work has specific bearing on ethical arguments and principles of access to ART treatments.

Therefore we would like to comment firstly on the principle that the rights of the child should be paramount in considerations of ART.

Fact sheet 1 states that:

“(The) Welfare of the child provision retained, and strengthened: requiring the welfare of the child born as a result of the use of A.R.T. be considered as paramount and of fundamental importance in the application of the Act and in the provision of assisted reproductive treatment”.

This statement makes it clear that both psychological and physical harms to the child must be avoided. However, the current statement of principle does not explicitly include reference to health outcomes for the child. This is understandable as at the time the principle was drafted, the health consequences were largely unknown.

However, the absence of any reference to health of the child conceived can now be regarded as omission, since Fact sheet 2 further states that:

“Consideration of the welfare of children born as a result of A.R.T. may also include laws and practices that address whether there is long term follow up and research on such things as the social, emotional, and health outcomes for those conceived using A.R.T.”

We recommend that the statement of principle include wording that both the “...health and welfare...” of the child is paramount.

The explicit inclusion of health outcomes for the child has a series of implications for informing clinical practice, patient counselling, record keeping, and research direction. The inclusion of health of the child is important as is now apparent from studies conducted in several jurisdictions, including South Australia, that the health outcomes for children born from ART are significantly more likely to include the adverse outcomes of cerebral palsy, low birth weight, premature birth, stillbirth and neonatal death. Identifying the sources of risk, and creating risk reduction strategies is imperative.

With regards to record keeping, there is now the demonstrated capacity to link mode of conception data to routinely collected data for perinatal outcomes. It would be invaluable for the timely assessment of technical innovation within clinics in SA to provide, as a matter of routine, patient identifying data, and certain treatment data items, to the Department of Health to facilitate identification of the health outcomes from treatment.

We recommend that patient and treatment data be made linkable to health records within SA.

Our research together with mounting international data demonstrates clear evidence for adverse outcomes of cerebral palsy, low birth weight, premature birth, stillbirth and neonatal death in pregnancies conceived by ART. There is emerging evidence for metabolic and cardiovascular changes in ART children. New preclinical studies

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raise alarming concerns about impact of ART on the epigenetic patterns in IVF embryos, as well as changes to cellular structures such as mitochondria and telomeres. We believe it is imperative that intending patients are provided with clear information on the known risks as well as emerging concerns, in order to make an informed decision to access ART procedures.

We recommend that information provided to prospective parents on the risks and consequences of ART treatments include wording that acknowledges emerging evidence that there is a small but quantifiable risk of adverse health outcomes for the child.

Additionally, our research uncovers new treatment options that may improve likelihood of achieving pregnancy and improved treatment outcomes for some subsets of patients. We are aware that there are disparities across Australia in terms of access to advice and information of treatment options for two groups of individuals who may wish to access fertility services.

With advances in the technology of the cryopreservation of oocytes it is now possible to cryopreserve oocytes from women with a reasonable prospect that the oocytes can be thawed and used to conceive a child. We are aware that there are differences between states in access to information on this technology, such that women in NSW, Vic and Qld can visit their clinician and discuss the medical implications of this procedure for their personal circumstances. However, for women residing in SA, local clinics are prevented by the state law from assisting this women in preserving her fertility, as the law states she must be infertile to have this procedure.

Similarly, same sex couples in NSW, Vic and Qld may decide to start a family by donor conception and are able to visit a local clinic and discuss options and proceed with treatment should the medical specialists deem it appropriate. This same couple are not able to seek treatment in SA as local clinics are not permitted to treat same sex couples by the state legislation.

Additionally, single women in Vic, Qld and NSW may decide to pursue conception by donor insemination and are able to visit a local clinic and discuss options and proceed with treatment should the medical specialists deem it appropriate. In SA, since such women are considered not infertile, treatment cannot be sought.

We recommend that SA revise laws that prevent access to ART medical treatment by women seeking cryopreservation of oocytes, same sex couples, and single women, to ensure equity to access to medical care across Australian state jurisdictions.

Sincerely,



Professor Sarah A Robertson
Director, Robinson Research Institute