



The Fertility Society of Australia

Promoting and Improving Human Reproductive Health in Australia and New Zealand

www.fertilitysociety.com.au

26 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

Dear Sir / Madam

The Fertility Society of Australia (FSA) welcomes the review into the regulation of assisted reproductive treatment in South Australia

The Australian and New Zealand Infertility Counsellors Association, a sub-committee of the FSA Board have prepared the enclosed full and detailed submission to the review.

The Board of the FSA are fully supportive of their recommendations.

We look forward to the outcome of the review.

Kind regards

Prof Michael Chapman  
President  
Fertility Society of Australia

The Australian and New Zealand Association of Infertility Counsellors  
(ANZICA) –South Australian A.R.T submission

**Welfare of the child**

1. Please comment upon the requirement within the Act that the welfare of any child born as a consequence of assisted reproductive treatment (A.R.T.) is treated as being of paramount importance, and accepted as a fundamental principle, in respect of the operation of the Act, as well as in the provision of assisted reproductive treatment.

*(Note: If you need further information, or wish to consider questions that may assist you in providing us with information relevant to the review on this issue, please see [Fact Sheet 2](#).)*

*Questions:*

- 1. Is the paramountcy of the welfare of the child provision being upheld in practice?*
- 2. How is it being used, and to what effect?*
- 3. What sorts of considerations are being made and/or systems being put in place?*
- 4. What guidance is needed, if any, as to the sorts of considerations that should/should not be made?*
- 5. Does more need to be done to ensure the paramountcy of the welfare of the child principle is met?*
- 6. Feel free to provide any other comments that are relevant.*

The Australian and New Zealand Association of Infertility Counsellors (ANZICA) welcomes and strongly supports the fundamental *principle* of the 2010 A.R.T legislation with regard to the paramountcy of the welfare of the child. However it is our belief that this principle is currently not being upheld in *practice* in South Australia.

The 2010 legislation made provision for the Minister to set up a donor register recognizing the rights of donor conceived people to information about their biological heritage, regardless of where and when they were born. This is in keeping with the rights of people who have been adopted. It is also consistent with the United Nations' statement concerning rights of children to know their heritage. More than five years on this register is still not in place. As such, we believe that there is a major gap in current ethical guidance resulting in an inequality of access to information for donor conceived people and recipient parents dependent upon where treatment has taken place. It is our view that this inequality contravenes the principle of the paramountcy of the welfare of the child.

Within Australia registers operate in New South Wales, Western Australia, and Victoria. International jurisdictions requiring information recording and release operate in Argentina; Austria; Croatia; Finland; New Zealand; Norway; The Netherlands; Sweden; Switzerland; Washington State (USA); United Kingdom; Uruguay. ANZICA strongly believe that South Australia is severely lagging behind with this regard.

Please see our more detailed comments referring to Fact Sheet 6

## **Registration Scheme for A.R.T. Clinics**

### **Registration requirements do not apply in relation to assisted insemination outside of a clinic**

ANZICA would like to express its belief that not requiring registration in relation to assisted insemination outside of a clinic transgresses the paramountcy of the welfare of the child. A.R.T. clinics are required to comply with RTAC guidelines and auditing which includes providing Implications and Support Counselling for those involved in third party reproduction. This psycho-educational preparation provides the participants the opportunity, often the only opportunity, to give consideration to the best interests of the child and to deal with any grief and reproductive loss at not having a genetically registered child. Questions arise for the Review panel: will those non-registered providers of assisted insemination provide psycho-educational preparation for participants? How will they help participants address issues of telling the child and significant others? What requirement will there be on the non-registered provider to ensure the child's genetic heritage is accurately recorded and where it will be recorded?

### **Dissolution of SACRT & the Code of Ethical and Clinical Practice**

Please comment on the effectiveness and operation of the legislation regarding access to assisted reproductive treatment in South Australia. In particular, the conditions set out in the Act and in the regulations that relate to the circumstances in which, and to whom, A.R.T. may be provided.

*(Note: If you need further information, or wish to consider questions that may*

assist you in providing us with information relevant to the review on this issue, please see Fact Sheet 4.)

Questions:

1. Are you satisfied with the dissolution of SACRT? Why?
2. Are you satisfied that the South Australian Code of Ethical and Clinical Practice no longer exists? Why?
3. What is your experience with, and/or views of the Ethics Health and Advisory Council?
4. From whom do you seek guidance if you are unsure of what is lawful and/or ethical in South Australia concerning assisted reproductive treatment?
5. Is reference to the NHMRC Guidelines and RTAC accreditation scheme satisfactory? Why?
6. What is your view concerning the changes to the regulation and oversight of A.R.T in South Australia? Do you think they (1) went too far; (2) got it just right; (3) should never have occurred? Please explain.

**Summary of ANZICA's concerns and recommendations:**

1. A concern with the dissolution of SACRT and the South Australian Code of Ethical and Clinical Practice.
2. The identification of a gaping hole with regard to the voice of professional counsellors.
3. The establishment of a model of best practice as demonstrated by Victoria and the Victorian Assisted Reproductive Treatment Authority.

**1. A concern with the dissolution of SACRT and the South Australian Code of Ethical and Clinical Practice.**

ANZICA would like to express its concern regarding the dissolution of SACRT and the South Australian Code of Ethical and Clinical Practice. It is our belief that the dissolution of these bodies creates a substantial gap in the lawful and/or ethical guidance in South Australia with regard to assisted reproductive treatment.

**2. The identification of a gaping hole with regard to the voice of professional counsellors**

Furthermore, we would like to identify a specific hole in regard to the voice of professional counsellors who we believe provide a unique and significant perspective with regards to the paramountcy of the welfare of the child in A.R.T: a hole that both currently exists and one which also existed prior to the dissolution of the two aforementioned bodies. Recent legislation changes within South Australia with the introduction of the Family Relations Amendment Act 2015 demonstrate this point. This Act made a number of significant changes to the counselling requirements regarding Surrogacy agreements without consultation with a single member of the counselling body. ANZICA strongly believe that this is a grave oversight and omission in ethical guidelines. We firmly believe our role by its very nature, has the needs of the unborn child at its heart; we are thus best placed to be at the forefront of any advocacy work with this regard. Indeed it is critical that our voice be represented.

**3. The establishment of a model of best practice as demonstrated by Victoria and the Victorian Assisted Reproductive Treatment Authority.**

To this end, ANZICA would like to recommend the adoption of a model currently in practice in Victoria. In our view, The Victorian Assisted Reproductive Treatment Authority (VARTA) is an excellent example of best practice for a statutory authority. VARTA currently provides independent information and support for individual, couples and health professionals on fertility issues related to assisted reproductive treatment as well as assuming an important role in community education. This includes IVF, surrogacy and donor-conception. VARTA has responsibilities for the registration of A.R.T. clinics and approval of import and export of donated eggs, sperm and embryos formed from donor gametes in and out of Victoria. It is also responsible for monitoring developments, trends and activities relating to the causes and prevention of infertility and the A.R.T. industry in Victoria, Australia and internationally. Its work is guided by the principles set in the Assisted Reproductive Treatment Act 2008. Please see VARTA.

ANZICA firmly believes that South Australia would be well advised to adopt such a model of best practice.

**Access to Assisted Reproductive Treatment**

We are interested in hearing from people about their experience and views regarding the changes to eligibility criteria in 2010.

The South Australian Law Reform Institute has recently undertaken an audit of South Australia's laws to identify any legislative or regulatory discrimination against individuals and families on the grounds of sexual orientation, gender, gender identity, or intersex status. The audit has highlighted a number of discriminatory practices occurring at present in relation to South Australian A.R.T. ANZICA would like to draw attention to the following discriminatory practices based upon gender and sexual orientation:

1. The fact that current regulations require a woman to have a diagnosis of medical infertility before she can be offered the opportunity to preserve her fertility, and yet no such restrictions are held in place for a man wishing to preserve his sperm.
2. Furthermore, the requirement of women to have a diagnosis of medical infertility in order to seek A.R.T. particularly discriminates against same sex couples and single women. It is our belief that these current regulations:
  - encourage such women to seek help outside of South Australia;
  - increase the likelihood of women using unsafe and unregulated treatment options in their desire to have a child; and
  - potentially force women in a same sex couple to choose the gestational mother based not upon her desire to carry a child, but rather upon her medical status.

The above can result in serious and burdensome consequences for both parties involved.

As is the case with the Donor Conception Register, ANZICA believes that South Australia is lagging behind in its regulation of discriminatory practices relating to A.R.T.



## **Donor-Conception Register**

Please comment on the effectiveness and operation of the Act in relation to it providing for the establishment of a donor conception register.

*(Note: If you need further information, or wish to consider questions that may assist you in providing us with information relevant to the review on this issue, please see Fact Sheet 6.)*

Questions:

1. *Should a donor-conception register be established in South Australia*
2. *What information should be kept on the register?*
3. *Who should have access to the register? (for example, donors, donor-conceived people, siblings, recipients?)*
4. *How should the register work? (For example, what conditions might support the release of information?)*
5. *Should all donor-conceived people have the right to request information? If yes, how should this happen? If no, why not?*
6. *Please feel free to comment on anything else that is relevant.*

**Summary of ANZICA recommendations:**

1. **The urgent establishment of a uniform and central donor-conception register in order that the principle of the paramountcy of the welfare of the child is being upheld in practice as well as principle.**
2. **The inclusion of a comprehensive and integrated donor-linkage service providing mandatory counselling with an ANZICA registered counsellor.**

3. The creation of a Voluntary DNA bank to assist with the verification of genetic links where no or incomplete donor treatment records exist.

Please see detailed comment below:

1. Uniform and central donor-conception register

ANZICA believe that at present within SA the rights of donor-conceived individuals to access information regarding their biological and genetic heritage is largely dependent upon where and when their parent had treatment. It is our strong belief that this inequality of access once again contravenes the principle of paramountcy of the welfare of the child.

ANZICA strongly believes that in order for the principle of the paramountcy of the welfare of the child to be borne out in practice the establishment of a central and uniform Donor Conception Register needs to be recognised. This register would ensure the rights of all donor -conceived people to access information about their biological heritage regardless of where and when they were born, and that their rights were equal to those individuals who have been adopted. The establishment of this register would also ensure that A.R.T legislation in South Australia is maintained and progressing in line with other jurisdictions within Australia and other parts of the world.

It is our belief that this central register should follow the recommendations currently set out with the Victorian Infertility and Treatment Authority (VARTA) in allowing donor conceived individuals the rights to information about their

biological heritage including any genetic siblings regardless of when and where they were born. In our view VARTA is the leading authority in the world on issues pertaining to Donor-conception and as such, South Australia should take full advantage of this in-depth knowledge and model in the establishment of its own central register.

Specifically, and in keeping with VARTA, ANZICA believe that **all** donor-conceived individuals should have the right to access identifying information with the donor's consent once they reach 18 years of age, regardless of which clinic their mother attended and in what year they were born.

We also believe that **recipients** should also be allowed the right to request information about the donor whilst their child is **under** the age of 18 years but donor has the right to refuse this request. ANZICA would like to point out that within the current A.R.T legislation there remain some outdated assumptions. We believe that enshrined within the principle of donor anonymity is a starting belief that those donating gametes have a preferred wish to remain anonymous.

However, latest research carried out by VARTA has demonstrated that many donors, despite donating under conditions of anonymity are willing to provide both identifying and non-identifying information. This recent consultation with 42 pre 1998 donors found that  $\frac{3}{4}$  of those consulted were prepared to provide information and just under half were prepared to provide identifying information (VARTA, May 2013 -[www.varta.org.au/resources/publications.donor.consultation.report](http://www.varta.org.au/resources/publications.donor.consultation.report)).

Finally, ANZICA also believes that the **donor** has the right to request access to information from the donor register but the recipients (if the donor-conceived child is under the age of 18) or the donor-conceived (if over 18 years) has the right to

refuse.

ANZICA would like to further support the idea that information detailing the gender, month and year of birth and the number of siblings/family should also be provided to donor-conceived individuals and their recipient parents.

2. Inclusion of a comprehensive and integrated donor-linkage service providing mandatory counselling with an ANZICA registered counsellor.

With the establishment of a central register ANZICA would also like to argue for the inclusion of a comprehensive and integrated donor-linkage counselling service that forms an integral part of donor linking for both those seeking information and those whose information is being sought about. It is our firm belief that this counselling service should be more than a single mandatory information providing session; it should be available for all individual needs throughout the linking process and tailor-made to meet individual needs. It is our belief that an intermediary service such as "letter box" services should also be provided as occurs in adoption practices to enable parties to communicate in a non-identifying manner.

For Donors, finding out that children have been born is often quite confronting even though this was the intention of the donation. Donors often describe feeling quite overwhelmed when learning that a child or several children have been born. ANZICA would like to recommend that this information be provided by an accredited counsellor so the potential emotional impact of learning this information can be explored sensitively with the donor. If the Donor co-ordinator conveys this

information, the opportunity to discuss the ramifications with a counsellor should be routinely offered to the donor as if this is part of the program rather than the donor feeling he is not coping by agreeing to speak with the counsellor.

All donors should be routinely contacted by the clinic to update their contact details and health information. At this point they should also be asked if they are open to being contacted by offspring or recipient parents. This should be clearly recorded on the clinic database.

If a donor-conceived person or a recipient parent asks for information/contact with a donor, the donor should be contacted directly on their behalf and asked whether they would be willing to provide information. Information would be provided with consent only.

Given the clearly specialized and sensitive nature of this work it is also our firm belief and recommendation that all counsellors have the appropriate training, skills experience and accreditation necessary in order to comply within a current ethical framework. We strongly believe that ANZICA is best placed to offer such accreditation. It is recommended that all guidelines should specify ANZICA accreditation for full membership to ensure appropriate standards are met and maintained. Full membership of ANZICA requires the following:

A four year tertiary academic qualification from a recognised institution and is:

(i) registered to practise as a psychologist in Australia or New Zealand

OR

(ii) a member of, or is eligible for, membership of the Australian

Association of Social Workers or the New Zealand Association of Social Workers

OR

(iii) registered to practise as a psychiatrist in a State of Australia or New Zealand

OR

(iv) Has other equivalent professional and academic qualifications from Australia, New Zealand or from other countries

AND

(b) is counselling clients who are concerned about issues related to infertility

AND

(c) has at least two years full time or equivalent supervised postgraduate counselling experience.

AND

(d) has demonstrated current knowledge of infertility and infertility treatments.

ANZICA have detailed and specific counselling guidelines as to best practice when facilitating linking between donors and donor-conceived people.

See:<http://www.fertilitysociety.com.au/wp-content/uploads/20120504-anzica-guidelines-donor-linking-final-version.pdf>.

These guidelines provide clear professional standards of best counselling practice with reflect the spirit of NHMRC guidelines and both respect the interests of donor-conceived adults, recipient parents and donors. These guidelines recognize the individual sensitivities regarding privacy, utilising a model of mediation and facilitation.

### 3. The creation of a voluntary DNA bank

As already stated, ANZICA firmly believes that **all** donor-conceived individuals have the right to access information about their biological heritage regardless of where and when they were born. However, ANZICA is also well aware that some records, (e.g. those pertaining to pre 1988) are inconsistent and in some cases non-existent. It is vital that any information that still exists is verified and preserved. As such, we would like to recommend the establishment of a voluntary DNA bank to assist with the verification of genetic links where no or incomplete records exist. In keeping with a central register, all donor-conceived people would have the right to make an application for identifying information from the age of 18 years old. Great care needs to be taken however, to ensure that proper verification is undertaken, and before links are made to confirm the accuracy of the genetic link. Once again, it is our belief that such linkage should be undertaken by a comprehensive and integrated donor linkage service outlined above.