



Online Submission Form for the review of the Assisted Reproductive Treatment Act 1988 (SA)

Contact Details

Confidential No

Contact Name: Mrs Caroline Lorbach

Contact Address1: [REDACTED]

Contact Address2:

Suburb: [REDACTED]

Postcode: [REDACTED]

Email: [REDACTED]

Phone: [REDACTED]

Preliminary Data

What is your association to assisted reproductive treatment?: Parent of 3 donor conceived children (now adults) and National Coordinator of the DCSG

If you belong to a company or organisation – what is the name of that organisation?: Donor Conception Support Group of Australia (DCSG)

Do you make this submission in your individual or professional capacity?: Professional

If you live outside of Australia which country do you live in?: Australia

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.: Is the paramountcy of the welfare of the child provision being upheld in practice? Our group would prefer the use of the term "person" instead of "child" as an acknowledgement that the person will not always remain a child and that their needs may be very different as an adult than they were as a child. As children they may not voice any interest in their conception (if indeed they have been informed) for fear of upsetting their parent/s. Vice versa, as a child, they may be pushed by a parent to express the wish to meet their donor or half siblings. Our group has been contacted by a number of parents who would like their child to grow up knowing their half siblings and wanted to be able to have regular meetings with them. While there is no way of knowing the true

feelings of the donor conceived people concerned in these situations we need to be mindful that their opinions may change as they grow. We would like to make comment on the NHMRC guidelines which have just had a new version released in draft form while much of them is unchanged one of the main ethical principles has undergone a dangerous alteration. No longer is the welfare of the donor conceived person listed as paramount now respect for the people involved is called for with donor conceived people coming last on the list behind recipients and donors. While some may say that the listing order makes no difference our question would be then why change it? How is it being used, and to what effect? The one outstanding issue with stating that there is paramountcy given to one group is that, in practice, it is only part of that group. Access to information is only being guaranteed to those conceived after legislation. We believe strongly that the provision of retrospective, and therefore equal rights to information for all donor offspring can only be in their best interests. Currently the interests of older donor conceived people are secondary to those of the adults who decided to conceive them (i.e. parents, donors, medical professionals). This issue of paramountcy was argued decades ago in adoption and resolved across Australia with an agreement that all adoptees regardless of when they were born should have guaranteed right of access to identifying information about their birth parents. In NSW the Committee on Social Issues, expressed in its summary of its findings: "It is a unique form of discrimination against adult adoptees that they are not able to access identifying information about their own origins." (Accessing Adoption Information. Report of the NSW Legislative Council Standing Committee on Social Issues. 1989, pg xii.) It is sad that in 2016 this "unique form of discrimination" is still being perpetrated on what could be tens of thousands of Australians. Does more need to be done to ensure the paramountcy of the welfare of the child principle is met? Full retrospectivity of the sort that is currently passing through the Victorian Parliament

2. Please comment upon the replacement of the previous licensing scheme with a registration scheme for A.R.T. clinics In the domain of reproductive technology there is a long-standing tradition of self-regulation. Physicians have regulated their activities in accordance with their own understanding of what constitutes responsible practice. Up until recent times the practice of donor conception has been for the most part a result of this self-regulation. In 2007, the FSA decided to introduce independent (third-party) certification of ART clinics as the basis for licensing and accreditation. They asked JAS-ANZ (joint accreditation system of Australia & New Zealand) to work with them to develop and organize a new RTAC accreditation scheme. JAS-ANZ accredits CABs (conformity assessment bodies – also known as CB) who will then be employed by the clinics to check that they are adhering to the RTAC Code of Practice. Below is a simplified flowchart of how accreditation of fertility clinics works according to the RTAC Code of Practice.

- The organisation contacts a CB and then submits an application for certification to the CB.
- Primary audit conducted by the CB against all aspects of the Code.
- Final report, including any corrective actions undertaken, submitted to RTAC with recommendations for licence.
- RTAC reviews the report and recommendations and makes the decision to grant or not grant a Licence.
- RTAC sends licence to the ART unit. RTAC contacts ART unit if licence is not granted. As we can see from this chart RTAC has the final say on whether a clinic is accredited and RTAC is made up of people who work in the industry and one consumer representative that is the nominee of an organisation which is funded partially by the FSA and industry bodies. Comments about the accreditation of clinics have been made in the past in the

Federal Parliament. Senator Brian Harradine spoke about the monitoring of fertility clinics within the discussion of the Research Involving Embryos Bill in 2002 Senator Harradine: "Is not the Fertility Society of Australia, in effect, an IVF industry body? I would be obliged if the minister could show me where it is not an industry body. In fact, isn't it true that the Reproductive Technology Accreditation Committee is a committee of the Fertility Society of Australia? If you have a look at that disinterested body—this gatekeeper appointed by the government; it is to be imported into the bill by the government and it is going to end up in an act of parliament, so that is why I am raising this—it is to be appointed as the appropriate independent body to grant accreditation to IVF centres." (Senator Harradine

<http://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;db=CHAMBER;id=chamber%2Fhansards%2F2002-12-02%2F0127;query=id%3A%22chamber%2Fhansards%2F2002-12-02%2F0000%22>) It was decided through these discussions that an amendment to the RIHE Bill would be accepted. This amendment in Section 19(3) set up the NHMRC Licensing Committee which is required to table six monthly reports in either House of Parliament on or before 30 June and 31 December each year, and at any other time as required by either House of Parliament.

The reports must include information about both the operation of this Act and licences issued under the Act. The DCSG is saddened that this is required of a licensing committee which is dealing with embryos that will, in all likelihood never become living persons; but that when it comes to the lives of donor conceived people it is considered acceptable for the fertility industry to regulate itself and accredit itself. The requirement that registered people adhere to the NHMRC guidelines would be acceptable if indeed ART centres did adhere to those guidelines.

There is virtually no transparency in the accreditation of ART centres in Australia so it is very difficult to ascertain if all guidelines are being adhered to but there is one area that is obvious to our group that ART centres are ignoring.

• 6.1.3 Working with relevant professional organisations, clinics should use forums for public information to encourage people who were donors before the introduction of these guidelines, and those previously conceived using donated gametes, to contact the clinic and register their consent to being contacted by their genetic children or genetic siblings and half-siblings, respectively. (NHMRC guidelines This provision has been included in the NHMRC guidelines for many years and has again been included with altered wording in the latest Draft that is still undergoing consultation. 5.13.1

Working in collaboration with relevant professional organisations, clinics should use forums for public information to encourage people who were gamete donors before the introduction of the 2004 edition of these Ethical Guidelines, and those born from these donated gametes, to consider contacting the clinic and registering their consent for the release of information about themselves (as outlined in paragraphs 4.2.3 and 5.8) to persons born from the donated gametes or genetic siblings and half-siblings, respectively.

(<https://consultations.nhmrc.gov.au/files/consultations/drafts/artdraftethicalguidelines150722.pdf>)

Our group has been informed by the FSA in the past that RTAC did not inspect units based on particular clauses in the NHMRC guidelines and to our group's knowledge no clinic has ever used any forums for public information to encourage past donors to come forward. Associate Professor Bernadette Tobin, Director of the Plunkett Centre for Ethics, who has sat on many review panels covering assisted reproductive technology claimed that RTAC does not monitor compliance with ethical guidelines and that this is a gap in the system; she said "The Fertility Society of Australia's Reproductive Technology Accreditation Committee does not monitor compliance with ethical guidelines ... Nor do individual Human Research Ethics Committees:

they are too busy, and their membership is not appropriate for monitoring compliance with ethical guidelines. There is, thus, a significant gap in the arrangements for monitoring the compliance of IVF clinics with ethical guidelines.” (Report of the Independent Review of Assisted Reproductive Technologies 2006 Associate Professor Bernadette Tobin, Plunkett Centre for Ethics, Australian Catholic University Submission LRC550) The NHMRC guidelines are far too vague and open to different interpretations. For example the guidelines state: 6.3.1 Gametes from one donor should be used in a limited number of families Nowhere does it give a number of families, it is totally up to the individual clinic. It has always been extremely difficult for our group to ascertain whether a registration requirement has been met as our group has not always been able to get clear answers from some clinics and in the past we relied on SACRT to give us answers but they no longer exist.

3. Please comment on the dissolution of the SA Council on Reproductive Technology and its Code of Ethical Clinical Practice.: Our group was very upset that SACRT was dissolved as they had always been helpful to the DCSG by keeping us informed of any changes or proposed changes to legislations and we very much up to date in operations of the SA clinics. They were very good at letting us know about how to proceed with a particular clinic in getting information about donors etc., this made it much easier for our group to pass on accurate information to people who had made inquiries of our group. It is not acceptable that a South Australian Code of Ethical Clinical Practice no longer exists, there needs to be a standard of ethical practice because we are creating human beings. As we have stated in the previous section there is no transparency in how clinics accredit themselves and there appears to be no desire on the part of clinics to make any changes in this situation. We do not know if clinics are truly following the NHMRC guidelines. The DCSG asked the NHMRC Centre for Health Advice, Policy and Ethics in 2005 about accreditation of clinics and were informed by the then Acting Executive Director that in order to be accredited clinics had to comply with the NHMRC guidelines and that monitoring of compliance was the responsibility of RTAC. We then wrote to the then Chair of RTAC and also asked him about compliance with NHMRC guidelines. His response stated that the relationship between the RTAC accreditation process and the implementation of the NHMRC guidelines was different to that expressed by the NHMRC; he suggested that clinical practice could vary from the guidelines where the unit’s ethics committee had considered an issue and decided that a different ethical approach to that specified in the NHMRC guidelines should be followed. He then went on to say that RTAC did not inspect units based on particular clauses in the NHMRC Guidelines This is obviously serious cause for concern and before new legislation is created there needs to be an agreement as to exactly how accreditation of clinics is done and what it covers. Any gaps in that accreditation must be filled by the SA government. There also needs to be transparency in how clinics are accredited.

4. 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.:

5. Please comment on the effectiveness and operation of the Act in relation to it providing for the establishment of a donor conception register.: A Donor Conception Register should definitely be established in South Australai, this would be one huge step closer

to allowing all donor conceived people in South Australia to have the same rights as adoptees and not be the one group of individuals who are denied access to information about their genetic heritage. Historically there has been no recognized policies within clinics of how, when or what information may be requested by parents or donor conceived people. In the 1990's when our group first formed we had members who were the first parents to ever have requested donor information from clinics. It was not easy for them as they were going into uncharted waters. The clinics had no policies for what do to about requests like this and most had no idea how they should deal with the requests. The reactions parents were met with when requesting information from clinics varied from antagonistic to puzzlement through to a complete lack of understanding as to why a parent would want this information. Those pioneering parents had to be quietly determined and most of them did manage to get some information if it still existed. While today most clinics tend to have some sort of policy about requests for information they vary considerably from clinic to clinic and even within the same clinic they can be haphazard in their application. We would like to state here that even today most parents are quite fearful of asking for information and even more fearful of asking for communication with a donor. Clinics have still not realized what a position of power they are in and how this can make parents and donor conceived people feel. Having records held by a government authority means that all applications for information will be treated equally. One would think that the creation of a register would be happily greeted by clinics for whom it would surely mean a large time and cost saving because they no longer have to field inquiries from parents, donors and donor conceived people requesting information. The South Australian Government should legislate to set up a Donor Conception Register independent of service providers that will store the identity of gamete and embryo donors, recipient parents and donor conceived people past and present. • the Register should be maintained by an Authority set up by the SA Government. • service providers must notify the Authority of all treatment procedures that use donated gametes and embryos. • There must be compulsory notification by the service providers of all births (where known) from donated gametes and embryos. • That parents be encouraged to also inform the Authority of all births from donated gametes or embryos. • That the notification of births be linked to the Registers of Births, Deaths and Marriages so that Birth certificates of donor conceived people will have an appended note available only to the donor person which gives information about the nature of their conception. • All records, where they still exist, of past gamete and embryo donations plus treatments with donated gametes should be compulsorily acquired by the Authority as these records contain the identity of donor conceived people that cannot be obtained any other way. • All records that will be stored on the Authority Register must be kept in perpetuity. All donor conceived people no matter when they were born should be able to access identifying information on their donor (if this information is still in existence) through the Authority Register. • While donor conceived people should have the right to access identifying information about their donor a veto system akin to that used in adoption should be available to prevent unwanted contact between parties. • Donor conceived people who need to use DNA testing to obtain a match with a donor because of the destruction of records must not incur a charge for this service. • Donor conceived people and the children of the donors (in their own families) should be able to access, as of right, the year of birth and sex of all other of their half/full siblings (full in the case of embryo donation). • Donor conceived people, their half siblings (full in the case of embryo donation) and the children of the donors (in their own families) should be able to share information or make contact with each other on a voluntary

basis through the Authority Register. • Counselling must be a mandatory part of entry onto a donor conception programme. The Authority must make counsellors available to all people requesting information from the Register. In the event of making contact for the first time, counselling should be made compulsory. The Authority must conduct campaigns to: • Advertise the Register • Encourage past donors to come forward • To encourage parents to tell their children the truth about their conception • Raise awareness of donor conception.

6. Please comment on the effectiveness and operation of provisions within the Act for record keeping and confidentiality.:

Any Other Matter: Limit on Number of Births from Donated Sperm, Eggs and Embryos • The number of families allowed to be created from one donors must be limited to no more than 5 including the donor's own family. Payment of Donors • Donors must be truly 'donors'. Reimbursement for travel expenses or parking may be allowed. The definition of reimbursement must be defined.



Government of
South Australia