

# **Submission to Parliament of Australia Senate Legal and Constitutional Committee**

## **“Inquiry into Donor Conception in Australia”**

### **Opening Statement**

I tender this personal submission as an infertility counsellor who has been working for the past 10 years in donor conception practice at Royal Prince Alfred Hospital in Sydney. I am an executive member of the Australian and New Zealand Infertility Counsellors Association (ANZICA). This submission reflects my personal views as a result of my professional experience.

My practice has always been informed by

- Relevant Commonwealth, State and Territory legislation
- The Code of Practice(COP) for Assisted Reproductive Technology Units of the Reproductive Technology Accreditation Committee(RTAC) of the Fertility Society of Australia
- National Health and Medical Research Council “Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research” June 2007 and
- Australian Health Ethics Committee (AHEC)

My interest in past practices of donor conception is relevant in so far as it has informed current practice within fertility clinics. The lessons learnt from past practice are evident in the development of current policy and established counselling guidelines. The other legacy of past practice relates to the needs/ rights of donor conceived persons who do not have the legal right or statutory mechanism available to access relevant information about their donor.

The main recommendations of this submission are

- The principle that donor conceived adults have the right to know their genetic origins is a guiding premise of any regulations or legislation pertaining to donor conception in Australia.
- Donors must be identifiable and full information records must be maintained.
- Maintenance of the RTAC COP as the principle basis of accreditation of clinics to regulate the clinical practice of Third Party Reproduction i.e. donor conception.
- Ongoing review of the NHMRC Ethical guidelines to reflect new technological developments and changing community attitudes to inform ethical aspects of practice.
- Establishment of uniform legislation to give equal rights to knowledge of their donors and genetic siblings to donor conceived persons throughout Australia.
- Limiting the number of recipient families for a single donor to five families.

- Maintenance of the practice of altruistic donation.
- Provision of counselling services by suitably qualified ANZICA counsellors to be available to all parties undergoing third party reproduction to ensure adequate information to guide decision making and informed consent.
- Establishment of a retrospective National Donor Registry to centralize donor information thereby precluding state variation of details collated, accessed or updated.
- Provision of longer term counselling/education services by suitably qualified ANZICA counsellors be available for donor conceived families and individuals. An integrated counselling service is vital to the operation of a National Donor Register.

This remainder of this submission therefore relates to discussion of the above recommendations in relation to current practice following the terms of reference of the enquiry.

**(a) Donor conception regulation and legislation across federal and state jurisdictions.**

With regard to regulation,

- The RTAC COP has continued to provide an excellent standard for accreditation of Assisted Reproductive Technology Units throughout Australia. The COP has continued to be revised and improved to further advance standards of best practice and the introduction of external auditors has enhanced this process.

**Recommendation: Maintenance of the RTAC COP as the principle basis of accreditation of clinics to regulate the clinical practice of Third Party Reproduction i.e. donor conception.**

- Similarly, The National Health and Medical Research Council “Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research” June 2007 provide important and valuable guidelines to inform clinical practice. It is recommended that these guidelines continue to be reviewed to inform changes in technology and gauge stakeholder attitudes.

**Recommendation: Ongoing review of the NHMRC Ethical guidelines to reflect new technological developments and changing community attitudes to inform ethical aspects of practice.**

With regard to legislation,

- the Family Law Act 1975 pertains to parentage of donor conceived children.
- Four states have enacted legislation impacting on donor conception – the Assisted Reproductive Technology Act 2007 in NSW, the Assisted Reproductive Treatment Act 2008 in Victoria, the Human Reproductive Technology Act 1991 in Western Australia and the Assisted Reproductive Treatment Act 1988 in South Australia. The ACT, Northern Territory, Queensland and Tasmania do not have relevant legislation.

The state legislation that currently exists has varying regulatory impact and is at times inconsistent with the above regulations and guidelines. This inconsistency means Australians have different rights to, ART eligibility, access to treatment and rights in relation to donor conception depending on their state of residence. With the acknowledgement that many of the issues surrounding donor conception are as much social and political issues as ethical issues, AHEC has long recommended that legislation be enacted to nationally regulate ART such that laws governing donor conception can be harmonized. Without uniform legislation, there is inequality of eligibility and inequity of rights for Australians depending on their state of origin in regards to treatment options as a recipient of donated gametes, being a donor and being a donor conceived person. In addition, without uniform legislation, regulation of national data collection and systemized monitoring of biographical information, research and/or treatment outcomes cannot be achieved.

**Recommendation: Establishment of uniform legislation throughout Australia pertaining to equal rights for donor conceived persons to knowledge of their donors and genetic siblings**

**(b)The conduct of clinics and medical services including**

**i) Payment for donors;**

It is recommended that current practice of only altruistic gamete donation be maintained so as to prevent the commodification of human gametes and the increasing internet trade of “fertility tourists”.

However it is also acknowledged that reimbursement of reasonable ‘out of pocket’ expenses for donors is acceptable practice. Such expenses would include transport, reasonable accommodation costs related to the act of donating, implications counselling and medical procedures and will be variable depending on where the donor comes from.

It is noted that use of overseas sperm donors does not always comply with the concept of altruistic donation because those donors have received payment in the country of origin. Furthermore management of data re such donors is inadequate in relation to the rights for information of donor conceived persons.

**Recommendation: Maintenance of the practice of altruistic donation.**

**ii) Management of data relating to donor conception**

Systems for management of data relating to donor conception are inadequate due to the lack of uniform legislation. Some limited data are available through the Australian Institute of Health and Welfare and the National Perinatal Statistical Unit pertaining to the number of pregnancies from donor sperm, oocytes or embryos.

However there is considerable variation across Australia as to the requirements for collection of clinical data. In states where no regulation exists it remains the responsibility of clinics to maintain a database of information about donor conception. The RTAC COP requires that clinics retain records about donors and recipients. However significant problems

arise about responsibility for that information if a clinic closes. (Specifically data may no longer be accessible to adult donor conceived persons and thereby preclude the options to accessing both identifying and non identifying information about their donor.) Some clinics maintain voluntary registers to allow donor conceived person to access information about their donor. In summary, in order to uphold the principle of a donor conceived person's right to knowledge of their genetic origins, donors must be identifiable and full information records must be maintained so donor conceived people can access their records.

The establishment of a National Donor Registry is recommended because

- Rights/responsibilities to provide information depend upon where and when a person was conceived
- The potentially lifelong emotional impact of identity loss and kinship issues have been identified. Specifically, others who have been deprived of information pertaining to their identity have been recognised by the Federal Government i.e. Adoptees, Child Migrants, the Stolen generation, and more recently the forgotten Australians.
- It is difficult to categorically monitor the activity of donors. Donors can donate to multiple clinics in different states and some IVF clinics permit the importation/exportation of sperm. Consequently a national registry is needed as a process of risk management and to safeguard the interests of donor conceived families/individuals.

**Recommendations: Donors must be identifiable and full information records must be maintained.**

**Establishment of a retrospective National Donor Registry to centralize donor information thereby precluding state variation of details collated, accessed or updated.**

**iii) Provision of counselling and support services:**

The RTAC COP requires provision of counselling services to all parties at the point of treatment in donor conception. The COP also maintains standards of qualifications of counsellors to provide this service within clinics by requiring eligibility for ANZICA membership. This practice is not always mandated by State legislation e.g. NSW. Some legislation e.g. Victoria and WA provides for a regulatory authority (for e.g. Victorian Assisted Reproductive Authority and The Reproductive Technology Council of W.A. respectively) to provide counselling/education to meet the ongoing and specific needs of donor conceived families and of donor conceived young adults to access biographical information about their donor. In summary at the point of treatment provision of implications counselling by an ANZICA counsellor is a requisite of accreditation of ART clinics. However qualified counselling to support the ongoing needs of donor conceived families and individuals remains inadequate.

If a National Donor Register is established then all parties accessing the Register or who have been contacted as a result should have mandatory counselling by a counsellor meeting the requirements for full ANZICA membership. The counsellor acts as a neutral mediator to facilitate

information exchange which is comfortable to each party. Donor-linking is very new and uncharted territory and people need support and education to guide them through what is usually a very emotionally challenging process. (See attachment outlining ANZICA donor-linking guidelines.)

**Recommendation: Provision of counselling services by suitably qualified ANZICA counsellors to be available to all parties undergoing third party reproduction to ensure adequate information to guide decision making and informed consent.**

**Provision of longer term counselling/education services by suitably qualified ANZICA counsellors be available for donor conceived families and individuals. An integrated counselling service is vital to the operation of a National Donor Register.**

**(c)The number of offspring born from each donor with reference to the risk of consanguine relationships**

In some states legislation will determine the number of donor conceived offspring permissible to each donor. In other states (e.g. W.A), number of recipient families (i.e. 5 family limit) defines the donation process.

The NHMRC guidelines also clearly state the need to limit the number of persons born from one gamete depending on a series of considerations. (See NHMRC guidelines 6.3)

The issue of consanguinity is a complex one as the risk may be greater in certain communities e.g. the lesbian community, than in the broader community. However, consideration of limiting the number of offspring born from each donor involves more than the risk of consanguine relationships. It also involves the responsibility for the donor in linking with offspring, and the identity and kinship issues for donor conceived person in linking with half genetic siblings.

With consideration of all of these factors it is recommended that the number of offspring born to each donor be limited to five families.

As previously discussed the community requires a mechanism to safeguard situations where a donor may donate in different clinics/states by the establishment of a National Donor Registry. (see comments above)

**Recommendation: Limiting the number of recipient families for a single donor to five families.**

**(d)The rights of donor conceived individuals**

Current clinic practice endorsed by the RTAC COP, NHMRC guidelines and State legislation all uphold the right of donor conceived individuals to knowledge of their genetic origins. This is consistent with Article 8 of the Convention on the Rights of the Child (an international treaty that recognises the rights of children in international law) that explicitly deals with the identity rights of a child.

This enforcement of this right however is dependent on when and where a donor conceived person was conceived. The establishment of a retrospective National Donor Register is again recommended to provide a mechanism to link consenting donors and their offspring where all parties are consenting. Donor-conceived adults, parents and donors should be able to request information about the other parties they are connected to. The other party should then be contacted and if they consent to information being shared, then this can be exchanged. Comprehensive counselling similar to the counselling offered in Adoption linking services is fundamental to this process occurring. Donor-linking of this nature already occurs successfully in several hospitals and clinics across Australia. The clinic in which I work has developed a policy for management of the exchange of information between donor conceived persons and their donor. This policy is available as a public document on the Royal Prince Alfred Hospital website.

**Recommendation: The principle that donor conceived adults have the right to know their genetic origins is a guiding premise of any regulations or legislation pertaining to donor conception in Australia.**

Responsible Person  
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