

DONOR CONCEPTION IN AUSTRALIA

SUBMISSION TO THE SENATE LEGAL AND CONSTITUTIONAL AFFAIRS COMMITTEE

TERMS OF REFERENCE

- (a) Donor conception regulation and legislation across federal and state jurisdictions.
- (b) The conduct of clinics and medical services, including:
 - (i) payments for donors;
 - (ii) management of data relating to donor conception; and
 - (iii) provision of appropriate counselling and support services.
- (c) The number of offspring born from each donor with reference to the risk of consanguine relationships; and
- (d) The rights of donor conceived individuals.

At Repromed we believe in treating each couple individually and personally, according to their needs and circumstances. We have a Donor Program that has a dedicated donor team with procedural pathways and dedicated medical, counselling and nursing staff. There is facilitation of contact and follow up, where requested, between our team and donors and recipients.

We would like to make the following submission to this enquiry.

INTRODUCTION

Reproduction is a basic human drive and access to donor gametes or embryos is a long established and essential part of provision of fertility treatments for those who through no fault of their own find themselves unable to conceive with their own gametes.

Donor conceived individuals who are informed about the circumstances of their conception in early childhood tend to have a better psychological outcome compared to donor conceived persons who find out about their conception in late adolescence or adulthood. Access to information about their donor allows a donor conceived individual to their social and genetic identity.

Historically donor conception has been associated with secrecy and anonymity. Public education and awareness regarding the reasons for needing donor treatment and increased social acceptance of donor conception may assist in encouraging disclosure and honesty by removing some of the perceived need for secrecy.

We agree that past practices involving the use of anonymous/untraceable donors have resulted in negative outcomes for some donor conceived individuals due to lack of availability of information regarding their donor, however more recent improvements have allowed excellent outcome for donor conceived individuals, their families and donors.

SPECIFIC COMMENTS ADDRESSING TERMS OF REFERENCE

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

- Should be non discriminatory including reference to Equal Opportunity legislation
- Should continue to enshrine the rights of recipients as the legal parents and for donors to have no legal parenting rights and no financial obligations
- Should require the formation of a national registry and compliance of clinics to adhere to this
- Should allow for a requirement for donors to be contactable long term and at least for provision of information, not necessarily to meet/be involved

(b) The conduct of clinics and medical services, including:

(i) Payments for donors

- Donors should be reimbursed for their medical and travel expenses, with no remuneration or payment for the actual donation – to encourage altruistic donation, minimize exploitation and avoid donation by those only motivated by financial gain

(ii) Management of data relating to donor conception

- In the future, clinics must seek and keep complete/exhaustive and regularly updated medical information relating to donor + his/her extended family.
- There should be a national body/register for donors' contact details, including clinic recruited, known/own donors and overseas donors. This is imperative for compliance with and monitoring of legislated family limits.
- In the future, clinics should have mandatory guidelines for recording and maintaining donors' data and for facilitation of contact between donors and recipients and donor conceived children. This could involve revision and expansion of the current RTAC code.
- Clinics should be able to facilitate contact between donors and recipients and donor conceived children where there is a mutual agreement to do so PRIOR to donor conceived children reaching age 16-18.
- In the future, clinics should be required to maintain regular contact with donors and make extraordinary attempts to find "lost" donors such as electoral roll search, Medicare number enquiry, etc.
- In the future, clinics and government should actively encourage-past donors to re-establish contact with clinics with regular advertising and public awareness campaigns.

(iii) Provision of appropriate counselling and support services

- Counseling should include strong encouragement for disclosure to child, including practical ways to achieve this.
- Consistent counselling services offered at the initial stages to be followed through as the patient progresses and follow up should be offered in the ensuing years if required.
- In the future, Fertility Clinics' websites should provide accurate and updated links to available support groups, including web based support groups/registers both Australian and International.
- In the future, clinics should offer regular "Talking and Telling" workshops to give ongoing assistance to recipient parents in providing honest information and disclosure to their children.
- In the future, clinics should be involved in ongoing research regarding outcome for donor conceived individuals and their families, donors, which should be funded by the NH&MRC.

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

- It is reasonable to limit the number of recipient families per donor however it is not acceptable to limit the number of children within a single family. A culture of transparency and disclosure to children about their origins, in combination with a National Register could prevent donor siblings forming consanguine relationships.
- Limits to the number of recipient families should be based on fact and mathematical calculation rather than whim or assumption. From a mathematical perspective a 10 family limit is no more problematic than 5 in relation to the risk of consanguine relationships.
- If a reduction in the family limit is considered, this must be balanced against the risk of reduced availability of donors. Public education and encouragement of donation could allow greater donor recruitment and reduction in maximum family limit.

(d) The rights of donor conceived individuals

- honesty
- non discrimination
- respect
- acceptance by society
- information
- access to counselling

REPROMED DONOR TEAM

28th July 2010