

**DRAFT SUBMISSION TO PARLIAMENT OF AUSTRALIA
SENATE
LEGAL AND CONSTITUTIONAL COMMITTEE**

“Inquiry into Donor Conception in Australia”

Opening Statement

Canberra Fertility Centre welcomes an inquiry into the practice of donor conception in Australia. Canberra Fertility Centre has been providing donor conception treatment for over 20 years currently providing over 200 donor treatment cycles per year, making it one of the major providers of donor conception in Australia. Our patients consist of both ACT residents and interstate patients who travel to the ACT to access donor treatment which is not available to them in their home state or territory. These donor treatments consist of treatments involving donor sperm, donor oocytes, or donated embryos.

The main recommendations of this submission are:

- Maintenance of accreditation of Assisted Reproductive Technology Units including regulation of donor conception by the Reproductive Technology Accreditation Committee (RTAC), and the associated Code of Practice.
- Establishment of uniform legislation involving donor conception throughout Australia, including legislation regarding the number of families who achieve a live birth using donated sperm or oocytes from a particular donor, or who achieve a live birth from embryos donated from a given couple.
- Maintenance of the principle of altruistic donation.
- Establishment of prescribed payments to be paid to donors to cover the expenses they incur as a result of donation.
- Maintenance of the management of data involved in donor conception by individual Assisted Reproductive Technology Units in preference to the establishment of national or state central donor registers, as we can see no advantages and several disadvantages regarding centralised registers as outlined in the body of this submission.
- Opposition to any retrospective legislative changes regarding the anonymity of donors who have previously made a donation of sperm, oocytes or embryos under the proviso that they would remain anonymous.
- Any legislation regarding donor conception needs to address with sensitivity the needs of all parties involved, and we feel that the responsibility of informing children conceived by donated gametes should rest with the social parents.

- The demand for donated gametes in Australia far exceeds the supply, and therefore we recommend that any regulatory or legislative changes regarding donor conception should take the rights and preferences of donors into consideration, in order to encourage donation, thereby allowing more Australians affected by infertility access to treatment with donor gametes.

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

There is no donor conception regulation or legislation in the ACT. The Canberra Fertility Centre is regulated by the dictates of the Reproductive Technology Accreditation Committee of the Fertility Society of Australia (RTAC). Canberra Fertility Centre also adheres to the NHMRC (National Health and Medical Research Council) ethical guidelines on the use of Assisted Reproductive Technology including donor conception.

(b) The conduct of clinics and medical services including

i. Payments for donors

The procedures involving the donation of sperm, oocytes and embryos differ markedly as shown below.

a. Sperm Donors

Donors undergo an interview and examination with a medical practitioner of the clinic and a long interview with the counsellor. They are required to read and sign a lengthy declaration and undergo a series of blood tests. They are then required to attend the clinic at regular intervals to provide semen samples and to return for further blood tests six months later.

b. Oocyte Donors

In addition to the interview, counselling and screening requirements as for sperm donors, egg donors are required to undergo a complete IVF cycle, involving daily blood tests, injections and ultrasounds, and an oocyte (egg) collection procedure under sedation, and further blood tests following the oocyte collection. This process is not without risk, and major morbidity occurs in approximately 2% of patients. Deaths associated with complications are reported.

c. Embryo Donation

At Canberra Fertility Centre embryo donation most commonly occurs as a result of patients who have successfully conceived and have completed their family and wish to donate any remaining embryos. The donating couple must undergo counselling sessions

and health tests including examinations and further blood screening.

In view of the above considerations, adequate financial compensation is indicated. We suggest that prescribed payments for sperm, oocyte and embryo donors be mandated nationally to provide consistency and transparency. We suggest for consideration, \$200 for sperm and embryo donors and \$1000 for oocyte donors.

ii. Management of data relating to donor conception

There is no donor register in the ACT and Canberra Fertility Centre maintains all donor records for our donors. Currently, all data concerning donors in the ACT is held in individual ART units.

In consideration of the usefulness of a central donor register we cannot think of any advantages regarding this system. One of the reasons for a central register may be to avoid any potential problems in the event of closure of an individual ART unit, however this has been addressed by RTAC which has a protocol to be followed in the event of closure of an individual unit. Another argument in favour of state or national donor registers is to prevent a donor from donating at multiple clinics, however in our experience this has not been demonstrated, and in fact the willingness of donors to come forward for donation is very low in spite of advertising designed to recruit more donors to meet the demand for donated gametes.

Another argument that may be put forward to support a central donor register is the rights of children conceived from donated gametes to be informed of their genetic parents. Canberra Fertility Centre is not totally opposed to a central state or national donor register if it acted in the best interest of all parties involved. However, we are totally opposed to the system in Western Australia where the state donor register mails a letter to all donor conceived children at age 16 years informing them of the identity of their genetic parents. This is incredibly insensitive and may be devastating to the child. Not

surprisingly the level of gamete donation in Western Australia is virtually zero, and unfortunately this leads to unsafe practices such as one night stands and 'turkey basting' where women inseminate themselves using sperm from unscreened donors. In addition to the safety issues concerning the use of sperm unscreened for infections or genetic diseases, children born from such unsafe practices have no access to medical records regarding their genetic heritage.

We consider that the disadvantages involved in centralised donor registers far outweigh any potential advantages. For instance, we are concerned that the implementation of state or national registers would be likely to discourage some people to be donors, because they may prefer for their identifying information to be held outside government departments due to confidentiality concerns. Some donors may prefer for their identifying information to be accessible only to a small number of people within the fertility clinic at which they donate. Establishment of central registers could therefore lead to a situation worsening the shortage of donated gametes.

Unfortunately, the level of sperm, oocyte and embryo donation is very low in Australia. For instance at Canberra Fertility Centre, we presently have only three local sperm donors, and only approximately one embryo donation per year, with the waiting list for donated embryos being three years, and many patients withdraw from the waiting list due to the low likelihood of receiving embryos. The rate of oocyte donation to unknown recipients is even lower because virtually all oocyte donations are made by a woman who is a known family member or friend of the recipients. Therefore, patients requiring an oocyte or embryo donation are encouraged to seek treatment overseas where they have a more realistic chance of treatment. The vast majority of the approximately 200 donor treatment cycles we perform annually are using donor sperm imported from overseas.

Given the low level of sperm, oocyte and embryo donation in Australia, and the time consuming, often inconvenient, and in the case of oocyte donors, the invasive nature of donation, we recommend that the

preferences of donors be a major consideration in the management of data relating to donor identity. Furthermore, if a national or state donor registers were established how would known donors such as oocyte donors be dealt with? Even more importantly, considering that the vast majority of our 200 donor cycles per year are reliant upon imported donor sperm, how would a central register affect the availability of overseas donor sperm?

iii. Provision of appropriate counselling and support services

Counselling is a mandatory requirement for all donors, recipients and their partners. Fertility counselling is regulated by the following regulatory bodies: RTAC, FSA (Fertility Society of Australia), and ANZICA (Australia and New Zealand Infertility Counsellors Association). NHMRC ethical guidelines are also adhered to, and legislation in the ACT is via the Parentage Act 2004.

All donors are required to provide identifying information and consent to such information becoming available to an adult, donor-conceived person upon request after the age of 18. Canberra Fertility Centre will only import sperm from donors who have consented to this disclosure. All donors and recipients are provided with resource material regarding using donated gametes.

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

Canberra Fertility Centre recognises the importance of limiting the number of families per donor to minimise the risk of consanguine relationships and also for the benefit of children conceived by each donor if these children wish to make contact with half-siblings or siblings from other families from the same donor.

Currently there is no legislation in the ACT regarding the maximum number of offspring born from each donor. Canberra Fertility Centre adheres to the guidelines set down by the NHMRC (National Health and Medical Research Council) in 2004 in an Issued Ethical Statement. Canberra Fertility Centre limits the number of families for each sperm, oocyte or embryo donor to five in Australia including any family or families

the donor may currently have. Currently some states such as NSW, Victoria and WA have legislation limiting the number of families to five world-wide, however this seems to be unnecessarily restrictive, and severely limits the use of overseas donated sperm. The two major providers of overseas sperm we use, Xytex and Fairfax, currently limit the use of donated sperm per donor to five families in the ACT, and as far as we know, five families in Australia.

We recommend the policy of five families per sperm, oocyte or embryo donor in Australia be legislated and implemented throughout Australia to provide consistency. In practice, the level of donation of oocytes and embryos is exceedingly low and it is highly unlikely that five families would receive oocytes from a given donor or embryos from a given donor couple.

(d) The rights of donor conceived individuals

All donor conceived individuals after age 18 years have the right to access identifying information regarding the donor upon request. We regard our current system of enquiry regarding disclosure as effective in meeting the needs of all parties involved. Currently there is no withholding of information. If the conceived child enquires about the identifying information of the donor, there is a delay of 30 days designed as a cooling off period, during which time the donor is notified that the child has made an enquiry, and that the identifying information will be released. This period gives the donor and his or her family time to prepare for a potential release of information and possible contact with the child and/or recipient parents. Donors were informed about the possibility of contact with any conceived children and have consented to this during the initial interviews and counselling. The child and recipient parents have the reassurance that the donor is prepared for contact and signed consents at the time of donation indicating a willingness to participate in contact.

In the case that either the recipient parents or the donor request contact with the other party, then upon enquiry to Canberra Fertility Centre, the other party is notified and it is only upon the agreement of the other party that information is released. Therefore the recipient parents and the donor must mutually consent to release of information, and Canberra Fertility Centre acts as the gatekeeper for the release of information.

Canberra Fertility Centre is emphatically opposed to any retrospective legislation regarding disclosure of identifying information, as this would seem unfair to donors who donated under the impression that they would remain anonymous. It may also be devastating to a child or the recipient parents if their attempt at contact with the donor was rebuffed. However, in the case of donors who donated prior to the recent disclosure requirements, Canberra Fertility Centre continues the practice of contacting the donor to put forth the request for contact by the donor child or recipient parents. In this case disclosure of identifying information is dependent upon the donor's agreement.

The issue of donor gametes and the associated disclosure responsibilities is of a highly sensitive and complicated nature, and therefore any legislation concerning this area needs to be thoroughly investigated. In contrast to the Western Australian system, we view the responsibility of disclosure as being the domain of the social parents. We are also concerned that the needs of all parties involved in gamete donation be thoroughly considered. Furthermore, given the extremely low level of donation in Australia relative to the demand for donated gametes, issues surrounding the importation of overseas gametes are highly pertinent to any consideration regarding donor legislation in Australia.

This document was prepared collaboratively by following staff at Canberra Fertility Centre:

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