FERTILITY FIRST
Centre for Reproductive Health

Submission to the Senate Standing Committee on Legal and Constitutional Affairs

"Inquiry into donor conception in Australia"

Fertility First was established in 1997 by Dr. Anne Clark, who has been working in the area of reproductive medicine for over 25 years in Australia, New Zealand and the United Kingdom. Fertility First specialises in personalised fertility care for men and women. Our patients include heterosexual and single sex couples, and single women – all of whom may require the use of donor gametes (sperm, oocytes) or embryos in trying to conceive. As such, the topic of donor conception and related issues is highly relevant to our practice and to our patients.

As an accredited unit practicing in NSW, we adhere to the following:

- The Reproductive Technology Accreditation Committee's (RTAC) Code of Practice (2008)
- National Health and Medical Research Council (NHMRC) Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research, June 2007
- Assisted Reproductive Technology (ART) Act, 2007

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

The regulation and legislation relating to donor conception has changed significantly over time. The concerns of donor conceived children are most often related to the absence of sufficient regulation and legislation regarding record keeping which occurred in the past. It is a requirement of RTAC accredited clinics that detailed records are kept.

Whilst all clinics must adhere to the RTAC Code of Practice and the NHMRC Ethical Guidelines, there is no consistency between states and territories in that some states and territories have no legislation and there are differences between those that do have legislation. These differences are often confusing to patients. On this basis, we would like to see uniform legislation for all states and territories.

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

i. Payment for donors

Due to the shortage of sperm donors in Australia, the Fertility First donor program includes both local and imported identity disclosure donors. All donors must be compliant with State and Federal legislation. Fertility First donors are reimbursed $50 for time and travel expenses when they donate. However, there is no reimbursement for time or travel associated with attending medical and counseling appointments. After a six month quarantine period, the donor must return for repeat blood, urine and semen screens. On successful completion of these screens, the donor is reimbursed $50 for each donation.

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This equates to $100 per donation. Thus, donors are paid a nominal fee; as such their donation is not financially motivated. Overseas donors imported by Fertility First are reimbursed $US100 per donation for out of pocket expenses. We agree that donors should not profit from their donation but should be compensated for the out of pocket expenses associated with donating.

ii. Management of data relating to donor conception

Fertility First follows the recommendations set out by the NHMRC regarding the management of data including maintaining the integrity and privacy of personal information, recording and monitoring procedures and outcomes and information about donation, use and storage of gametes and embryos. Details of all pregnancies and live births are recorded by Fertility First. As required by the ART Act, 2007 from the1st January 2010, identifying information regarding donors, recipients and donor offspring will also be provided to the NSW Central ART Donor Register.

iii. Provision of appropriate counselling and support services.

Implications counselling is mandatory for donors (local and imported) and recipients at Fertility First. In addition, all patients are informed of the availability of supportive counselling if desired.

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

Fertility First agrees that the number of offspring per donor should be limited and this limit should be determined by evidence based research. At present, such research is lacking. Prior to the commencement of the ART Act, 2007 Fertility First managed a 10 family limit per donor. A family was defined as a heterosexual or single sex female couple or single woman. As of commencement of the new act, a limit of 5 women (not families) per donor was imposed. There was no evidence-based research to support this reduction in donor limit. Furthermore, by changing the terminology from families to women, single sex couples are specifically disadvantaged in that many single sex couples wish both women to experience a pregnancy with the same donor so that there is a genetic relationship between their children. As there is no risk of a consanguine relationship between siblings in the same family, Fertility First recommends that there be a "family" limit rather than a "woman" limit. This would be consistent with recent changes to NSW legislation including the recognition of a single sex couple as parents on their child's birth certificate (Miscellaneous Acts Amendment (Same Sex Relationships) Act 2008).

To further minimise the risk of consanguine relationships, the local and imported donors and recipients of donor gametes are made aware of the existence of the Donor Sibling Registry (www.donorsiblingregistry.com). Many of our patients have registered with the Donor Sibling Registry.

Despite an increasing demand for donor sperm, data from the Australian and New Zealand Assisted Reproduction Database (ANZARD) has documented an almost 50% reduction in the number of donor insemination cycles from 2000 to 2008. Since 2007, Fertility First has been recording the number of contacts made by potential sperm donors (either by email or phone). There have been 64 documented contacts and of these only 2 completed ALL of the requirements and became Fertility First sperm donors. In addition, Fertility First launched a sperm donor website in June 2010. There have been 16 contacts but only one of the contacts has booked the relevant appointments. Restricting the donor limit to 5 women places more pressure on the already limited supplies and will ultimately make donor sperm more expensive for patients to access. Essentially there will be fewer patients to bear the expenses associated with advertising, recruiting, screening and maintaining a compliant donor sperm program.

The chronic shortage of Australian compliant registered sperm donors throughout Australia has necessitated the importation of donor sperm from overseas for the continuation of an identity disclosure donor program for some clinics. The importation of donor sperm from overseas allows for a more varied selection of donors with differing characteristics which is particularly important for patients from specific ethnic backgrounds. Clinics that rely on local donors typically have waiting lists of over a year and this is problematic for the many women who are accessing fertility treatment toward the end of their reproductive life. Additionally, these clinics usually require their patients to undertake a more invasive procedure (IVF) rather than the simpler treatment option of intrauterine insemination (IUI), partly as it is more efficient in terms of sperm usage. Others have had to close their identity disclosure donor program. There is anecdotal evidence that patients have been travelling interstate to access treatment with donor sperm to avoid lengthy waiting lists or the unavailability of donor sperm. The non-availability of clinic registered sperm has encouraged a move toward internet sites promoting 'free sperm'. For instance, one site advertises 325 Australian sperm donors. These internet sites are unregulated. Further, their donors do not have to comply with any legislation or regulations, in particular infection screening, screening for inherited diseases, compliance with any family number or appropriate arrangements for contact with the child(ren) into the future.

The importation of overseas sperm from consenting donors who are compliant with all relevant Australian legislation should be encouraged because it safeguards patients from using sperm that may not have been subjected to the appropriate screening and allows accurate monitoring of the donor limit. Further, these donors can be more readily tracked by the sperm bank in the future as they have access to the donor's social security number. In contrast, the donor offspring of Australian donors can only rely on the donor's name, residential address and date of birth provided at the time of donation (i.e. at least 18 years ago).

d) The rights of donor conceived individuals

Fertility First supports the rights of donor conceived individuals to have access to identifying information about their donors after the age of 18. Fertility First recognises that some recipients or donor offspring may desire contact with the donor prior to the age of 18. In this event, Fertility First attempts to facilitate contact provided both parties are willing and initial contact occurs through the forwarding of letters containing non-identifying information only. Evidence-based research has demonstrated that donor-conceived offspring function well and do not differ on measures of psychological adjustment when compared with naturally conceived children (Golombok et al, 2002).

Summary Points

1. Many concerns expressed by donor conceived children relate to a lack of guidelines and legislation in the past. However, this is no longer the case especially since 2005 when fertility units could only practice if they used identity disclosure donors.
2. The implementation of regulations and legislation has reduced the availability of compliant donor sperm. Any additional constraints would further compromise the availability of compliant donor sperm. Demand will remain the same resulting in patients accessing internet sites and other options to seek treatment outside any legislative framework. This puts them and their potential children at risk and also increases the risk of consanguinity.
3. The importation of compliant sperm from overseas offers patients a choice of screened donors with diverse ethnic backgrounds and the ability to undergo the appropriate fertility treatment without a lengthy wait.
4. Increased awareness and understanding of donor conception by the community would encourage a greater willingness to donate. It would also assist families to be more open about their children's donor conception.

This document was prepared in collaboration by;

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30th July 2010

Reference

Golombok, Brewaeys, Giavazzi, Guerra, MacCallum & Rust (2002). The European study of assisted reproduction families: the transition to adolescence. *Human Reproduction, 17(3*), 830-840.