

SUBMISSION TO THE LEGAL AND CONSTITUTIONAL AFFAIRS REFERENCES COMMITTEE OF THE AUSTRALIAN SENATE

On 23 June 2010 the Senate referred the following matter to the Legal and Constitutional Affairs Committee for inquiry and report.

The past and present practices of donor conception in Australia, with particular reference to:

(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.

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Terminology

Donor

Is used to describe sperm, oocyte (eggs) and embryo.

NHMRC

National Health and Medical Research Council (of Australia)

RTAC

Reproductive Technology Accreditation Committee of the Fertility Society of Australia

ART Provider

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Describes registered IVF units.

Introduction:

A. Donor sperm providers

There are 2 current groups of providers of donor sperm in Australia, registered ART providers and Non ART providers who are non medical, cannot be quantified, often untested or controlled and exist as they fulfill a desperate need in a large part of society as a result of the restrictive laws governing registered ART providers which limits availability of donors.

B. NSW submission

In view of the different state legislations governing donor this submission pertains to NSW only.

CURRENT STATUS (Post 1.1.2010)

ART Providers

1. Donor is currently governed by Federal legislation, State legislation and guidelines provided by RTAC and NHMRC.
2. Adherence to guidelines allow RTAC and NHMRC accreditation without which the Fertility Providers i.e. IVF units will not be able to receive Medicare Funding. This financial "control" means that no IVF unit functions without accreditation. Certain appropriately constituted bodies carry out the accreditation of IVF units, at defined intervals.
3. Fertility East functions in NSW and so this submission only applies to NSW, which since 1 January is governed by:
Assisted Reproductive Technology Act 2007
Assisted Reproductive Technology Regulation 2009
4. These regulations cover in detail the spectrum of the Inquiry and while providing a sound basis still leave some areas in need of modification and improvement.
5. One specific area that requires careful study is the actual risks of

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consanguinity as there is no scientific evidence to base the current limit of 5 women in NSW. Available evidence would suggest much higher numbers than the previous 10 family limit or current 5 women limit. In fact small numbers actually increase the consanguinity risk by placing higher demands on limited sperm resources at individual clinics. In addition restricting sperm donor to 5 women world wide further aggravates this problem.

Non ART Providers (General Public)

A significant home industry exists amongst the general public whom for a number of reasons do not wish to approach ART Providers for donor treatments especially sperm which does not require special laboratory facilities.

The ease and availability of current electronic communication modalities further promotes this home option.

I have personally questioned many patients seeking donor treatment with our unit and list some of the reasons that many of our patients have given for trying these "Irresponsible" Alternatives:

- Lack of availability of donor sperm (as a result of legislation)

- Cost of treatment with donor sperm

- Refusal to register both their and their potential offspring's confidential data with State authorities

- Government intrusion into their reproductive rights if they seek Responsible Reproduction, but no Governmental control of irresponsible reproduction. Thus 2 standards at work one for responsible patients and NONE for the others who "do it on their own"

In fact the legal option is probably one of the main reasons for patients avoiding it and seeking their own solutions, which of course put both patients and future children at risk.

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PRE 2010 STATUS

At least in NSW there has been a progressive tightening of legislation leading to the most recent law changes.

Prior to this time we have progressed from completely anonymous (non identifiable) donors to fully identifiable donors (for approximately 5 years) whose rights together with patients and offspring are protected.

The anonymous element of donation is what spurs the current emotional concerns expressed however it should be understood that parents made informed reproductive decisions at a time where anonymity was common donor practice.

It should also be remembered that certain cultures and nations still have legislation, which only allows anonymity and prevents known donation. To make donor details available to offspring is not a scientifically established fact, despite emotional arguments and beliefs. What is required are properly constituted studies rather than emotive assumptions.

FUTURE

Shortage of Sperm Donors

Concern is often expressed by people not involved in reproductive technology regarding the payment of donors. They will incorrectly associate the current shortage as a result of the lack of adequate reimbursement of donors for sperm.

In reality this is incorrect.

The reasons for the shortage of donors is the fact that all donors have to be identifiable i.e. when the offspring reaches 18 years of age the law allows them to contact the donor. Since this became law the donor shortage has occurred. On average only 10% of eligible donors will pass the rigorous screening process and when discussing any form of compensation for their time, travel etc the majority are not interested having undertaken donation for altruistic reasons

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Effect of Legislation

Unfortunately the paradox exists that the more laws that are passed regarding the control of donor sperm the more patients are driven away from Responsible Reproduction to the non ART home options with its attendant risks and complications not only for the recipient but the offspring and ultimately for the country at large.

“3 Objects of Act ” (See ART ACT 2007 Part 1,3)

The objects of this Act are:

- (a) to prevent the commercialisation of human reproduction, and*
- (b) to protect the interests of the following persons:*
 - (i) a person born as a result of ART treatment,*
 - (ii) a person providing a gamete for use in ART treatment or for research in connection with ART treatment,*
 - (iii) a woman undergoing ART treatment.*

In commenting on objects of the act:

a. Commercialisation (not actually defined)

The use of donor gametes is one more treatment modality provided by ART providers. Treatment modalities are billed accordingly. Commercialisation is more likely to exist amongst NON ART “providers” and it is interesting that this should be the first point mentioned in the act, over and above the well being of patients.

B Protection

- i. To protect the interests of the person born has been the object of all treatment in NSW before the act as it was covered by the guidelines but once again by driving patients to NON ART “providers” or “Do it yourself” options, it defeats the object.
- ii. Protection of the donor again was provided so nothing new has been added
- iii. Protection of the woman was also provided and again for her to seek NON ART “providers” puts her more at risk.

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In essence one wonders about the real objectives of the act and the reason for its promulgation. One hopes that a positive approach would overcome the negative impact of harsh legislation as the infertile minority of patients seeking good medical care are victimised and the those seeking do it yourself solutions can continue without control or victimisation.

Difference between issues and problems

All participants in this field must be made aware that issues for discussion do not necessarily imply problems, merely things to be discussed, and all too often the mention of an issue is wrongly interpreted as a problem.

Sensitive Comprehensive Approach

The government needs to pursue a positive sensitive approach actively promoting sperm donation and sperm banks. It should at all times have the necessary input from the professionals in the field who are actively engaged in providing this service and not figureheads who deal with things conceptually.

Input of the actual end user - the patient/s have been sorely neglected as each so called interest group tries to pursue its own agenda.

Parents have a right to decide on their own reproduction and need to be assisted not governed.

Extreme caution needs to be taken with small highly emotive special interest groups who are vocal and visual and attempt to hijack attention from the actual patients who because of their fertility issues prefer to remain unseen and unheard, which is understandable.

Government needs a new approach i.e. non authoritarian but rather positively empowering as the only people they can legislate for are the minority i.e. IVF providers who are already over legislated and completely compliant as opposed to the majority i.e. infertile patients for whom reproductive choices like intercourse cannot be legislated for and so the public can do whatever they wish.

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