

The past and present practices of donor conception in Australia

- A) *Donor conception regulation and legislation across federal and state jurisdictions*
- B) *The conduct of clinics and medical services, including:*
 - 1) *Payments of donors,*
 - 2) *Management of data relating to donor conception, and*
 - 3) *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.*

Fertility East is an assisted conception clinic in Bondi Junction which has a non-discriminatory treatment policy and can assist women and couples to achieve pregnancy through treatments which include IVF, ICSI and IUI. Our core philosophy is that no woman should be denied the right to have a child of their own.

Our patients have been acutely affected by the changes in legislation here in New South Wales relating to the use of donor sperm. The most crucial changes to legislation affecting our patients and the supply of donor sperm are:

1. Every donor must consent to having their identifying information kept on the Central Donor Register operated by New South Wales Health for access by any offspring born to their donation once the offspring turns 18.
2. Donors used in New South Wales are only able to assist a maximum of five families globally.

We have spent an enormous amount of time and money on deciphering the changes in legislation to ensure we are able to accurately and effectively communicate these changes to our patients and the interpretations of what this often confusing legislation is saying.

Whilst we have implemented these changes in legislation accordingly, we believe we enforce tighter regulations on the use of donor sperm, specifically the restrictions placed on donors themselves relating to the issues of identifying information and the issues of disclosure to any offspring born to the recipients of donor sperm. We believe that because the law stops with ART Providers, huge gaps in the legislation have become apparent.

- A) *Donor conception regulation and legislation across federal and state jurisdictions*

Donor conception, when provided by health care professionals (ART Providers), is the most tightly regulated and controlled aspect of Assisted Reproduction in Australia. The lack of cohesion amongst federal and state jurisdictions means patients can easily travel interstate to receive treatment (defeating the purpose of having regulations in the first place), however men wishing to become sperm donors in some states are faced with obstacles so great it is unlikely they will ever be able to

assist the thousands of women and couples who need donor sperm in their area.

The NSW Department of Health Central Donor Register which came into effect on 1 January 2010 is certainly a deterrent for many people enquiring about becoming donors, however it is a relevant introduction to the regulations relating to donor conception and one that will primarily assist the recipients of donor sperm and their offspring. However, no law should be introduced retrospectively. The Central Donor Database will also be a valuable tool for the NSW Department of Health to collate statistics across a wide range of demographics.

Should the Central donor database become a national base and therefore regulated across the federal jurisdiction, who would control that database or would there be a duplicate database: one in New South Wales and one federally? There is no reason whatsoever to duplicate this database and should a national database be introduced the state based one for New South Wales should be removed with all data being merged into the federal one.

The problem with trying to enforce and control regulations across any federal or state jurisdiction is that regulations and laws only apply to the ART providers and not the individuals who choose to perform “irresponsible reproduction” at home with donors who advertise, meet and ‘Turkey Baste’ each other with complete disregard of the regulations which are in place to protect them.

The more regulations and higher costs involved in the use of donor conception the more people are choosing this form of “underground conception”. We know this is happening and believe that better access to donors and the promotion of ‘responsible reproduction’ would protect every party involved. The lack of screening, testing, counselling and legal framework these individuals are subjecting themselves to is frightening and putting the lives of the recipient and offspring at risk.

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

- 1) Payments of donors,*
- 2) Management of data relating to donor conception, and*
- 3) Provision of appropriate counselling and support services*

As clinics are currently the only controlled providers of donor conception, there is no alternative but to provide services based on the current legislation and restrictions placed on all parties. Fertility East has started an entire Donor department, set up to ensure every donor and conception via donor gametes is accurately recorded, monitored and reported according to the NSW law ART Act 2007 and regulations 2009.

Fertility East implemented a transparent operating system when the amendment to the ART Act was announced in 2007 and have made it mandatory for all donors to comply with the following as a minimum:

- No payment is made for any donation
- Every donor must agree to have their identifying information kept at the clinic and for any donation used post 1 January 2010 this information must be submitted to the NSW Donor Register should any offspring be borne as a result of the use of donated gametes.
- All donors and their partners MUST undergo counselling to explore their motivation for donating, the implications of donating and future outcomes of their donation
- Donors must have extensive screens and genetic tests completed
- Donors must sign legally binding consent forms about ownership of donated gametes, what will happen to donated gametes in the event of the death of the donor, at what point a

donation can be withdrawn and many other aspects of the donation of gametes that may affect a recipient, offspring or the donor themselves in the future.

- All donor sperm, regardless if the donor is known or un-known to the recipient MUST be held in quarantine for a minimum period of six months. There is NO OPTION whatsoever to use fresh sperm for any donor sperm procedure.
- All consents and wishes of the donor must be signed and agreed upon prior to the donation taking place, unless the donor wishes to withdraw the use of their donation.

Please note that the above mentioned points are some and not all the points we cover relating to the donation of gametes and the consent forms we use for both donors and recipients.

Whilst we agree and comply with the new legislation relating to donated gametes, we believe the legislation should cover individuals as well as clinics.

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

Based on research conducted, the risk of consanguine relationships due to the use of donor conception is low. The risk of this happening through the use of open-identity donors is virtually zero.

At Fertility East, much emphasis is placed on the issue of disclosure when recipients of donor gametes are being counselled. We believe the recipient understanding the benefits of being pro-disclosure is an essential part of the donor conception process.

The worldwide shortage of donor sperm in particular experienced post 1 January 2010 caused unnecessary delays in treatment for patients. Had clinics had access to the exact details of the changes in legislation well before the date they came into affect, provisions could have been made to avoid the distress caused to patients and recipients.

One of the most significant points causing confusion is the 'Five Women Rule'. The NSW Govt interpretation of this is that the five women rule is global, although the restriction is only controlled in New South Wales.

We respect this rule however believe the five women rule should only relate to the use of donors in New South Wales not globally. This would increase the number of donors available and therefore reduce the chance of consanguine relationships even further.

There should be no restriction or limit placed on the number of children a recipient is allowed to have from the one donor, rather the number of recipients each donor is allowed to help.

The wording of the legislation should also be changed from Five Women Limit to Five Recipient Limit.

D) *The rights of donor conceived individuals.*

We believe the current legislation has made sufficient provisions regarding disclosure and the donor conceived individual's right to information about their genetic background. However we believe it could also be expanded to provide offspring with information which is non-identifying prior to the age of 18 as long as the recipient has chosen to inform the offspring they were conceived through

donor gametes.

Every donor needs to have identifying information kept on file with the NSW Donor Register. Each donor should then have a code (like a four digit number) issued by the NSW Donor Register which will be given to the recipient at the time of birth of the offspring. The recipient is the 'Social Parent' of the offspring and it is up to them to determine when and if the information is passed onto the offspring, rather than any government having control of this process.

Known donors have not been considered thoroughly in the current legislation. There is no distinction between known donors and un-known donors when it comes to the Central Donor Register controlled by the New South Wales Department of Health. In every case of a known donor, the donor will be known to the recipient. Why then does the same identifying information need to be recorded on the Central Donor Register from a known donor as an unknown donor?

The five family limit on donors also deters some sperm donors as they are concerned that there will be action taken against them if reach their five family limit by donating as an unknown donor to a clinic and then if at some point in the future they wish to become a known donor.

The limit on the number of recipients should be removed in known donor cases as well as the need for identifying information being kept on the Central Donor Register. The only time information about a known donor should be required to be included on the Central Donor Database is if they have previously donated at any clinic as an unknown donor.

Recommendations

1. **Legislation should cover individuals as well as clinics to promote 'responsible reproduction' across the board. Individuals should have better access to donors and not forced to use "underground conception" methods.**
2. **Laws about 'payment for donations' should include more flexibility in the terminology relating to the reimbursement of time and travelling expenses**
3. **The 'Five Women Limit' should be rephrased to be 'Five Recipient Limit' per donor**
4. **The 'Five Recipient Limit' should be applied locally not globally**
5. **The limit of five recipients be removed from Known Donors**
6. **The need for identifying information being stored on the Central Donor Database be removed for Known Donors**
7. **There should be a 'Donor Code' introduced for every donor listed on the NSW Central Donor Register**