

## Inquiry into Donor Conception in Australia

### Legal and Constitutional Affairs Committee

I am the parent of a child conceived via donor conception in 2002 and born in 2003.

I conceived prior to the RTAC Code of Practice changing to identity release donors but was lucky enough to have chosen a donor that while being classed as anonymous was open to being contacted. I was informed by the clinic on my first visit that they no longer used anonymous sperm donors in anticipation of changes with the NSW legislation and that they had a ten family limit. We had to wait another eight years for changes to be made to NSW state legislation.

After hearing about a family who had tried with the assistance of their clinic to contact their donor only to find that he had moved and not contacted the clinic with a forwarding address I decided it was time to write the letter I had been thinking about for a couple of years.

In 2005 I wrote a thank you letter to our donor and asked the clinic to pass the letter on. I am grateful that they had the foresight to think that this was acceptable. Many Australian clinics do not forward any form of contact (even if the donor has indicated that they are open to contact prior to the offspring turning 18) and are not proactive in keeping in touch with past donors. Our donor responded to my letter and we have been in contact since 2005. This experience has proved most positive for my child. Her ability to know from a young age about her genetic other half has helped answer many of the questions she has had. The fact that she knows his name and can talk about him has no doubt helped her understand about her family structure. I am sure that having access to this information from a young age will continue to be a positive for us. I have not got my head in the sand about issues that may arise but lots of the literature and research available on donor conception points to less problems for the children if they know about their conception from the beginning and having access to donor information adds to a good outcome.

We are in contact with another family who used the same donor – this contact was not organised via the clinic. It has proved most positive for both children.

The clinic will not put us in contact with sibling families till my child turns 18 and approaches the clinic herself.

I am involved with SMC Australia, an organisation that has over 450 members Australia wide and with international links. This group consists of women who are either thinking of becoming, trying to become or have become a Sole Mother by Choice. The group provides unbelievable support and education for women and their children. Set up to ensure that the children knew that there are a great number of children in families just the same as them, it links children and parents nationally and internationally who know they are not the only ones who have been conceived via a donor. With local gatherings and

annual holidays this group has proved a great support to both me and my child. The group is completely self-funded with no government or corporate support.

The past and present practices of donor conception in Australia

While the FSA guidelines cover clinics nationally, legislation in some states needs to also be taken into account. This has proven in some states to be more lip service than effective.

While there are NHRMC guidelines they are not strictly adhered to by all the Fertility clinics.

We need a National approach to regulation and legislation, not just guidelines. Federal legislation is needed so the clinics do not brush it off, as an issue not relevant to them. Some progress was made in Victoria some years ago – it has taken New South Wales a long time to make a half hearted approach to catching up. Western Australia has a registry system that doesn't work while Queensland has no registry at all. ACT, TAS, SA & NT have nothing formal. NSW and WA have no budget for either the voluntary registry or legislated registry. How do current and past donors get to know about the registries? How do the children who would like to see if there is a possibility of connecting with their donor, know where to list their details?

Where do the children conceived prior to donor codes being used go? How do they search for information when the clinics their parents used have often closed or been sold on and records destroyed?

A huge number of people who use donor conception still don't tell their children that they used a donor to conceive. This is of course mostly not the case for single or gay women.

A National Register is required to ensure that the information is available in one area (e.g. a selected government department or independent body) and to ensure that the practices of the past are not repeated and that donors and their offspring can be assured of the number of families and offspring and that the information that is held is up to date.

Different states of Australia have different ages of contact with donor information – mostly between 16 and 18. For many children this is too old. If both the donor and the offspring are interested in contact earlier and with appropriate counselling this option should be offered to those who wish to make contact earlier than 16 or 18.

It is extremely important that a registry be retrospective and set up to ensure past donors and their offspring can connect. I am sure many past donors are interested in knowing if their donations resulted in children being born, but many have no way of finding this information especially as clinics have been sold and information has been destroyed.

It is imperative that a budget must be allocated to these registries – unlike the lip service of the NSW & WA registries. Past donors are unlikely to know about the registries

without some advertising, PR and media exposure.

A voluntary DNA registry like the UK system would be a great step in the right direction, especially for matching previous donors and offspring. This would be a wonderful addition to any National Register.

The conduct of clinics and medical services, including:

(i) Payments for donors,

I believe that the current practice of non payment works well. Reimbursement of minimal costs, e.g. travel and medical etc as is the current status quo appears to work at present.

(ii) Management of data relating to donor conception, and

My own story shows that there are some good outcomes with the management of data but as you will read the management of the 10 family limit did not work for us. I know of other examples in Western Australia and South Australia of good data management in clinics. Unfortunately the examples of bad data management far outweigh the good.

This is an area that has been very badly managed in the past and in some cases continues to be presently.

I know of at least one clinic in Queensland that has sold sperm to at least two clinics in New South Wales and one in the Australian Capital Territory. The recipients of the sperm had no idea that the sperm had been sourced from Queensland until they started searching for additional vials to conceive siblings. This is recent, less than five years ago.

These situations then beg questions about family limits. Was the Queensland clinic limiting the donor to 10 families in Queensland? Did they ship the same donor to more than one New South Wales clinic? Did each New South Wales clinic think they had exclusive use of the donor in New South Wales? A number of people have been very surprised to find siblings in a different state to their own as first knowledge of their donor being used in a different clinic.

In the recent past American sperm banks with apparently exclusive agreements with specific Australian clinics (there by offering exclusive access to a set number of id release donors) have been found to have had the same donor available in Queensland and New South Wales. Again this information has been found out via social conversation. Who ensures that the five family limit is exactly that in New South Wales while Queensland uses the FSA 10 family rule?

Donors have changed from anonymous to id release with the information passed on in casual conversations with clinics which surely should have been advised to the recipient when the status of the donor changed.

Parents have done their best to ensure that their children were conceived with id release

sperm only to be told that the clinic has made a mistake after they are pregnant and been told, “sorry we have made a mistake and your donor actually isn’t id release”. This happened well after the 2005 change to guidelines. This example leaves a family with one child conceived with an id release donor and a younger child conceived with an anonymous donor with no legal recourse till the child turns 18.

Clinics need to be aware of the impact of their possible errors. While they are all clinicians focussed on a positive pregnancy outcome so their bottom line figures continue to look good, they need to spend a bit more time on delivering good outcomes to their patients – which are not exclusively a positive pregnancy. Risk management and patient management needs to be looked at in greater detail by the clinics.

A growing number of people are using known donors, some of whom are sourced via web advertisements. Some of these donors may have donated to clinics in the past; you would hope that they are willing to pass this information on to their recipients to ensure that all are aware of the number of possible offspring out there.

(iii) Provision of appropriate counselling and support services;  
Counselling services offered at the initial stages should be followed through as the patient progresses through the clinic system and follow up should be offered in the ensuing years if required. Information given at the first appointment is often not fully picked up until after the child has been born.

There appears to be a wide standard of counselling both across all clinics and within the same clinic groups. Appointments can last 10 minutes or multiple meetings.

The explanation of id release donors doesn’t always appear to be very well explained. Some people even after counselling appointments appear not to clearly understand the difference between id release and anonymous donors. Anonymous donors have supposedly not been available via clinics since 2005.

The impact both short and long term of issues that might arise as the longed for child ages does not appear to be discussed at much length in some clinics.

Various states have registries and it should be part of the counselling process that the lodgement of the forms, to the registries needs to be completed and sent off to the registries once the child is born.

(c) The number of offspring born from each donor with reference to the risk of consanguine relationships; and  
I believe that the limit of five families including the donors is acceptable. While I was told there was a 10 family limit on my donor, I know that the donor has been used by 13 families not including his own family.

(d) The rights of donor conceived individuals.

I believe VERY strongly that donor conceived individuals should have the ability to gain access to information about their donor and siblings and with due acceptance from all parties this should be given when requested, whether it is when the child is five, seven, 10, 13, 16 or 18. The current age of 16 or 18 (depending on which state you conceived in) can prove to be too late.

It is extremely important that a National Registry is set up for the current and past generations of donor conceived children, especially those conceived before id release guidelines came into being. Many individuals are looking for donors or siblings with a very small amount of information given to them by their parents or treating doctors. Many donors would like to know the results of their donations and if the registry is managed well information can be exchanged without exposing people not wishing to meet up.

We do not need to reinvent the wheel. Adoption laws changed years ago in Australia and donor conceived individuals should be given the same access to their family background as adopted individuals. The UK has managed this process for a number of years, even Victoria doesn't do too bad a job at it.

I am more than happy to speak and present to the committee.

Yours sincerely,