Submission
No 29

MANAGING INFORMATION RELATED TO DONOR CONCEPTION

Name: Name Suppressed

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Inquiry into Managing Information Related to Donor Conception

To: Committee on Law and Safety, NSW Legislative Assembly

Date: 15 February 2013

I'm very pleased that the NSW Parliament is accepting submissions on Managing Information Related to Donor Conception.

I make this submission as the parent of the donor conceived child born in 2003 who was conceived in 2002 with an anonymous donor.

1) Should people conceived by donor-conceived prior to 2010 have access to donors' identifying details?

Yes, they should.

I know that having access to identifying details helps donor-conceived children deal with issues relating to family background that may come up during their lives. I suggest that this information become available at 16 years of age or earlier if all parties are open to this.

Our family has been lucky enough to have used a clinic that was open to passing on a non-identifying letter to our anonymous donor, which included a non-identifying email. We have corresponded with our donor since my child was 18 months old. The exchange of medical, ancestry and family information has greatly assisted my child to know some of their background and where some of their features and interests might come from.

Non-identifying information could be released from birth to the parents and this information should be retrospectively given to children and parents born prior to 2010.

I understand that the clinics hold very strongly to the anonymity offered to past donors. Many past donors have never been offered the option of being asked if they are open to either non-identifying or identifying information being passed on. I'm not sure that the clinics keep in touch with donors to ensure that medical details are up to date. Internationally, both anecdotally and researched studies show that many past donors would be happy to supply information or be contacted if they are followed up.

I think that past offers of anonymity should not come before the need for donor-conceived children to have access to their donor information.

2) If retrospective access were granted what conditions should apply?

Adoption dealt with this issue very successfully many years ago and should be used as a model going forward. The donor-conceived could gain non-identifying information on their donor, and the donor could gain non-identifying information on the results of their donation (i.e. number of births, year of birth and sex). Both the donor and the donor conceived should have the right to veto passing on of **identifying** information.

Victoria has dealt well with this issue. In March 2012 the Victorian Parliament Law Reform Committee Inquiry into Access by Donor Conceived People to Information About Donors was released.

3) What other issues would be raised by granting retrospective access?

For many donor conceived children the desire to connect with possible siblings can be stronger than the desire to obtain information on their donor. Clinics have anecdotally not been keen at all on asking recipient families if they are interested in connecting. While IVF Australia recently set up Siblinks for their NSW Clinics, this option will only work if all families know about the service. The vast majority of heterosexual couples who use Donor Conception to build their families still do not tell their children the truth about their conception, despite their intention to do so prior to the child arriving. Many children find out later in life that they are donor conceived and having a correctly functioning register with a budget behind it would help siblings connect should they so desire. All people involved should have the right to veto the passing on of identifying information.

4) Which agency is best placed to manage the donor register? Is the current management of the register adequate?

While the gold standard should be a National Register, the way that the Federal and State legislation operates means that that is very unlikely to happen unless all of the States agree to move forward together. Many donors have been used by clinics across Australia and a National Register would assist in making linkages.

The NSW Register should NOT be managed by the Department of Health as it is currently. The current management of the register is totally inadequate. The Department has no way of publicising the register to past or present donors. Unless you really wanted to search for information, people would have no idea that there is a voluntary registry in NSW.

5) Should a standalone body be established to manage the register? What other areas could it have responsibility for?

Yes a standalone body should be established to manage the register. It might come under the remit of Family and Community services. A standalone body should have responsibility for all services to do with Donor Conception. The registry, counselling services, sibling links, education, and PR campaigns are but some of the services they could have responsibility for.

6) Should counselling and support services be offered to those seeking Donor conception information from the donor register?

Absolutely. All parties should have counselling prior to information being distributed – there may be different levels of counselling required. These services should be offered to both donors and the donor conceived.

Again the Victorian Inquiry has some good recommendations. The United Kingdom has done extensive work in this area. Their national Donor Conception organisation www.dcnetwork.org has a raft of information on its website.

7) Are there other types of support that could be offered?

Fertility Clinics have, in the past been very poor long-term record keepers. Information that should have been kept has been discarded and some Donor Conceived children may require advocacy on their behalf to gain the information they are seeking.

8) How would support services be funded? By the government, the individual seeking the service, or by assisted reproductive technology clinics?

Government department budgets, we are told are always being tightened. You can see by the lack of any public awareness campaign for the NSW registry that the issue of support for Donor Conception Issues will never be seen as a priority, so it won't ever go to the top of the budget request list. But lives have been impacted by past decisions, and this needs to change.

The government should make an initial donation for the setting up and ongoing operation of the body and supply basic services. The Fertility Clinics involved in Donor Conception services should make an annual donation. This would, I suspect make very little difference to their bottom line. Individuals making use of the services might be charged a nominal fee for accessing of information and counselling services – it might be means tested.

9) **How would such support be provided? By referral to the Department of Family and Community Services (as with adoption) or by a standalone body (as has been recommended in Victoria)?**

As above. I think that support should be provided via the body established to handle all Donor Conception issues, which should come under the Department of Family and Community Services. Again the Victorian report has some good recommendations.

10) **How long should ART clinics be required to retain records?**

Currently the NHMRC guidelines (guidelines being a key word) states that records should be maintained indefinitely. With clinics closing or being sold and the retirement of Doctors this has not happened in the past.

Clinics maintaining records should continue and all clinics should provide records of live births under legislation to the donor registry. Any changes should be data matched with the clinics on a regular basis to ensure that information is kept up to date.

While we have electronic contact with our donor, he has recently become un-contactable. Ensuring that records are kept up to date may make looking for further contact easier to establish. I've heard of donors who have changed addresses and not kept the clinic informed, thereby lessening greatly the possible opportunity of exchange of information – even if it's just a medical update.

11) **What should happen to records if a clinic closes?**

Should a clinic close the records should be stored by the registry till the patient is deceased. There may be a charge to the closing clinic for this service. Some clinics are merged with larger ones – all records should be kept as per the guidelines above.

12) **How can we ensure the integrity of records? For example, ensuring that they are not destroyed or tampered with.**

Legislation is needed to ensure that no medical records from the fertility clinics are destroyed or tampered with. Large fines should be in place and public announcements should be made if the legislation is ignored.

Thank you for reading this submission.

I would be more than happy to speak to the committee or provide further information should that be required.

Yours sincerely,