

Donor Conception in Australia

Submission to the Senate Legal and Constitutional Affairs Committee

30 July 2010

I am a solo mother of a delightful and precious child conceived with IVF. I always wanted to have a family and as my life did not quite turn out in the usual way, this was only possible due to the generosity of a clinic-recruited sperm donor. My child is the light of my life and to have been given the chance to be a mother has brought me more joy than anything before.

To protect the privacy of my child I have withheld my identity on the website however I am happy for the Senate Committee to know my details and am willing to provide more information if requested.

I have been honest about my child's conception from birth. Before taking this path I researched the issues surrounding donor conception and the clear message is that children cope well when they are given honest information as early as possible and are able to make sense of their genetic, biological and social connections. We have our own evolving story of my child's origins and we share and expand on this story frequently. My child is growing up in an environment of acceptance and understanding with no sense of shame or secrecy attached to the fact of being a donor-conceived child. We have a network of terrific family and friends who support this culture of honesty which gives my child the confidence and knowledge needed to form a strong identity. I am the Australian contact person for a US-based internet group of Single Mothers By Choice and am a member of Solo Mums By Choice (SMC) Australia, the Australian Donor Conception Support Group (DCSG) the Australian Donor Conception Forum (ADCF) and the US-based Donor Sibling Registry (DSR). Sharing experiences and knowledge with this broad range of people helps me remain informed and prepared for any issues that may arise for my donor-conceived child.

Unlike many other families with donor-conceived children, we are one of the lucky families who have been able to contact our donor. At the time of my treatment the clinic had recently put in place a policy, in line with NHMRC Guidelines, of only accepting new donors who are willing to provide release of identifying information and I was offered this choice. I decided to initiate contact when my child was young as it seemed wrong to wait until reaching legal age while wishing that we had been able to contact our donor earlier. As there is no actual legal requirement in Australia for donors to agree to identity release, I was also driven by anxiety that despite clinic policy, there was a chance I would be told there was no possibility of ever contacting our donor and I felt I could help my child cope more easily as time went by if we knew this early on. I was fortunate that my clinic agreed that in the interests of the welfare of the child it is reasonable to facilitate contact with a willing donor before the donor-conceived child reaches age 16 or 18 even though there is no legislation that allows for this.

Contact via email so far has been a wonderful experience for us all. I have been able to thank this amazing person whose kindness allowed me to bring my child into the world. It was a good feeling to be able to explain to my child our donor's motivation in his own words -

The reason I became a donor was because I realised it was an opportunity give someone the greatest gift possible - life. To help someone achieve their dreams of starting a family is something which costs nothing, yet is priceless in value. Knowing I could give this, it had been something I'd wanted to do for a long time. Actually, I find it quite difficult to understand why there are so few donors out there.

The donor has agreed to be 'an open book' for my child and we will certainly meet him one day. Although my child is very like me in many ways, there are things about the donor that strike a chord of recognition and familiarity for my child, with some questions answered and curiosity satisfied.

I have been unable to conceive successfully again and I am sad that my child will not grow up with a sibling in our family. I know that there are other families who had treatment using the same donor sperm. Unfortunately my clinic is not prepared at this stage to facilitate contact or even tell me if other families are interested. I hope that one day those families will decide that contact with us would be a positive experience for them and will find us on the DSR.

In relation to the terms of reference for the Senate Enquiry, I have the following opinions based on my own experience and research.

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

- should not discriminate on the basis of gender, marital or fertility status
- should be consistent across Australia
- should clearly state the rights and responsibilities of recipients as parents
- should allow for Medicare funding of counselling for donors and recipients and for all fertility treatment with donor gametes or embryos
- should require clinics to provide treatment only in accordance with NHMRC and other nationally agreed guidelines which should be updated to reflect best practice
- should require the establishment of national register of donors and recipient families including the facility to record information retrospectively
- should require that clinics only accept donors who agree to release of identity
- should require donors to remain in contact with clinics/recipient families in the long term, eg until the youngest donor-conceived child is 25 or older
- should allow clinics to re-establish contact with past donors by Electoral Roll search, Medicare/Tax File/Centrelink number matching or similar with exemption from Privacy legislation if necessary.

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

(i) Payments for donors

- Donors should be altruistic and not be offered any payment or inducement to become a donor
- Reasonable costs may be reimbursed to donors and clinics should provide specific information on limits to eligible expenses for potential donors
- Clinics should only charge the actual costs of counselling and other workup for potential recipients of donor gametes or embryos, with no profit to be made from the recipient preparation pathway.

(ii) Management of data relating to donor conception

- Clinics should record the full personal and family medical and social history of donors and should regularly update this information.
- Clinics should be required to strictly follow protocols, determined by an independent body, for recording and maintaining accurate contact details of donors and recipients and for providing this information to a national register.
- Clinics should be allowed to arrange mutually agreed contact between donors and recipient families at any time, not just when a donor-conceived child reaches legal age.
- Government-funded public awareness campaigns, with support from clinics, RTAC and NHMRC, should run regularly to encourage previous donors to reconsider their anonymous status and get back in contact with their original clinic or doctor.

(iii) Provision of appropriate counselling and support services

- All donors and recipients should receive extensive and consistent counselling prior to donating or undergoing treatment as a recipient and should be offered counselling on an ongoing basis even after any children are born.
- Counsellors should provide evidence to recipients that honest disclosure about donor conception is beneficial to the donor-conceived child and that secrecy is harmful. They should also provide specific, practical and ongoing advice on how to achieve this.
- Donors and recipients should be provided with accurate and extensive information about information sources, support groups and registers, including Australian and International internet-based information.
- Clinics should have active involvement with and give assistance to support organizations such as DSCG, ADCF, SMC and others.

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

- Research is needed to assess the actual rather than perceived or assumed risks of consanguinity for donor conceived individuals.
- The number of recipient families per donor should be limited at an international level for these limits to have any meaningful relevance in eliminating this risk.
- Both the encouragement of disclosure to children about their origins and a national register as noted above could contribute to lowering the potential for consanguine relationships between donor siblings.
- Lowering family limits may have the unintended consequence of reducing the availability of donor gametes. Public education to encourage those willing to be altruistic donors to come forward could allow a lower family limit without a reduction in access to treatment for those who need it.

d) The rights of donor conceived individuals

ENSHRINING THE RIGHTS OF DONOR-CONCEIVED INDIVIDUALS SHOULD BE THE PRIMARY FOCUS OF THIS ENQUIRY.

Donor conceived children should have the right to the same honesty, respect, acceptance and dignity that should be given to all human beings. The practice of donor conception must not encourage secrecy and should actively promote honest disclosure and open discussion. Donor-conceived individuals should have the right to detailed information about their genetic origin, honesty about the circumstances of their conception, and the opportunity to contact and meet their donor and any donor siblings.