

Submission to the Legal and Constitutional Affairs Committee of the Australian Senate

Inquiry into donor conception in Australia

I am the mother of two beautiful, healthy and happy young sons who were both conceived with the assistance of anonymous sperm donors (from Australia).

When my first son was conceived in 2004 (NSW clinic), I wasn't aware that donors could be sourced internationally. I was provided with scant information from the clinic (physical attributes, education level, basic medical history, a short report from the counsellor he saw) and this is what I have to help my son with the questions about his "dad" and "his story" until he turns 18. This donor is an id-release donor, and has agreed to have his identifying details released to offspring when they turn 18.

Through a mix-up at the clinic, I was not able to use this donor again to conceive my younger son in 2008, and had to find another donor. I did this through a different clinic (in Qld). As my eldest son will be able to access identifying information regarding his donor when he turns 18, I was adamant when selecting the new donor that my 2nd child be afforded the same right.

I was assured by the (new) clinic that this donor was an id-release donor and proceeded with treatment on that basis. When I was about 7 months pregnant I contacted to clinic regarding another matter, and I was advised that they had made a (monumental) mistake and that the donor was, in fact, a non id-release donor. The use of this donor sperm was in breach of the NHMRC guidelines and was not compliant with the RTAC Code of Practice issued by the Fertility Society of Australia.

This dreadful mistake is causing me much grief, and I struggle on a daily basis to determine how I am going to explain to my sons that not only do they have different donors (which I am comfortable doing), but that one of them will probably be able to contact his donor if he wishes, while the other one will never be able to contact his donor. I worry what the consequences of this will be for our little family of 3 and whether my younger son will ever get over this horrible injustice and forgive me. I will never regret my decision to have my wonderful little 2nd son, however, if I had known that his donor was not id-release I would not have chosen to use him.

Accordingly, I am extremely grateful and happy to see that the Australian Senate is conducting an Inquiry into donor conception in Australia. Gamete donation is so different from blood and organ donation. These donations create life; real

people with feelings, questions and curiosities that need so much more information than is currently provided. I hope that this Inquiry will bring some consistency and regulation to this industry and address these issues.

By using my personal experiences, I would like to make comments on the Terms of Reference for this Inquiry.

Terms of Reference:

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.

- Current donor legislation across Australia varies widely and there is no consistency between states regarding access to treatment, record keeping, and access to information for concerned parties to the donor treatment (including parents and the donor conceived person).
- Where there is no legislation it is up to individual clinics (and even doctors) to determine donor policy, which may lead to discrimination.

Recommendation:

- *There needs to be consistent, uniform legislation across Australia giving recognition to the donor conceived person's right to know their genetic history (including information about their donor and half-siblings).*
- *It must be possible to access this information, no matter when or where they were conceived.*
- *It must be introduced on a retrospective basis.*

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

(i) payments for donors,

- Donation, by definition, is a gift and as such should not be paid for.
- Free medical testing should be afforded to all donors.

Recommendation:

- *Donations should continue to be on an altruistic basis only with basic out of pockets expenses met.*
- *Donors should be given free medical testing which will also provide complete medical history for the donor conceived person (and their parents).*

(ii) management of data relating to donor conception,

- Currently donor registers have been established in Vic, WA & NSW. None of these have enabled retrospective access to information.
- Retrospective access was given to adoptees across Australia despite previous assurances of anonymity. The same right needs to be given to donor conceived people and other parties (eg their parents).
- Data relating to donor conception must be kept up to date for it to be of any use to the donor conceived person. Fertility clinics must be accountable for keeping this vital information up to date.
- This data affects lives and provides valuable information to donor conceived people. It is imperative that it is correct and that the correct information is given to recipients. The ramifications of incorrect information are life changing.

Recommendation:

- *A national Donor Register should be established to ensure this vital information is not lost or destroyed.*
- *Access to the donor information should be available prior to the donor conceived child turning 18, and be available to other interested parties (eg their parents).*
- *Access to donor information should be retrospective.*
- *Clinics need to have regular contact with past/present/future donors to ensure that data is kept up to date and relevant.*

(iii) provision of appropriate counselling and support services.

- It has been my experience to receive counselling at both the clinics (in NSW and Qld) prior to proceeding with treatment. However, I've not been offered any follow-up.
- When seeking fertility treatment using donor sperm, I was totally focused on having a baby, and didn't really consider the full ramifications of having a baby using a donor. This of course seems to be a fairly simple concept to a naïve "non-parent", but once the baby arrives and people start asking questions, it becomes obvious that this is a complex and sometimes challenging way to create a family.
- Prior to having my children I looked into International Adoption and gleaned from sessions at DoCS that "openness and honesty" regarding heritage was essential to the well-being of the child. I have been applying this principle to raising my boys, however this can be difficult at times and further professional counselling would be helpful.

- I have been lucky enough to establish a support network of other families who have donor conceived children. This provides me with ideas about talking to other people (such as teachers, friends, peers) and more importantly about talking with my boys about their conception.
- As my boys get older, I would like counselling to be available to them if they wanted it.

Recommendation:

- *Professional counselling be made available on an ongoing basis to parents, donors and donor conceived children as they require it.*
- *Counselling prior to fertility treatment should cover more of the complexities of creating a family using donor gametes.*
- *Counselling could be used to put patients in contact with support groups and/or other families undergoing treatment.*

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

- There is of course the possibility of consanguine relationships being formed between donor conceived people as at the moment there is a lack of information available to them regarding their genetic half-siblings.
- The more children born from a donor, the higher the chance of them meeting.
- At present it is possible for a donor to donate through a clinic, reach the family limit set by the clinic and then go onto donate privately to any number of women.
- Action needs to be taken to not only limit the number of families created by donors through clinics, but also by private donations.

Recommendation:

- *The number of children born from a donation should not be limited, however the number of families created should be limited to a manageable number.*
- *Given that many recipients of donor gametes will go onto have >1 child, the number of families should be set at a small number.*
- *The number of families will be arbitrary, but should be limited to <10.*

(d) The rights of donor conceived individuals.

- Donor conceived people need to have the same rights as all other people with regard to information about their genetic origins.
- As well as this, they also need to know such basic information as:
 - What is my donor like (physically, personality, medically)
 - Do I have any other ½ siblings
 - Can I contact my donor or ½ siblings
 - What made my donor want to donate
 - How do I contact my donor or ½ siblings
- Parents of donor conceived children may also have these queries and need to have access to accurate information regarding their child's donor to help the child

Recommendation:

- *National Legislation needs to be implemented to ensure that donor conceived individuals can have access to identifying and non-identifying information regarding their donor.*
- *This legislation needs to be made retrospectively so that regardless of when or where the child was conceived they will not be discriminated against.*