Submission

Past and Present Practices of Donor Conception

Legal and Constitutional Affairs References Committee Inquiry

My name is Kylie Dempsey. I am 27 and I am a donor conceived child. I am extremely grateful to my donor for his generosity that allowed my parents to have a child and for me to have such a wonderful life.

I would like to meet this man and thank him. See what he looks like and get a genetic history. If he was willing, I would like to get to know him and his family and share mine with him.

I have always known I was conceived by donor, it was just a fact. As I grew up, like all kids, I started to have questions, only my questions couldn't be answered; I was told that since I was conceived in 1982, there was no identifying information regarding my donor. In trying to explore my history, I have found that I sit amongst a special group of people; the first set of donor conceived children. As we have become adults and found our voices, we have been very clearly highlighting the impacts of donor conception. As a group, we are stating what we need (and want) – access to our donors for social and health reasons. Yet, regulation and legislation surrounding donor conception is still lacking and inconsistent across Australia, despite this observed impact on us and Australia's other donor conceived children.

Some States allow anonymous donations and some, including my State of conception, South Australia, don't oblige clinics to even share the non-identifying information they do have on donors, let alone help identify who the donors are. I find it difficult to understand why the Government, on behalf of all Australians, are not acting with the evidence that is before then. This part of the medical industry needs regulation and legislation to prevent heartache in its clients and medical emergencies in donor conceived children who don't have medical histories of their donor.

I write this submission, calling to action the Australian government, to ask Australia's leaders, our representatives, to regulate through legislation, responsibility for past and present donor conceived children:

a) Donor Conception regulation and legislation across federal and state jurisdictions

Donor Conception in each state should be monitored by a single national regulating body and fall under federal legislation.

Different Australian states have different regulations and legislation surrounding donor conception. Depending on the state in which your parents resided when they conceived you, you may or may not be able to gain access to information about your donor or their offspring, or they about you, and you may or may not be able to register on a database to find your donor or offspring, or the donor to find you.

As a donor conceived child this seems ridiculous. What is good enough for one Australian is good enough for another. Since when did we discriminate against an Aussie based on their conceived state?

- b) The conduct of clinics and medical services
 - a. Payments for donors

Donors should not be paid.

It is very important to acknowledge the contribution donors are making at the time of their contribution and that which they will make in the future as they think about their offspring and perhaps meet them. Although placing a cash value on something gives it value, sometimes things seem to be of more value and are held in a higher respect if a cash amount is not allocated to it. Further to this, by providing a cash incentive, people seeking money are attracted to donate. People attracted to be a donor for the cash are not well placed in their own lives to donate, let alone be a part of a donor conceived child's life.

As a donor conceived child, I would find it difficult to accept that my existence is the result of one random man's need for cash.

b. Management of data relating to donor conception, and

It should be the legislated responsibility of the clinics and medical services to collect and provide to a central managing body identifying and non-identifying information about the donor and donor conception. Additionally, complete medical histories of the family should be collated.

In my opinion the provision of donor conceived services has an inbuilt requirement to manage all and any data related to donor conception.

As a child conceived by donor in 1982, my hospital did not retain identifying records of my donor nor many non-identifying records. There certainly wasn't any detailed medical histories taken of the family. The later has hindered my medical treatment throughout my life and negated any opportunity for preventative measures. Any records my clinic does have, they are not obliged to provide to me. Clinics should be held accountable to record this information so that it can be supplied to families and this can be done through a central managing body.

c. Provision of appropriate counselling and support services

Interested donors and parents should have compulsory counselling.

Appropriate counselling and support services should be identified and/or made available for all involved, potential donors, parents, offspring, siblings and extended families in an ongoing capacity.

As a donor conceived child, I believe such services should be extended to offspring and their extended families. As I grew up and wanted to know more, my family were also taking the journey of discovery (or lack of discovery) with me.

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

A federal limit should be imposed with the provision of 'holding' donations for families that may wish to have more than one child. One donor should be allocated to each family seeking donor support. This should not be allowed to used by other families.

This eliminates future issues of consanguine relationships.

As a donor conceived child who has no identifying information about her donor or potential siblings, including how many others there may be, I am at risk of unknowingly forming consanguine relationships. This is an obvious concern to me and short of DNA testing, this is a risk that can not be mitigated unless one donor is allocated to each family and secondly the provision of identifying information of the donor and their offspring.

d) The rights of donor conceived individuals

Legislation regarding the provision of identifying and non-identifying information on donors to donor conceived children should be passed. This legislation should be made effective immediately and be retrospective.

To facilitate this, all clinics, current and previous should surrender copies of all records to a central coordinating body employed by the federal government. This coordinating body should, in the case where there is no identifying information, be proactive in finding past donors. The body should facilitate a national database where donors, donor conceived children (and the children of donor conceived children) can register.

As a donor conceived child, I would only accept DNA as conclusive evidence of any links with others in the database.

Parents, both Mother and Father, of donor children should be allowed access to identifying and non-identifying information about donors.

Currently, in South Australia at the Flinders Hospital, only the mother of a donor conceived child can access non-identifying information. This is discriminatory to the father who is equally a parent of the donor conceived child.

Young children are unlikely to fully comprehend the consequences of their requests for information about their donor for themselves, their family and their donor and donor's family. Both young and older children are impressionable and require significant support

through this self discovery process; parents and guardians are best placed to ensure this happens.

As an adult donor conceived child, I can see that when I was under 18 I did not possess the skills to adequately process all that I would have come across without the presence of guiding parents. I had the right to ask questions and to have answers. Access to information with guardian support is known to be a gentler way of addressing sensitive issues.

As a donor conceived child, I see no common sense in preventing the father access to information that the mother can access, I strongly recommend that this discrimination is prevented by legislation.

Children 18 years old or over should be granted access to identifying and non-identifying information about their donor without the need for parental permission.

Children with parents who would not allow them access to identifying and non-identifying information about their donors should have access to the information when they become adults and are more capable of seeking support as needed. Ultimately it is the donor conceived child's decision to seek further information on their donor, not the parents.

At 18, donor conceived children are adults and despite the wishes of their parents they have the right to make their own decisions. This should be no different in regards to accessing identifying and non-identifying information about donors.

Donors are not given identifying information about their offspring by clinics or the coordinating body.

The donor donates openly and knowingly. The child is conceived through donation without choice. As the child grows and starts to become a young adult, it must be the child's choice to seek out the donor.

As hard as this might be for the adult donor, what's best for the child, even an adult donor conceived child, that must be at heart. In my case, I would like to know my donor, but some may not or may not be ready.

Kylie Dempsey

I am prepared to attend committee hearings to answer questions.