

Inquiry into donor conception in Australia

Dear Senators,

My submission is made from my unusual perspective as both a single mother by choice¹ of a donor conceived child and as a sociologist working in the field of the ethical, legal and social implications of the so-called 'new genetics'. I write this submission from the heart, with my family's story in mind, but also taking into consideration the professional knowledge I have which is directly relevant to the issues under consideration.

As with most issues to do with parenting, public perceptions surrounding donor conception vary wildly and can be based on widespread myths and ignorance about the process and outcomes associated with donor conception. For example, it is widely believed in Australia that sperm donors are paid (more than a nominal fee) to donate and that would-be recipients choose their donors like they might choose a new pair of shoes, with little thought given to the ramifications of their decision. Such ideas are fed by the tabloid news media. As the Senators will now know (if they didn't before) these common misconceptions (no pun intended) do an injustice to the majority of donors and recipients who give their decisions great consideration.

I urge the Senators to put their 'commonsense assumptions' aside and to consider all submissions on their merits. I believe in reading the submissions (as I have done to as many as possible), an obvious and compelling way forward will become apparent. Donor conception in Australia is a magnificent, life-giving and –changing social practice which deeply affirms everything good about community. It is one person altruistically helping another family come to life. I hope the Senators will do everything in their power to protect the rights of donors, recipients and donor conceived individuals across Australia.

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.

As with so many areas of regulation in Australia, our federal system has created a dogs' breakfast of contradiction and confusion when it comes to donor conception. What is legal and commonplace in one State is illegal and impossible in another. In practice this means people travel to access the services they need, thus rendering jurisdictional difference both farcical and pointless.

While it might not be so important when it comes to rail gauges, it's absolutely essential that the right regulations are in place nationally and are uniformly administered when it comes to donor conception. We are talking about people's lives and thus it is essential that

¹ Hereafter referred to as SMC.

all donor conceived people are treated fairly and equally regardless of which side of a State or Territory border they were conceived.

The most critical reform required is to immediately establish a National Donor Conception Registry which records all pregnancies and births involving donor gametes. This must be in the form of a publically accessible database to which donors, recipients, donor conceived people and all other interested parties can refer. All clinic donors must be identified using a unique identifier which must in turn be used by all clinics. Basic descriptive (but non-identifying) information (i.e. donor profiles) must be provided about each donor so that donors who have donated privately are also covered by this registry. All clinics must be compelled to provide information to this registry in a timely and accurate manner. Lapses must be regulated by an independent authority (not industry regulated).

The National Registry must be set up in such a way as to facilitate contact between donors, recipients, donor conceived people and donor siblings. It must be retrospective. That is, it must allow for both past and present donors, recipients and donor conceived people to register their information in the hope of establishing contact (if that is what all parties wish).

Such a reform would remove the current situation where recipients and donor conceived people are reliant on the goodwill and competence of clinics to keep good records and to effectively facilitate contact. It would remove the need for people to resort to databases such as www.donorsiblingregistry.com in order to try to make contact where contact has been otherwise not possible.

In Australia, we register births to show the social and legal parentage of children. We do so successfully and uniformly and with little fanfare. The contrast between that system and the system of recording and registering donor conceptions is profound. 'Missing' or 'lost' information has diabolical implications for donor conceived people trying to find a more complete picture of their genetic heritage. It is their right to have ready access to accurate and complete information about their donor, and to have contact if both parties are amenable. These rights should not be stymied by jurisdictional difference or industry intransigence.

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

(i) payments for donors,

It is my very strong view that we must continue the practice of altruistic donation in Australia. I believe that is the most ethical practice for all parties. I personally would never have chosen a donor who donated for payment. I understand that the altruistic requirement is probably the reason we have a shortage of sperm donors in Australia. However I feel that enough clinics are providing ready access to sperm from America (where payment is the norm) to overcome this issue. As it stands, recipients can choose between sperm from an altruistic Australian donor or from an overseas donor who has accepted payment. I believe this is appropriate and desirable and should not change.

(ii) management of data relating to donor conception,

I refer the Senators to the submission by SMC Australia which provides a long list of some examples of the many egregious and potentially life-changing errors and poor practice demonstrated by some clinics in this matter. My own story is briefly mentioned in that submission and I will expand upon it here.

When I was selecting my donor one of the things I took into account was whether or not that donor had indicated he was willing to make contact prior to the child turning 18. I wanted a donor who was open to early contact as I saw this as a crucial element of my strategy to normalise my child/ren's conception and to ensure that my child/ren's donor did not become some remote and elusive figure of imagination but was instead a real human being with whom we had some limited but positive contact. I had researched early disclosure and found it was an important element in the stories of donor conceived children who had successfully assimilated and adjusted to their conception. I had also spoken to other SMCs with older children who had met their donors and whose children had met their donors and found that this had been an overwhelmingly positive and helpful experience for all parties.

When I reviewed the donor profiles I saw that the clinic had provided a tick box option for donors to say whether they were open to early contact. By this I assumed that there was an established procedure for early contact to be facilitated by the clinic, and that the clinic supported early contact. Why else provide the option? Accordingly I chose a donor who had agreed to early contact.

I had planned to initiate contact when my first child was in early primary school. However I became concerned that my donor might move without notifying the clinic and thus become un-contactable. I decided to initiate contact when my daughter was a few months old. I phoned the clinic and spoke to the donor coordinator and told her my intentions. She was encouraging but said it was new to her as it hadn't happened before to her knowledge. I was surprised and told her of the many examples I knew of early contact being facilitated by other clinics. I told her that I intended to write the donor a letter; that I would send it to her unsealed; that she was welcome to read and 'check' it; and that I wanted her to then forward it to him as per my wishes (and his, as he'd indicated when donating).

I sent the letter and waited a while before following it up. I didn't want to be pushy. When eventually I phoned to enquire if my letter had been forwarded, it became evident that there had been some confusion. My letter had been filed. If I hadn't followed it up I don't know what would have happened to it. After some discussion I was told there would have to be a meeting between the donor coordinator, the fertility specialist and the lab manager. There would be some delay as the FS would be away on holidays in the coming weeks. After waiting about four weeks I again followed this up. To date I have been told the meeting has not yet taken place but will take place soon. I understand from what I have been told that the issue has been complicated by some contradictory guidelines in the two policies which

the clinic is drawing from. I'm not clear exactly what those policies are. I don't have copies of them. I have offered to forward a letter detailing my concerns which offer has been accepted. I hope that the meeting will take place soon. I have been told that even if it is agreed to forward my letter (to the donor), both myself and the donor will have to undergo further counselling before my letter will be made available to him.

I do understand that something new can be complicated and unnerving. I do understand the important stakes. It is my daughter. I feel that my parental autonomy has been undermined by this process because I am now relying on the clinic to *allow* me to do something that I believe is my right (which is to make decisions in my daughter's best interests). I believe the donor's rights are also being undermined. No doubt he is expecting to hear from recipients sooner or later. What will he think when no-one contacts him? What frame of mind would that put him in, were he to not meet my daughter until after she turns 18 (assuming we can find him given the passage of time)?

I must also take this opportunity to stress that I have no beef with my clinic. I am forever grateful for the professionalism and compassion they have shown to me when I needed help and was vulnerable. I am frustrated by this turn of events but I do understand how the situation has arisen. I regard myself as being in discussion with the clinic and not in dispute. I am hoping for an outcome that is mutually satisfactory.

(iii) provision of appropriate counselling and support services;

From my discussions with other SMCs it is apparent that there is wide variation in the cost, content and outcomes of counselling and support services provided by clinics. In my case, I told the counsellor I saw about SMC Australia, what a great organisation it was, how much information and support it had provided to me, and I recommended she tell other potential SMCs about it. I had expected that *she* would have been telling *me* about SMC Australia, given it is the only national support group specifically for single mothers by choice in Australia. When I tried to give my fertility specialist some flyers about SMC Australia to display in his waiting room, he suggested that would not be appropriate but offered to give them to clients directly. Why not appropriate? I don't know if he has distributed the flyers. I know I haven't been asked for any more copies. I know that particular clinic has many single women clients but I don't know how many, if any, are referred to SMC Australia for support. In fact my clinic referred me to ACCESS, the infertility support group. This was wholly inappropriate as I was not infertile.

I found my compulsory counselling sessions neither helpful nor unhelpful. Like most other SMCs I know, I had spent years considering my decision and had done a lot of research. I didn't have very many questions myself. However my counsellor had lots of questions for me. Amongst other things I was asked about whether and how I intended to talk to my future child/ren about their conception story. I explained that I'd done a lot of research both scholarly and amongst other SMCs and as a result I intended to be open and honest from the start. I said that part of my strategy would be to make contact with the donor early so that he did not become a remote or elusive focal figure for my child. I wanted him to be a known quantity. The counsellor congratulated me on the approach I planned to take

and agreed it would be the best way forward. At no point did the counsellor advise me that making contact with my donor through the clinic would be problematic, or that it hadn't been done before (at this clinic).

I have been informed that if my clinic ultimately consents to forward my contact letter to my donor, that both he and I will be required to undergo further counselling *before they will actually forward the letter*. I am quite frustrated and resentful about this as it was not disclosed to me that this was a requirement at the time that I underwent treatment. It is this clinic's requirement and not something mandated by jurisdictional regulation or recommended by industry practice. To me it seems another example of the *ad hoc* manner in which some clinics go about administering this vital aspect of their business. Counselling in this way becomes a part of the business process. Participation is coerced and can never therefore be truly effective. It is highly unethical to coerce participation in psychological counselling.

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

It's clear that the 5/10 family limits which are in place in some jurisdictions are not working effectively. Some clinics transfer sperm to and from other clinics in other jurisdictions without regard for implications of this practice on family limits. It is known that some privately recruited donors have donated at clinics as well as privately thus exceeding family limits (in some cases many times).

In my view, a ten family limit *across Australia* is appropriate. It may be that in some jurisdictions a small population suggests a smaller sub-limit should apply. So, for example, a donor may be able to donate to 10 families overall (within Australia) but of those 10, no more than 5 could be in Tasmania.

In order to make family limits more effective, a national donor registry must be established, to be administered independently of clinics and other industry interests (see my comments in part a above). Clinics must be compelled to lodge information regarding pregnancies and births there using a unique identifier for each donor (so that multiple donor ID numbers do not obscure statistics). Donors and recipients of privately donated sperm could lodge information there as well. The registry must be publically accessible so that potential recipients can check for themselves how many families each donor has assisted.

The risk of consanguinal relationships is greatly minimised in the children of single women and Lesbians by the widespread practice of early disclosure. These children typically grow up knowing they are donor conceived and are aware of the risk of consanguinal relationships. It's an easy thing to avoid if both parties are fully informed. Where risk is much higher is in the children of heterosexual couples where denial and conception secrets are much more prevalent. Counselling of heterosexual couples seeking donor gametes must emphasise the risks inherent where children are not informed of their donor conception. Those risks of course are far greater than consanguinal relationships and include the high

probability of fundamental social and genetic identity dislocation if the truth about their conception is discovered in late adolescence or in adulthood.

(d) the rights of donor conceived individuals.

The rights of donor conceived children are the rights of children everywhere. To know your identity is a basic human right and as such is recognised in Article 8 of the United Nations Declaration on the Rights of the Child. Australia is a signatory to this Declaration. I believe it is incumbent upon the Senators to bring about reforms which will allow this to happen more effectively than currently occurs. I will refer Senators again to my earlier comments regarding a comprehensive, retrospective, compulsory National Donor Conception Registry.