Submission No 6

MANAGING INFORMATION RELATED TO DONOR CONCEPTION

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Inquiry into Managing Information Related to Donor Conception

Submission to the Legislative Assembly Committee on Law and Safety

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1 Recommendations

The Committee should frame its recommendations for changes to the current arrangements for donor conceived people in terms of the broad guiding principles of openness, honesty and disclosure. Reform guided by these principles is required in order to replace the failed policy of secrecy and lies that has led to parents being afraid to disclose the truth to their children. This policy failure has also created discriminatory practises whereby some donor conceived people are denied full information about their genetic identity, including such basic information as who they are, and who they are related to. An intermediary service is required that is adequately resourced to provide counselling to assist donor conceived people, donors and their respective families.

1) The preservation of all records linking donor conceived people to their biological identity and kin, including important information such as medical history, should be given paramount priority. All records pertaining to donor conception from clinics and medical private practice should be compulsory acquired and protected in perpetuity in a NSW Donor Register. Where records have been destroyed, past donors should be encouraged to add their details to the register via a public education campaign. They should have the option to undergo free DNA testing to assist in matching them to their biological relatives. Legal children of donors should also be encouraged to add their details to the register.

2) State legislation should be enacted allowing all donor conceived persons aged over 18 years to apply for information about their biological donor parent(s) and siblings on the newly created NSW Donor Register, regardless of when they were born. This information should be available earlier with the consent of the child's legal parents.

3) The keystone to the functioning of a reformed system based on openness and honesty is resourcing the Authority managing the NSW Donor Register to offer donor linking services with specialised counselling available in each state to any person who requests it. The Authority must be properly resourced to employ counsellors who are able to act as intermediaries, facilitating contact between donors, donor conceived people and their half-siblings. The Victorian Infertility Treatment Authority (now called the Victorian Assisted Reproductive Treatment Authority) could be used as a best practise model for providing such services to donor conceived people, donors and their families.

4) If cost is a barrier to the government providing counselling services to those affected by donor conception, the Committee could consider the paradigm of infertility treatment clinics contributing towards the cost of providing these services, in recognition of their duty of care towards the people they helped create.

5) In cases where donors do not agree to voluntarily release identifying information about themselves to their offspring after counselling provided by the intermediary service, they should be advised of their right to place a contact preference or contact veto on their donor register record, which applies only to themselves and not other members of their family, similar to provisions of the NSW Adoption Act. If a contact veto is revoked, the person about whom it applies should be informed directly by the Authority managing the donor register.

6) After donor-linking and counselling has been supplied by the intermediary Authority, donor conceived people should be permitted to apply for identifying information about their donor, but be required to comply with any contact vetoes placed by the donor. This process should also apply in the reverse when a donor is seeking information about their donor offspring.

7) Donor conceived people should have the right to apply for information about their half-siblings via the intermediary Authority. In cases where information within the records is insufficient to locate the half-sibling, the Authority should contact the parents of the half-siblings.

8) That NSW Donor Register should be linked to the Registers of Births, Deaths and Marriages so that birth certificates of donor conceived people will have an appended note available only to the donor person, which gives information about the nature of their conception. This measure could be applied prospectively. This process has recently been enacted in Victoria as per the provisions of the Assisted Reproductive Treatment Act.

9) People deserve at least as much protection as embryos. Public information should be available as to the adherence or otherwise of assisted reproductive treatment clinics to NHMRC guidelines as per the requirements of the Research Involving Human Embryos Act. Accreditation of assisted reproductive treatment clinics should be conducted by an independent licensing committee who are obliged to regularly report to government on key issues such as information collection, use of anonymous gametes, and number of children born from each donor.

2 My Story

One afternoon in early January 2005, when I was 21 and my sister 24, my mother sat us down and said she had something to tell us. She sat on the creased leather couch, eyes downcast, hands shaking softly. In an awkward conversation she revealed the truth, that we were both donor conceived. Finding out so late was a huge shock. My identity was splintered and the social and biological aspects of parenthood carved up. I learned my biological father was a vial of frozen sperm labelled C11.

For the next three years I didn't discuss being donor conceived, but I thought about it almost every day. I mourned the human face behind that vial, somebody I had never and would never meet. I wondered about my missing kin, who they were, what they looked like and where their interests lay. I empathised with people whose relatives have gone missing. They don't know if they are alive or dead, happy or miserable, and when, if ever, they might see each other again. It is important to recognise that the impact of the status quo is not benign. It can place donor conceived people in an awful limbo. I thought about carrying this burden for the rest of my life and I was afraid.

In the early days I had only a vague notion of the laws governing my situation. I am Victorian and I knew enough to know the law gave me no protection and I was held liable to a promise of anonymity that I had never agreed to. Eventually in 2007 my mother wrote to the Infertility Treatment Authority (ITA) who revealed non-identifying information about my donor and the existence of three half siblings, two boys and a girl born in Dec '81, July '84 and Aug '81, all to separate families. My sister and I joined the voluntary register, but there were no matches.

Things began to change when for the first time I met other donor conceived people, through an organised called Tangled Webs. I could finally talk about the questions I dared not articulate to my family and people who didn't have a personal experience of my situation. As my awareness of the legal situation increased, so did my sense of injustice. I found it incredibly frustrating that the ITA had my donor's name, but were not empowered to write to him on my behalf because of a lack of legislation. Eventually I found a loophole by writing to the actual doctor who facilitated my conception. Professor David de Kretser had since gained high status in the community as the Governor of Victoria. I found him to be a man of high integrity who actually listened to my concerns. In July 2009 he emailed to tell me he had sent the letter. However he could have easily made the opposite decision. A common theme of being donor conceived is being powerless, and beholden to other people's decisions when it comes to crucial information.

After that things moved quickly. Just a few days later David de Kretser's outreach to my donor elucidated a response. In fact, I never again had to refer to my biological father in that impersonal, medical misnomer 'donor'. His name is Ben. I was most fortunate in that I found myself in the capable hands of the counsellors at the ITA, who were wonderful in helping Ben and I forge our fragile connection. I went in to the ITA for an interview and listed a short resumé of my personality and interests and discussed my short and long term goals for contact. I wrote the first letter to Ben using a mailbox service that did not require us to exchange full names or contact details. I was advised to be patient because sometimes people require a lot of time to process the information and become ready to reply. We exchanged letters and photographs and talked on the phone. In November 2009 I went to visit Ben for the first time and met his teenage children, my half siblings, two girls and a boy. I was very nervous prior to the meeting, but when I arrived I felt at ease. We all share many characteristics, both in appearance and temperament, and even mannerisms.

The overwhelming feeling I took from this meeting was relief. Relief that I had found a small chink in the imposing wall of legal structures designed to separate me from truth. Most of all, relief that I finally had answers to questions about the source of my personality and interests and no longer faced an uncertain future of missing knowledge concerning my biological heritage and identity.

I still feel tremendous empathy for other donor conceived people who don't have the opportunity to make contact with their kin. Driven by the injustice that some donor conceived people are still second class citizens when it comes to basic personal information motivated me to seek redress through the political system. I also want to send a message to my three lost half siblings or their parents who might be reading this submission. I hope someday we can meet. I miss you and I am waiting for you.

3 Terms of Reference

3.1 Whether people conceived by donor conception prior to January 2010 should have access to donor conception information, including information that identifies their donor and donor conceived siblings.

All donor conceived people should have access to donor conception information, regardless of when they were born.

This conclusion is drawn from many existing precedents in law and ethics. In assisted reproductive treatment the best interests of the child must be considered paramount. This is enshrined in the guiding principles of the Victorian Assisted Reproductive Treatment Act. The federal Family Law Act also recognises the best interests of the child as being paramount.

Donor conceived people born in NSW after 2010 have the right to access information about their biological parent(s). Adopted people in NSW have the right to access records relating to the identity of their biological parents. Children born through sexual intercourse have the right to know their biological parents. It is legal to seek DNA confirmation of parentage in such instances when parentage is in dispute, and if the father refuses to be tested then parentage is inferred.

Donor conceived people born prior to 2010 are currently the only group of citizens in NSW who are denied access to information about their biological identity and this anomaly should be rectified in a timely manner in the interests of fairness, equality and natural justice.

In Victoria a similar inquiry yielded the recommendation that all donor conceived people should have access to information about their biological parents. However this recommendation is yet to be implemented, pending an extension of the inquiry to further canvass the views of donors.

Many people sympathise with the unfairness of the position of donor conceived people who are unable to discover information about their biological identity, but might also feel it would be unfair to renege on promises of anonymity given to donors. There can be a sense that ‘two wrongs don't make a right'. However it is important to recognise that many, if not most donors are altruistic people who understand and empathise with donor conceived peoples need for information. In Victoria as of 2012 there were 174 donors on the voluntary register, compared to 142 recipient parents and 70 donor conceived people. The Victorian Assisted Reproductive Treatment Authority is currently undertaking research on the views of sperm donors who were recruited under condition of anonymity, and this research will be finalised within 6 months and should be consulted by the Committee.

It is also important to consider that in cases where donor conceived people are seeking information and their donor does not wish to release information there must be a balance between the rights and interests of both parties. Information release subject to contact veto is an example of a balance whereby the donor conceived person receives information and the donor is not contacted. Prohibiting the release of information, or only allowing information to be released after the donor is found, contacted and gives consent skews the balance towards only considering the rights and interests of the donor. In some cases donors cannot be found to give consent, or they might have died. In such situations a 'contact first and ask' approach will leave the donor conceived person in the horrible limbo of never being about to find out anything about their biological identity.

3.2 Which agency should manage donor conception information and provide services related to the release of this information.

It is crucial that the agency managing donor conception information be separate and independent from assisted reproductive treatment clinics and related bodies such as the Fertility Society of Australia. This is to ensure impartiality and minimise the possibility for conflicts of interest, for example where a donor being contacted is part of the medical fraternity, or where a clinic has acted in a manner that might be perceived as unethical, for example used a single donor to create dozens, or even hundreds of children.

In Victoria the now defunct Infertility Treatment Authority (ITA) previously managed the Victorian donor registers and was well respected by their service user clientele consisting of donor conceived people, donors and recipient parents. The ITA was a government funded authority. Currently in Victoria the authority for the donor registers is held by the Victorian Registry of Births Deaths and Marriages, however services associated with making an application to the donor registers, including counselling, is managed by a separate government body called Family Information Networks and Discovery (FIND). This splintering of authority and services is not ideal. It is preferably that the agency managing donor conception has both full authority and full responsibility for undertaking services related to application to the donor registers, including information management, counselling, and release of information.

In principle the Donor Register could be managed by the NSW Registry of Births Death and Marriages. This has the advantage that the agency is guaranteed long term funding and continuity and is not likely to disappear in the future. However, as noted, it would be important to frame the legislation in such a way that services such as counselling and information release were integrated into a 'one stop shop' so that people are not shunted between multiple agencies and relevant information is available to personalise counselling sessions, rather than counselling degenerating into merely providing generic information.

3.3 What counselling or support services and public education measures are necessary to support people who are seeking access to donor conception information.

I have lived through the experience of linking up with my biological father as an adult and therefore have personal experience in regards to counselling and support services. I found it helpful to be able to speak to a counsellor and have access to an intermediary service. I also found it helpful that my donor had access to a counsellor and was able to talk about any uncertainties or fears in regards to proposed contact. It was also initially useful to have access to a 'mailbox service' whereby we could exchange letters without having to use our full names or addresses. However after one letter, my biological father replied with his full contact details, after which we were able to correspond directly.

Actually in my experience the most useful support service was simply meeting other adult donor conceived people. They instinctually understood how I felt because of our similar histories. Therefore it would be an ideal and very effective use of funds to establish peer support groups. In 2012 I helped establish a support group for adult donor conceived people through the post-adoption organisation VANISH (I am also on the committee of management of VANISH). This has been very successful and we regularly have 10 or more people at the bi-monthly meetings.

Counselling should be freely available and encouraged, but not mandatory. Counselling should be available via face-to-face and other methods, for example Skype, over the phone or via email. This would be helpful for people who would otherwise have to travel long distances to access counselling.

It is crucial to find the right counsellors. Ideally the counsellor should have professional experience in dealing with disenfranchised grief and the losses associated with separation from family of origin through donor conception, adoption or family breakdown. I believe it is a mistake to assume that all fertility counsellors, who have previously counselled infertile people seeking to have a baby will have an understanding of the issues faced by donor conceived people. In fact, in my experience most fertility counsellors have never encountered a donor conceived person in their professional practice. Counsellors could be recruited with relevant experience, or undergo professional training. Organisations such as VARTA who have employees with donor linking experience, or post-adoption services such as the Post Adoption Resource Centre (PARC) should be consulted.

It is important that post-donor conception services are not provided by infertility treatment clinics for the same reasons listed under section 3.2. However, as an option, funding for the donor registers, counselling and support could be provided by a small levy on assisted reproductive clinics that was then transferred, via government, to fund the appropriate authority.

3.4 Any other relevant matter.

Donor conceived people should not have to be reliant on their parents telling them the truth. Even in today's society with more enlightened views a recent study found that only 35% of parents had told their children about their donor conceived status (refer Kovacs et al, "Functioning of families with primary school-age children conceived using anonymous donor sperm", *Human Reproduction*, 2012).

Parents often put off indefinitely telling their child that they are donor conceived because of sensitivities related to infertility and not wanting to hurt the feelings of the non-genetic social parent. However, parents not being honest with their children can lead to late or accidental disclosure due to a myriad of unforeseen circumstances (e.g. divorce, family conflict, medical issues etc).

It is much better to have an independent mechanism whereby people can discover they are donor conceived. This naturally encourages parents to be honest. The birth certificate of donor conceived people should be altered to list all the social and biological parents associated with the conception of a child. Alternatively the NSW Donor Register should be linked to the Registers of Births, Deaths and Marriages so that birth certificates of donor conceived people will have an appended note which gives information about the nature of their conception. This measure could be applied prospectively. This process has recently been enacted in Victoria as per the provisions of the Assisted Reproductive Treatment Act.

Thank you for reading and I hope this inquiry leads to some meaningful change in the not too distant future.