

## Submission to senate inquiry on Donor Conception

We are parents of two children conceived through donor insemination because of male infertility, who have the same donor and were born in 1994 and 1996. We went through a public hospital clinic in Sydney and were fortunate in having excellent counselling prior to making the decision to use an anonymous donor. Our concerns were always about not only creating a family, but also about how those children would judge our actions in going down this route. Of particular concern was the issue of identity – we felt strongly that this information should be available to them if they wanted it.

In selecting a donor we had a choice of about 20. The clinic nurse recommended a particular donor as a good physical match, who also happened to be a similar age to my husband. He had children of his own and was prepared to be identified should the donor conceived children be interested. Feeling reassured we asked about how often the donor is used, and were told that although the clinic had a limit of 10 families per donor, this limit was rarely achieved. At this point we decided to go ahead with treatment, and again felt very grateful to be able to use the same donor for our second child.

When our son was about 2 years old I realised that the information held about the donor was not legally protected, and that if clinic policy or the sympathetic counsellor were to change, our children's identity may be lost. At this point I contacted the counsellor and requested as much information, including about any half siblings that the clinic was willing to release. To my shock, I discovered the donor lived locally, had been used for 11 families (many local to this clinic), and that there were 17 other children, including 11 born within 6 months of my daughter. The clinic counsellor requested the donor to come in for an updated interview and then the additional shock was the donor himself has seven children. Fortunately our donor did not retract his willingness to be identified given the large number children conceived using his sperm, and he gave a more complete picture of his work, interests and medical history.

As an active member of the donor conception support group, I had edited our newsletter and included a phone number for contact. To my great surprise I received a call when the children were aged about 8 and 6, from a person who I quickly realised was our donor, requesting that the children should meet his mother who was out from overseas, given that she was their biological grandmother. I felt very apprehensive about being contacted in this way, as our children's understanding of the ramifications of being part of a donor conceived family was still fairly basic and they certainly viewed my husband's father who had looked after them since they were small as their grandfather. I was also uneasy about the fact the donor knew our phone number, possibly our address, and I didn't even know his full name or what he looked like. I contacted the clinic to set up an urgent meeting with the donor where the counsellor could be present to establish some basic ground rules.

The meeting was excellent, with the donor agreeing that he would respond to contact but not initiate it, and reassuring us that he respected our privacy as a family, but was acting in what he thought were the best interests of the children. I feel the benefit of having the counsellor there cannot be overstated. She was an excellent mediator and

sensitive to all our concerns and was able to provide neutral territory, which left all of us feeling very positive. We exchanged contact details so that it would be possible to follow up in the future rather than having to go through the clinic.

Unfortunately the clinic was subsequently privatised and then changed hands again, so I am very grateful for being able to obtain that information when I did. The status of their records ( and record of their identity ) is uncertain to me but I know they have no legal protection. The counsellor also had her hours reduced and was told she could only see people prior to and during treatment. She did not agree with this change in philosophy and no longer works as an infertility counsellor.

Over the years I have had some email exchange with our donor and a further phone call when he googled me and rang me at work. I have discovered that he has continued to donate to a couple as a known donor, and that he was also previously a donor overseas before coming to Australia. It would seem that my children have many half siblings and that consanguinity is a real potential issue. In discussing this with my children I have suggested that were they to get into a serious relationship, they may wish to do DNA testing to ensure it is not consanguineous.

Raising our children has been the most meaningful part of my life and I feel incredibly grateful for the opportunity to do it this way, and to the donor for being willing to help. As they are now teenagers it has been really important to be able to share information including identity about the donor and at this stage it appears that is enough for them. They are very curious about half siblings, and would certainly like to know more, but were also surprised about the number of families used. When asked, my daughter said she thought the donor should only be used for one family, and they have identified that they are as closely related biologically, as their cousin is to his half siblings from a second marriage.

I feel very strongly that a persons identity should not be known only to a third party (ie clinic) who may or may not care to reveal it and may or may not preserve the record. There needs to be a national register where the donors identity and the identity of all conceived children (including his own) are stored. This should be with an independent body rather than a clinic and must have the capacity to record donations from the same donor that may be made at multiple clinics. There should be no more than 5 families per donor , but the limit should be based on families rather than number of children to enable a donor conceived child to have full siblings.

Counselling is essential and should be available to any involved party at any time. Donor conception is an ethical maze, and requires very careful navigation – the potential for serious harm to our most intimate relationships and our mental health is great and independent counselling is the only safeguard we have. In this day where social networking sites abound it is possible to locate people very easily and more than ever we must have access to professional support. Without the support of the counsellor when I was tracked down and contacted by the donor, our relationship with him may have broken down to the detriment of our family.

In summary there needs to be a national register protecting offspring identity and making non- identifiable donations illegal, freely available expert counselling and a limit on the number of families per donor. With these safeguards in place, donor

conception can be a fantastic way to have a family.