

Submission to the Review of the Assisted Reproductive Treatment Act 1998 (SA)

My name is Natalie Parker and I was an embryo donor in NSW, although I feel that my experiences are also relevant to the South Australian embryo donation process. My experience has illustrated that the NSW legislation is flawed and contains 'loopholes' that enable consumers to 'dodge the system'. I would like to point out these flaws so that South Australia can provide a more robust and reliable system of governance among Assisted Reproductive Technology providers.

My husband and I had 3 embryos left from an ART procedure in 2011 and found a couple to donate these embryos to via the Embryo Donation Network. We completed the donation process through the recipient's ART provider in NSW in late 2014. I was contacted by the clinic at the end of 2015 to be informed that the recipient had two embryos transferred which didn't work and they had decided not to use the remaining embryo.

This contact was made via a phone call (no follow up written correspondence) and in the meantime I found out that the recipient had a child who would have been conceived at the same time as the embryos were transferred to her clinic.

We had made an agreement with the recipient couple during the mandatory counselling sessions with the clinic regarding further contact and I felt completely disappointed that this agreement was not being upheld. Therefore, I contacted the clinic straight away to ask why I had been told that the recipient had been unsuccessful when I had evidence to prove the contrary. The clinic's quality compliance and risk manager informed me that the recipient had told the clinic she experienced bleeding after the transfer of the first two embryos and therefore was not required to come in for a blood test to confirm if she was pregnant or not.

From my understanding, record keeping is an important issue that has been identified in the Assisted Reproductive Treatment Act 1988. As stated in Fact Sheet 7;

"Records may provide information about the types of treatment applied, and the treatment outcomes – for example, the number of cycles of treatment a person undergoes, and whether there is a successful pregnancy and subsequent birth of a healthy child."

Based on my personal experience, I feel that there was not sufficient record keeping because the clinic had no strict guidelines to see the process of my donation through from start to finish.

As it stands, the remaining embryo is still in limbo somewhere after the clinic's quality compliance and risk manager told me that a follow up was on her "list of things to do". I have since not been notified of what the clinic have done with the third embryo or what the options are.

The clinic relied on the honesty of the recipient instead of a medical procedure (blood test) to prove or disprove whether a pregnancy had occurred. As a donor, I was required to provide a full blood test to prove my health, they did not just take my word for it.

I was also informed by the clinic that the information we had provided for the NSW Donor Registry had not been passed on because the clinic had not been notified of a successful pregnancy. I feel that the clinic was being sympathetic to the recipient by not requiring her to have a blood test, however this has been at a cost of considerable angst to my family and I. Furthermore, my understanding of the ART Act is that it is designed to protect, amongst other things, the interests of a person providing a gamete for use in ART treatment.

I am very concerned that this may have happened to other people in the past and has the potential to happen in the future. Had I not searched for my recipient on social media after finding out that she didn't want to use the remaining embryo, I would have never been aware that a child which according to the medical director of the ART provider "is very likely a product of the embryo donation based on dates etc." There is even less chance for children on anonymous donations being able to access their donor's details if they haven't been passed on to the central register.

I note that a donor registry has not yet been established in South Australia. In relation to my personal situation (which may well be more common), one could question the integrity of a system that relies so heavily on honesty rather than evidence. What is the point of having an accurate register with partial information? In my opinion, it is up to policy makers to objectively ensure that the sufficient details are recorded and procedures are in place to maintain this.

I am writing this submission so that updated legislation can prevent events like this occurring in the future. Donor conception is a very complicated procedure and affects so many stakeholders and extends in to the future. Some clinics also opt not to offer this because they see it

as “akin to adoption”. However, in adoption there is a physical child exchanged at the end of the process, there is no relying on the honesty of those involved. Furthermore, there has been stronger legislation put in place that ensures adopted children have access to information about their genetic background included in their pre adoption birth certificate.

I recognise that the South Australian A.R.T. Act 1988 has identified that the welfare of any child born as a result of assisted reproductive treatment is of “paramount importance”. Therefore, based on my personal experience I see it as crucial for tighter legislation to maintain accountability and accurate record keeping in the future. It is the responsibility of policy makers to ensure that foreseeable risks to the child’s welfare are removed by creating guidelines that are over arching.

Thank you for the opportunity to share my experiences that will be taken in to consideration when updating the Assisted Reproductive Treatment Act. I trust that the committee will make a decision that prevents loopholes within the system and provides the best outcome for the child.

