Submission for Federal Inquiry into Donor Conception Practices

Background

My husband was diagnosed with Klinefelters Syndrome during his teenage years, and one facet of this condition is having sperm which are immature or non-existent. As such from the time of meeting my husband-to-be it was clear that if we wanted children, we would have to pursue alternative conception options.

Once we became engaged and prepared for our wedding, we joined DCSG so that we would gain a better understanding of our options and the implications of becoming parents of a child conceived with the assistance of a donor. We found the Donor Conception Support Group to be invaluable in helping us to understand what lay ahead of us, and how essential it is to be open and honest with any children that we may be lucky enough bring into this world. Unfortunately this point of view was not widely accepted amongst some of our family members.

We found a very strong point of view amongst the older generations of our family who believed that under no circumstances should we tell our potential children of their true biological history. While this saddened us, it would in no way deter us from our belief that it is a child's right to understand their heritage. Having said this, we were stunned that the current legislation surrounding donor conception only serves to support the point of view of the older generation and reinforce that donor conception should be kept hidden and donor offspring should have their rights ignored. Why when we have come so far in supporting the rights of the adopted children to know their biological heritage should this be the case?

Experience with the clinic

After 3 years of marriage we started on our journey to have children with the Westmead Fertility Centre. Our experience with the clinic was a positive one where we found all the staff to be very professional. Our initial meeting with the counsellor was very short as we were regarded as well prepared given our membership of DCSG and time spent thinking about how we would tell our child / children of their conception.

Our choice of donor was made from 3 potential candidates and had to be based on an extremely limited amount of non-identifying information. We were made aware that the donor had donated 10 years prior and that we were the 10th, and most likely the last, family to use his sperm. We were not told how many children had been conceived using his sperm but we were naturally concerned about the potential number of offspring in the local area and their chances of meeting one another in the future.

We conceived our first child after only one round of insemination and were overjoyed when our son, “J”, arrived in mid 2002. In 2004 we decided to begin our journey for a second child using the same donor. This was a considerably more difficult process as we had no success with 4 rounds of insemination and due to a very limited supply of sperm were told that we would need to move onto an IVF program. Our first attempt at IVF failed, our second round was cancelled due to hyper stimulation and then our world cam crashing down as we embarked on our third attempt. We were told that we could not continue with our IVF treatment using or current donor’s sperm as the release of the draft guidelines from the NHMRC in late 2004 prohibited the use of anonymous donors:

> *“Persons conceived using ART procedures are entitled to know their genetic parents. Clinics must not use donated gametes in reproductive procedures unless the donor has consented to the release of identifying information about himself or herself to the persons conceived using his or her gametes.”*
> ***Ethical guidelines on the use of assisted reproductive technology in clinical practice and research 2004 (as revised in 2007 to take into account the changes in legislation)***

While we agreed with this change for the future, the impact of being told we could no longer pursue the expansion of our family in the middle of an IVF cycle after many months of treatment had a devastating impact at a personal level.

Our obvious question at this point was whether the clinic had any success in tracking down our donor and if so what was his feedback regarding his anonymity. It was at this point we gained a glimpse into the process of the Westmead Fertility Centre’s policy for tracking down donors. We were surprised to find that it was the lab assistants and scientists job to track down the donors rather than the counsellors. We felt that this method was less likely to generate success given that counsellors have the most appropriate training for this job. Contacting donors was perceived by us to be a very low priority for the scientific staff who had many other demands on their time. Ultimately we were told that the centre had gone to the extent of using the electoral role as a means of finding the donor and that we couldn’t expect the centre to do any thing more. Our impression was that the task was made all the harder because the donor had quite a common name. We are still confused as to whether the donor was ever contacted or not as we never received a direct answer to our question.

Fortunately the clinic worked through all of the changes to the guidelines and determined that because it was a second child, we were allowed to continue to use the same donor sperm as was used for our first child. We became pregnant on that third round of IVF and now have a beautiful healthy daughter, “A”, born in late 2005.

Health

During my second pregnancy my son, nearly 3, was rushed to hospital in an ambulance after suffering from extended episode of convulsions concentrated down one side of his body. This caused substantial concern amongst the medical staff. Many tests were conducted, everything from MRI’s to spinal taps. As would be expected, the hospital staff asked for a comprehensive family medical history. It was at this point we discovered that we had an intellectual understanding of what we had done when we decided to use an anonymous donor; however, nothing truly prepared us for the reality of our decision. Being unable to give a comprehensive medical history made us feel helpless as we could not provide all of the pieces of the puzzle to help our son.

We were lucky in that instance as “J” recovered completely and is now a happy healthy boy. When we pursued the medical history of our donor through the fertility centre we were told that there was very little information on his file and that staff were sceptical due to the lack of details. This lack of information causes us great concern and we feel that it is fundamental right of donor conceived children to have access to their complete medical history. An additional facility that allows donors to update their medical details would be welcomed.

The future

We now have two very intelligent children who are constantly questioning everything that they come across. Aged 8 years and 4 years both have been told that they are here because of the generosity and help of another man called the “donor” and both have accepted it at face value. As yet there has not been any concern or questions, however, the time will come when they want to know “why they aren’t like dad”, how they should answer the questions at school when they cover genetics or how many half bothers or sisters they might have.

As parents we want our children to be comfortable with their identity and where they have come from, particularly as they go through the challenging teenage years.

It has already been acknowledged that donor offspring conceived after January 2011 have the right to identifying information regarding their donor. These same rights need to be extended to offspring born prior to this date.

We experienced the high level of professionalism of the doctors and nurses at the Westmead Fertility Centre who pride themselves on their ethical application the NH&MRC guidelines without question. Our question is “why do we not see the same ethical duty of care regarding rights of the donor conceived offspring that have already been born?”