I am writing in response to the Senate enquiry into donor conception.

The following opinions are based on my experience:

- As a recipient of donor insemination in 2004 and subsequently having two donor conceived children through the Queensland Fertility Group.
- Of donating eggs to an unknown couple through Queensland Fertility Group.

## b) The conduct of Clinic and medical services:

Initially I chose another donor but on the day before IVF I had to call to confirm my egg pick up and was told they had run out of sperm for that donor and I had to decide on another. I felt that this was short notice and was disorganised on behalf of the clinic and that the clinic had failed to contact me regarding this.

#### i)Payment for donors.

Using the same clinic in 2008 I became an altruistic egg donor. The payment covered my expenses however I felt there was contradictions in the payments between men and women. Men are paid and women are not able to be.

# iii)The provision of appropriate counselling and support services.

Due to the emotional and desperate roller-coaster that I experienced during IVF treatment for my own infertility I did not ask during counselling about other recipients receiving the same donor. Furthermore, when donating my eggs I suffered serious health complications due to the fertility drugs. These issues were not addressed through counselling despite these having a significant emotional impact on me. I suggest that counselling and support services may need regular up-to date training in order to assist clients make informed decisions.

During my donation of eggs, counselling was mandatory to myself and to my partner. It was policy that my partner had to attend counselling as a part of this process but it was difficult to access due to having to travel a lengthy distance from a rural area, my partner working full time and the demands of caring for our own children. Luckily, the clinic arranged telephone counselling for my partner to take place which was positive according to my partner. The clinic advised that this wasn't usual practise but perhaps this should be considered as a possibility in order to assist access.

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

At the time of receiving donor insemination I understand there was no legislation that limited the number of families to receive the one donor. As a result ten families in a similar area as myself received the same donor resulting in over thirty-two children being born in 2007. I do not know of any further children being born however it would appear as most of these 10 families had young children more would of been born since. I understand that legislation has positively changed since 2004 and it is now limited to three families. However due to past practices by Clinics and a lack of regulation, my children in the future will have a significant number of people that they will have a genetic link with in the area they grow up in. This increases their chances of consanguine. An establishment of a registry for donor conceived children will assist in addressing these problems.

Furthermore, whilst being a donor I became concerned about the number of connections my children already had through donor sperm and the possibility of them having more genetic links through donation. As I did not know the recipients of the eggs I expressed this concern to the clinic. I needed reassurance from the recipient that they would eventually make contact with our family in order for my children to know their identity. The clinic advised me that they were going against their policy but would contact the recipient and ask their views. I therefore had to rely on the recipients word who would of agreed to anything at that point due to their desperation to receive my

eggs. In hindsight this needed to be addressed more formally prior to treatment.

## d) The rights of donor conceived individuals.

When donating eggs I became concerned that the recipients beliefs and culture may be opposed to my own. Consequently this may have caused the donor conceived child/children to have a negative genetic reference and contact. I believe this could be addressed by the donor and recipient exchanging letters via the fertility clinic prior to donation.

I believe that it is important for my children to know their connection to others in order to form a healthy and positive identity. Children's self reference comes from others and will shape their identity in adulthood. These beliefs underpinned my behaviour when in 2007 I rang Queensland Fertility Group and enquired about other children born using the same donor as my children's. I wanted to know how many children my children had genetic links to and to send a letter to be noted on my file that I was open for contact from other families who had the same donor and also to the donor. I was regarded with suspicion and this information was difficult to obtain. I have since sent this letter however have learnt that it was ignored. Realising that the QLD fertility Clinic would not assist I registered on a website called the Donor Sibling Registry. Registering on this website was worrying as I did not know if it was credible and was exposing information about my children over the internet. I felt a government registry would have been more appropriate and regulated however this did not exist in QLD.

I have since made several contact visits with another family who also registered for this website and had received the same donor. This has been a very positive experience for my family. During contact the mother of family informed me she also wrote a letter to the same fertility clinic requesting contact with other families however she was told no other families had made contact. I am appalled by the Clinics subsequent conduct in providing services to donated children despite their hand in making these genetic linkages with children and possible consanguine relationships. I now realise that fertility clinics are a business and unless closely regulated will not provide any moral or ethical response to donor offspring.

I hope that this assists with your enquiry.