Submission to: The Legal and Constitutional Affairs References into the Past & Present Practices of Donor Conception.

From: Lynette Mason - New Zealand

My name is Lynette Mason. I am the oldest mother to conceive two children by egg donation in New Zealand. I am now 61 years old, and my son and daughter are 8 years old and 5 & half years old respectively.

The children I now have due to egg donation have known their egg donor from the very beginning. We speak of donor mum freely when ever the occasion arises. She attended early birthday parties. She has three teenage children off her own. We welcome the contact and friendship with her and her family. Being open is paramount to all parties.

Husband's Sperm Donation:

My husband was a sperm donor in Hamilton New Zealand in the mid 1980's. The giving at the time prompted by me, made us feel we were helping others to have a family, following our own personal tragedies of trying to have a family. We were then forced to proceed with our lives for the next 7 years believing we were unable to have our own family.

Now some years later, and following IVF treatment ourselves, we both understand the implications of anonymous sperm donation. All my husbands' donation records were destroyed by the practicing doctor on retirement. This is a tragic circumstance, which leaves no trace of sperm donor number, and of any sperm recipient matches, or if or how many children were conceived.

• At the time following our own IVF treatment, and wondering if in fact there were offspring trying to make enquires/contact my husband and I agreed to make every effort to make his details available from whatever avenues were open.

I am the contact person for the 'Donor Conception Network NZ' and an advocate for the donor conceived in New Zealand born prior to the implementation of the *Human Assisted Reproductive Technology* (HART Act) which came into place 22 August 2005.

Post the HART Act requires that all records are to be kept, and births reported by clinics to Births Deaths and Marriages within the Department of Internal Affairs.

Attached to the HART Act is the voluntary HART register which caters for donors/offspring born prior to the Act.

• It is my and others view that those who register on any voluntary register where records are minimal should have made available to them DNA testing funded by government and for this to be kept on record in the register.

• Many donors are now nearing retirement age or have reached retirement. DNA would be the only way to verify a match if either party became deceased, or where records have been destroyed.

Payments for donors

In New Zealand there is no cost to donors for any of the tests or appointments with the doctors or counsellors. Travel expenses for coming to the clinic's are reimbursed at \$30 per visit. This is paid after the final "clearance" blood test. The HART Act has substantial penalties (fines and imprisonment) for paying for, or providing financial inducement for, donor sperm. This excludes reimbursement of travelling expenses by the clinic.

• I agree with these guidelines, as if there were substantial sums paid out to donors, the principal of the donation would be lost.

Management of Data

I have carried out many hours of voluntary research into the whereabouts of retired, or shortly to retire Doctors who had used DI in their practice throughout NZ, making contact with them, to establish where their particular records were being held prior to the HART Act.

- From these investigations, it was clearly established that the Doctors practicing early Donor Insemination (DI) work had no formal guidance as to what to do with the records they were still holding or what to do with them on retirement.
- It is imperative that doctors are informed of their moral obligations to have their records preserved for a minimum of 50 years ideally indefinitely.
- Those that destroyed these precious early records gave anonymity as the reason for destruction. The work to save old DI records is ongoing.
- All data/records should be held by (handed over on retirement to) a national entity where registers have been formed.

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

I feel numbers should be restricted to a maximum of no more than 5 families. By keeping true and appropriate record keeping the future issue around consanguine relationships should be minimised, compared to inadequate records and information of the immediate past being open to disastrous consequences.

The rights of donor conceived individuals.

It has become highly apparent through my voluntary work in this field that denying identifying information to offspring relating to their donor and half-siblings is very soul destroying to individual's world wide. Many past anonymous donors, now realizing the implications of their past donations wish to be made known to their offspring.

- Donors/Donor offspring and parents of offspring should have a national voluntary register, including DNA testing for accuracy in linking.
- All records relating to the donor conceived should be made available on request at age 18, or earlier with agreement with their legal parents.
- The denial of the human rights of donor conceived children to know their true identity must be addressed from all perspectives and rectified.
- Ones genome is part of ones very essence of life; it cannot be rewritten or edited.
- It is as useless to deny ones genetic origins as it once was to say the world is flat.

The donor conceived has the right to 'the rest of their life's story' - their genetic heritage. They want to know their story and resolve their life equation of chromosomes -X + Y = Them!

Openness Honesty and Integrity to all parties concerned must prevail.

In all instances, to obtain a persons sense of identity there must be full transparency.

Secrecy does not support the stance that it is morally right to lie to children about their family history and their genetic heritage.

The importance of openness and honesty in adoption has taught us that keeping family secrets from the adoptee is a time bomb that can be destructive of family relationships. In contrast openness and honesty enhances family relations. The same applies to DI.

The NZ adoption reform movement began in 1976. People came from a wide range of backgrounds, skills and professions and empowered Reform. In 1881 the 'N.Z. Adoption of Children Act' was the first in the British Empire.

The practice's associated with donor conception has been lagging behind miserably the reforms of adoption for many years.

Provision of appropriate counselling and support services

• Counselling for donor, offspring and also parent/guardians where appropriate should be supplied by an appropriate counsellor in the field, as this is an important part of the connection process.

In Summary:

.

Many of the issues being faced in the field of donor conception by countries world wide – are of a similar circumstance.

There must be leaders/government representatives prepared to come forward in this field and work to unite as a world wide force to openly communicate and correct all the issues surrounding donor conception.