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Because of the stage at which my daughter is at in seeking her donor and half siblings she has asked for privacy and therefore for our names to be withheld.

Thank you for allowing a late submission. While living & working in Perth I received donor sperm. I begin by acknowledging and thanking the donor for his gift and my precious children.

Please may I have permission to open with a **mihi (Māori introduction protocol at any forum or gathering which always acknowledges the importance of ancestry, heritage and sense of place /tūrangawaewae).** I was brought up where 90% of the people were Māori.

Kia ora e ngā hau e wha	***Greetings to people from the 4 winds*** *(across country / world)*
kua haere mai nei	***who have gathered in this forum***
ki tēnei huihuinga	***to learn and share, under the umbrella of***
o tēnei wanaga o te ***Senate Inquiry into Donor Conception in Australia***	
ka nui te aroha	***We do this with love***
mō tō koutou maia	***and strength***
ke te huihui mai	***as we "assemble"***
ke te awhina	***and support each other***
i ngā tikanga	***respecting the protocol and customs***
e pa ana ki tēnei wahi	***of this place and forum***
[redacted] nga awa	[redacted] ***are my rivers***
ko Moehau te maunga	***Moehau is my mountain***
ko ss "*Vittoria*" te waka	***ss " Victoria" is my canoe (steamship my family came to NZ)***
ko ngāti [redacted] tōku iwi	***My "tribe" (regional identity/ancestry) is*** [redacted]
no te Puaha o [redacted] ahau	***My ancestoral grounds are in the*** [redacted] [redacted]
ko tōku tupuna, moe mai, moe mai, moe mai	***I acknowledge & honour my ancestors***
i nāinei e noho ana ahau ki (*place*)	***I now live in*** ________________
ko (*my name*) ahau	***My name is*** ________________
Ka mutu noa iho ngā kōrero no tēnei wā	***I now conclude my mihi***
No reira tēnā koutou, tēnā koutou, tena koutou katoa	***and offer my thanks to you all***

(Note: Usually my parents and children would also be mentioned by name)

Reason for Making Submission

At 5pm on Saturday 18 September 2010 I received a phone call from my 20-year-old daughter, who is at university, to say she was coming home for a few days. I assumed she meant as soon as she could get the usual cheap airfare, and just needed a break.
When she told me she would be arriving at 8.30 that night (a 75 minute flight) alarm bells rang.

My daughter had recently discovered that we had been "sold" a lie and she was devastated

I sought professional ethical advice and consequently was made aware of the Senate Inquiry into Donor Conception in Australia, and urged to submit.

I have always been absolutely honest with my children, about the circumstances of their birth. And, when I didn't know answers to their questions I wrote to the clinic. In 1988 when I chose my donor I was specifically told at Medical Centre that they used sperm for a **maximum of five families only per donor,** and that I was the fifth.

In 1995 I wrote to Medical Centre to ask for details of children in the other families, as a result of my children's queries. I received a **reply** (copy submitted confidentially) from **, the owner** and medical director of the clinic listing the non-identifying details of the children and families summarised below:

> **Nine children** had been **conceived from the same donor** (including mine)
>
> These children are in **5 families** (including mine).
>
> The **first children** born in each of the other **four families** were **born in 1988**.
>
> **Families 1 to 5 were specified** (not named) including children's **sex & year of birth**

My children, though still young, were really pleased to have this information and I gave them each a copy. It was **important for them both to have these details.** I was happy with the response from , at the time.

Voluntary Register, Department of Health, WA

My daughter is on this register. Her brother has chosen not to – not for any particular reason, he doesn't have the need right now. I respect and support both. The people at the WA Voluntary Register have been wonderful and easy to communicate with.

Good News: My daughter recently received a letter from the register with good news – that the **parents of a half sister had previously registered** and now that my daughter's sister was over 18 they were awaiting new papers to be signed before information sharing could commence. It was especially reassuring to know that the family of a half sibling have been totally honest about conception circumstances and made it a priority to register before the child was an adult.

The Crushing Blow

Also in that letter was *"**updated information** from Medical Centre about **other families created from the donor** used in your conception".*

There are **nine families (not five as told)** and **nineteen children –** more than double the original half siblings. We had, of course, accepted the possibility of any of the five families having more children, but not this.

The 9 Families

Two families had their first children in 1987

Five families had their first children in 1988

One family in 1990

One family in 1991

Nineteen children born between 1987 and 1992 and most brought up in a small city, Perth.

Chances of consanguinity? I consider this irresponsible and absolutely unethical and a breach of human rights.

We have been deceived and betrayed by Medical Centre

Consequences for my Daughter

She was **crushed, and shocked** that it was possible that there were **no procedures, processes or audits in place to prevent such a lie** about her personal heritage. I had taken so much care all their lives to be so honest and **a doctor who owned and ran a business could destroy all that**, with no apparent accountability.

Her first phone call **"*Mum, I now feel like I have been factory farmed".***

Next phone call **"*I am so glad I didn't go to school in Perth or Western Australia".***

Phone call before flying home at short notice **"*No wonder the donor isn't on the voluntary register. He has a tribe and probably his own children as well."***

Consequences for Myself

This is an **invasion of my mana** (a Māori word used regularly in New Zealand – there is no word in the English language to translate – a group of words together may attempt the meaning of **"*mana*":** *whole being, integrity, honour, principle, character, fair-mindedness, wholeness, scrupulousness, wisdom, spirituality, holistic, standing/respect in the community or family or forum*).

I believed I had a responsibility to my children to have the correct information and to share all of that with them and that they should be the owners of the knowledge.

robbed me of this commitment to my children.

Counselling for my Daughter

Before my daughter registered on the voluntary register she **met with a specialist counsellor** with years of experience in this field (and many successful outcomes). She has much respect for him, his principles, his ethics and his holistic and honest approach. My daughter was in a different city, to him, when she learnt that we had been feed a lie. She has since been in touch with him. They will meet after her exams. Meanwhile she has sought help from a (non-specialist) doctor at her university.

Conduct of Clinic

Patient vulnerability

People who use assisted reproduction clinics are very vulnerable and the **"power" is all with the clinic.** It is **especially so with those requiring donor assistance**, because of the shortage and waiting lists. It is not a place that most people would choose to be. It is far more fun, less time-consuming and less expensive to conceive children naturally.

Breach of Ethics

A few days before my second IVF attempt I had completed a **“consent” form** choosing one of several options for **excess eggs**. I felt and I know others did too, a lot of **pressure at , to donate** to either their research or to other couples.

One option was to have the eggs destroyed. At the time, and with surgery in a few days, I felt I was not in a position to remove myself sufficiently to consider the implications of donating. **My eggs are part of me, my ancestors and my family** and a donation like that requires more consideration than merely dropping $5 in a bucket. I therefore **chose to have my eggs destroyed**. I was **never given a copy of anything I ever signed at**

As a family we always pass on good fortune. I was mindful that I had been **fortunate to be given donor sperm**. However, I do feel I have the right to make decisions in my own time and without pressure, and consult those whom I respect. I already had eggs or fertilised eggs stored and I was even having doubts about my decision to do that.

As I waited in the area just outside theatre, and **after my pre-med,** who was the doctor rostered to perform the procedure stood next to where I lay, **holding the consent form I had previously signed, and pressured me into changing my mind** (this scene has never left me). As a result, **I altered my original decision** from having my excess eggs destroyed to donating them.

When I came to **after surgery I was distraught and overwhelmed** by what had happened. I was still **sure I did not want to donate eggs.** This consumed me. Despite feeling groggy I got up

at dawn the next day and went into to put a note under his door, to ask him to destroy the eggs. I felt lonely and betrayed. Trust and respect had been abused. I never received an apology.

Soon after, by sheer coincidence, I found myself sitting on a ferry (on the Swan River) next to a medical ethics expert from Monash University, who was visiting WA. I was fortunate to be able to share this experience with her.

Donor Sperm, Eggs/Fertilised Eggs for Research

I don't believe that should have been allowed to **ask patients to donate sperm or eggs to their research.**

Patients pay for treatment at because **they want a child, not to support a research facility.** I do have **reservations about a clinic's laboratory being used for both human assisted reproduction as well as research.** This donor material **has the potential to be around for hundreds of years** and this could have **repercussions for my children** (their donor half siblings) and their descendants. A strong line should be drawn in the sand with **nationally recognised protocols.**

I have no problem with a clinic collaborating with or funding research at universities.

Staff at Medical Centre

I found all other staff to be professional, helpful and kind. In particular my doctor, and nurses were absolutely amazing. In fact went beyond the call of duty. Soon after my experience above I made an appointment with to tell him that I was done with . He generously offered to come in to to do the procedure (3rd attempt) regardless of whether he was rostered. This attempt was successful.

Written Requests for Information from

When I wrote asking for information I have always found to be very helpful.
At the time I had no reason to doubt the letter from in 1995, outlining the five families from the same donor.
At one stage I wrote asking for a list of all the drugs that I had taken or been injected with (I needed to know to become a blood donor). I received a reply in good time with all the drugs listed and I did appreciate the time involved.
In 1999 there were several questions from my children that I was unable to answer. eg the donor must be musician as they were, because their mother is tone deaf! I wrote to with these questions and asked if they would mind writing a personal letter to each child in their own personally addressed envelope. We really appreciated that did this and I still remember my children sitting on the couch together holding their letters and comparing notes.
They treasured those letters.

Māori Culture

Our family is not Māori but I was brought up among Māori

There are **many things in Māori culture that are relevant to this discussion,** for example

Māori have always practised open adoption with no problems

Secrecy about genetic origins is something that would totally cripple Māori culture.

Māori, whenever they gather they honour their ancestors

(e.g. mihi as at the start of my submission). They recognise that **they are who they are because of their ancestors**. Does anyone have the right to veto this?

Māori have a word for family "whanau", now commonly used by non-Māori in New Zealand.

It can mean your immediate family, or distant relations. It doesn't matter; they are all important and welcomed unconditionally. As a young Māori woman said on TV recently ***"we're not just two parents and two children, we're all family*".** I feel this is a good example of how important it is for siblings of donor conception to know each other and to know the donor. They may not all be close, or have a lot in common, but at least they own their knowledge and have no missing pieces. **These young people did not ask to be born into a giant jigsaw puzzle.** We have responsibilities. **We must listen to them, the young, and the lateral thinkers.** We must get it right.

Turangawaewae or home ground, a very important concept for **Māori.**

It would not be possible to be Māori with secrecy surrounding a donor. **Māori must know where they come from, their tribal land.** With secrecy it is not possible to know their home ground. They can live anywhere in the world but they always know their home ground.

I have never lived on or owned the farms associated with my family in but that is the locality that determines the root of my culture, who I am. I have been there; my children have been there. We were happy to meet the people but we had no desire or need to move in with them.

Why should my daughter only know half her picture?

Animals are genetically programmed to return to their home ground

How is it that godwits know to fly 11,000 kilometres every year from the same Alaskan tundra to the same river estuary in New Zealand? Why don't they end up at other river estuaries that other godwits are going to? And how do they nest in the exact same Alaskan tundra every year, an area covering many hundreds of kilometres? They know their "village", they know their "culture". Like humans they even have food associated with their places. We consider humans more developed, yet we deny the need of humans to know their home ground by allowing secrecy surrounding donor conception.

Would I have donated?

I would certainly have been open to seriously considering it, but only if it was totally open and no one was left with missing puzzle pieces. I like how open adoption happens in New Zealand and I would have wanted to meet any recipients and also be able to choose them. I would have had no interest in being the child's "mother" but I would have always acknowledged my responsibility to a genetic offspring of mine.

A young woman I know chose the parents she would adopt her child to, and she continued on with her university studies. They are the parents but she has the child occasionally and so do her parents, the grandparents. This child has a wide family, no one is interested in "ownership" and the African saying "it takes a village to raise a child" is truly practised. I think my experience of going through assisted reproductive treatment at the clinic makes me more open to donating. I definitely think it is a decision to be made after I have had my family. I would not have wanted money.

Would I have been a surrogate mother?

Because I enjoyed being pregnant and was radiant in that state I certainly would have considered carrying another couple's child, but only for someone I knew, like a sister or a friend. I would not have wanted to be paid, other than help with pregnancy-related expenses.

Would I encourage my son to donate?

If I was asked, my reply would be:

- Only if it was completely open and transparent for everyone
- Only after he feels he has completed any family he may be considering
- Only if there was no puzzle missing surrounding his own conception
- I would point out that I would find it essential that he tells his own children early
- Only if there was no payment involved

What if a donor sibling, who has not been told of the circumstances of his conception, goes on to donate? It's a can of worms. The longer the deceit continues the bigger the can.

Some Things I Found Out in Waiting Rooms

A couple had a successful pregnancy with the donated embryo of a couple who at the time had not had a successful pregnancy.

Another couple found out the identity of the donor (Perth is a small place) before they conceived

Quote from a recent court case

"*He had recently found out he had half sisters he did not know about and this unexpected news had led him to behave in that way".*

It is quite obvious when people find this information out as adults, whether by donor conception or otherwise, it is traumatic.

Conclusions

Change of Culture

There quite obviously needs to be a change from the culture of secrecy, secrecy about the donor, secrecy about the circumstances of a child's conception, and a sense of treating the whole donor conception community like "freaks". Many thousands of these children are conceived each year. They are entitled to openness, to transparency, to honesty, to have a voice. They should not be "sequestered". This covert culture was not created by them. It's a game they are not prepared to play. There are serious implications about UN breaches of human rights.

Biggest Secret Society on Earth

Anonymous donor-conceived people belong to the biggest secret society on earth, their only initiation ceremony – that they were born. It makes the free masons look tame.

How to Change the Culture

Research is necessary. It will depend on anonymous donors, parents who haven't told their children that they were donor conceived, and doctors who encouraged this culture coming forward. It will need to be done with compassion, understanding and discretion, and without judgement. It will need the availability of excellent and free counselling.

This should also be available to parents who regret, or are having second thoughts, that they have kept these secrets but don't know how to tell adult children without the fear of them turning against the parents. The same applies to donors who have not told their partners or their own children. I believe there will be people out there who could be having doubts and just don't know what to do, so far down the track. They don't want to "hurt" or shock their children/partners and probably don't know, that with professional and specialised counselling, there could be other ways to move forward.

Will donors "Dry Up"?

I don't think so, with a cultural change from a secret society to openness, altruism, generosity, public-spiritedness, benevolence, good will, humanitarianism, and a well thought out motto (in the manner of "it takes a whole village to raise a child"). A positive attitude that things can change for the better good is the start. I believe with this new culture the donors will actually increase.

Tadpole Lotto

I think the terminology needs to change. There are not many nice words associated with donor reproduction. Who wants to be a half-sibling? Isn't it better to have a sister, than a half a one? Māori don't have half relations. The words associated with the culture of secrecy, including lack of names, need to become positive and celebratory, but not patronising. My daughter, when she chooses to share the circumstances of her conception, never knows whether to call the donor – her donor or her father. Those two words could not be further apart. "Donor" could be someone funding a university faculty or it could be someone giving to the cancer society. A father is part of you. Other children have celebratory words surrounding their genetic history, why shouldn't donor-conceived children?

Ask donor conceived people to find better terminology

I believe the "children" of donor conception should be asked to brainstorm, possibly on line (after an identity check and by registering – to ensure their privacy and their own forum), to come up with more appropriate names than "donor", "donor parent/s", half siblings, etc.

Publicity in Western Australia

I understand that the Voluntary Register is carrying out advertising campaigns to advise of the existence of the voluntary register so that those born before compulsory records have a much better chance of making contact with donor, donor offspring or siblings. The ads should be the start of a new culture encouraging openness, transparency and honesty rather than secrecy and deceit. I am impressed with the efforts of the register, under current laws.

Education

I think there should be a national advertising programme educating people about the number of children conceived by donor sperm, the efforts gone through to conceive these children, etc

validating their place in society, removing the secrecy. Many of these young people are the decision-makers of the future and it is only courteous that they are given a voice, a proud voice. Care should be taken that the advertisements are strong and gracious, rather than anything "cute" and cheesy, like the some of the impotency ads.

Ombudsman

Why, if it is good enough for banking and insurance to have ombudsmen, is there no ombudsman for Donor Conception & Assisted Human Production? I ask for one to be appointed with urgency and that this person travels monthly (or according to appointments received) to each centre where there is an assisted human reproduction clinic. Each clinic must be required to hand all new patients, or potential patients and donors written information stating the existence of an ombudsman and contact details.

Audit of Clinics

The office where the federal government register is held should audit donor and donor recipient recording procedures and registers at clinics, including checking and matching with stored items. A federal audit should be carried out the month prior to any clinic closing down or being sold.

Birth Certificates

Birth certificates should contain the names of the parents and the donor/s. I don't believe there is any 'stigma' to a birth certificate reflecting the true circumstances of one's conception. What is really important in this regard is that no 'parent' will ever be able to hide the true circumstances of a child's conception.

Patient Rights & Responsibilities at Clinics

I believe all human assisted reproduction clinics should be compelled to give new patients and prospective patients or donors written information stating the rights and responsibilities of the patients/donors. These should be compiled by the Federal Register/Organisation and be consistent in all states. I would like to see this Federal Register/Organisation produce a poster with this information, requiring all human assisted reproduction clinics to display in all waiting rooms.

Retrospective Legislation

As withholding personal genetic information is quite clearly a breach of UN human rights laws, retrospective legislation should be implemented to enable donor conceived children to know the

name of the donor and to make contact. All clinics should be required to immediately hand over files to a national registry. They do not have the right to "own" the personal information of these children. At the same time it must be made illegal to destroy any such records, with very serious repercussions. I believe at all times protocols should be in place to ensure that any retrospective legislation has guidelines (such as compulsory counselling) to ensure respect and sensitivity to the donor, any partner and their children.

Tagging and Tracking Protocol of Donor Sperm, Eggs and Embryos worldwide

In this very small global village there is quite clearly a need for a worldwide uniform identifying or tagging system. I believe this issue is so serious it should come under the banner of the United Nations. It seems bizarre that there seem to be more standardised world-wide tracking systems for animal semen, eggs and embryos.

- This **protocol should start from the time the sperm, eggs or embryos are collected.**
- The data should be held by an impartial national register which should receive the details of the collection (i.e. quantity, all identifying details of the donor, allocated international number, name of clinic, where and how stored) within 24 hours. I believe this material should be signed in by 3 people at the clinic with their names typed below signatures.
- Any change in the above data eg change of storage facility, advised to the national register within 24 hours.
- When donor material is used national register must be advised, within 24 hours, what it was used for, who received it, what method was used, how much was used, how much is left.
- Reporting outcomes eg successful pregnancy tests and date and the name of relevant donor recipient, live birth and date, miscarriage and date
- All research using donor reproductive material should acknowledge the donor number as a courtesy, as a tracking record, and just as references are stated in reports or books.

- There should be 4 copies of all papers signed by donor and donor recipients with a copy to the donor, the donor recipients, the clinic and the national register.
- All documents signed by the above should be countersigned by the clinic or party requesting the signature.

- All these documents should be witnessed and I would believe it advisable that the donor or donor recipient sign in the company of a support person (I don't mean a lawyer).
- All names on these documents to be typed under the signature and also include date.
- Outcomes of any research to be reported to national data base and to the donors within
  7 days of knowing the outcomes.
- Donor and the other recipients of his/her donated sperm/eggs/embryos should be advised of successful pregnancies and births within 7 days, i.e. any change in status, outcomes or use of the donated material. This could be linked in to the Births, Deaths and Marriages register.

Prerequisite to being a donor

That his/her/their details are on the birth certificate and that their information will be made available to offspring when they are 16 or 18. That with the agreement of both parties contact can be initiated earlier. The donor/s is/are not the parent/s. That the donor tells his/her own children of half-siblings (a system for checks needs to be brainstormed – ie the national donor register being linked to births, deaths and marriages). Donors should not be paid.

Prerequisite to being a donor parent

is the obligation to tell all offspring, the true circumstances of their birth ie that the birth father or mother is not the genetic father or mother. No child/parent relationship should start with a lie. To withhold information that belongs to a child is, in my mind, theft. As parents we do not own our children or their genetic information. We are a vessel to nourish, nurture and love. Honesty and transparency are essential parts of this equation. The donor's details on the birth certificate would ensure this.

Voluntary Register WA

I believe the voluntary register, once it has the names of those conceived before 1993, should be able to make all attempts to find the donor and other siblings, and contact them and tell them that there are donor conceived children wanting to make contact.

The contact should be made directly with the adult children (not their parents as parents should not be able to veto), with the excellent counselling requirements that are already in place.

I think it is unsatisfactory to have laws where these young people, requiring their own genetic knowledge, have to just wait and hope that these genetic relatives will make contact. They should not have to go on national TV to find their donor, or the myriad of other exhaustive and expensive ways to acquire knowledge that they rightly own, and that others have access to.

I would also like the voluntary register to be able to pass on letters or other information the donor conceived children offer.

DNA

Prior to donating, both donor and donor recipients should be required to supply DNA to the national register, separate from the clinic.

Consanguinity

The 17 half-siblings of my children (plus any the donor may have) now aged between 18 and 23 could all be living in Perth. At this stage I believe only one of those 17 could be aware of her tribal clan. **They could have gone to school together, to university together, be working together, they could be friends or even dating each other. These people are related to my children**. I ask that, at the very least, they are advised of this situation. **This is a moral and ethic issue.** There is not much more than 2 degrees separation in a city the size of Perth.

Rights of the Donor's Children

These children have an equal right to know they have other siblings, especially because of the chances of consanguinity.

He does not want to know outcomes, so therefore his children will never be given a choice to know their half siblings.

Donors right to choose Donor Recipient or Veto

While, as a single heterosexual woman at the time of conception, I would probably have been vetoed by many donors I still believe in their absolute right to veto or set conditions for their donor recipients. This is the most important gift a donor will ever give away and as with any gift a donor has the right to choose who he gives it to. People who adopt out children are allowed that right and so should the donor be. I do not believe a donor should be made to feel out of order because of his/her choices. He/she is doing no more than consider the things we take into account when, say, we choose a partner.

How long should donor sperm, eggs or embryos be stored?

Other than families who are storing their own (usually through reasons of illness) I believe all this donor material should be destroyed within five years of the first pregnancy or when the donor dies (national donor registry should be tied in with Births, Deaths & Marriages). When you consider our tribe of 19 children from 9 families, it does appear that five years is adequate.

No Financial Claim Against Donor

While I don't believe anyone would consider such a thing I do think legislation should be in place to make this clear-cut.

Researchers using own genetic material

I have no problem with this as long as the same tracking and recording is used.

Owners of Clinics

As history shows, clinics close down and change hands. I believe it should be required by law that the reception area and website of every clinic clearly displays the names of all owners or shareholders in the business. I also believe that it is these people who are ultimately accountable. They are responsible for some of the most important transactions and record keeping on earth.

Baby in a Box

When my children were little babies I heard the story of a woman who as a baby was abandoned in a cardboard box, with a brief note and a blanket, on the steps of a London hospital. She could not begin to understand why no one had kept the blanket or the note, the only connection to her mother. She would have done anything to hold the note, to see her mother's handwriting.

This moved me to buy two beautiful cards (with several extra pages) and handwrite the story to each child, of their conception. I sealed it and put it away, just in case I died before I could tell them the story myself. To this day they treasure having my thoughts from that time, and explanation.

Politically Correct

When considering the review of legislation I would urge you to take into account that this is about ownership of knowledge, the knowledge of the identity of other people in the puzzle, the knowledge that comes from contacting/meeting them. It is not about ensuring close relationships or outcomes. We must be mindful that in families conceived naturally there are all types of people and personalities involved. Some are much closer than others. The same is inevitable in this process. Some meetings may result in "oh yeah" (i.e. I now know) and move on and others may form long and lasting friendships. For my daughter, I know that whatever the outcome with this first sister she is making contact with, there will be respect and consideration of differences and diversity – and our attitude of always seeing our cup half full (or probably more like full), rather than half empty.

I appreciate this opportunity, thank you.

I am Available to Answer Questions via Skype

Note: copies of two confidential letters sent by post