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**Submission re: Review of the Human Reproductive Technology Act 1991 & the Surrogacy Act 2008**

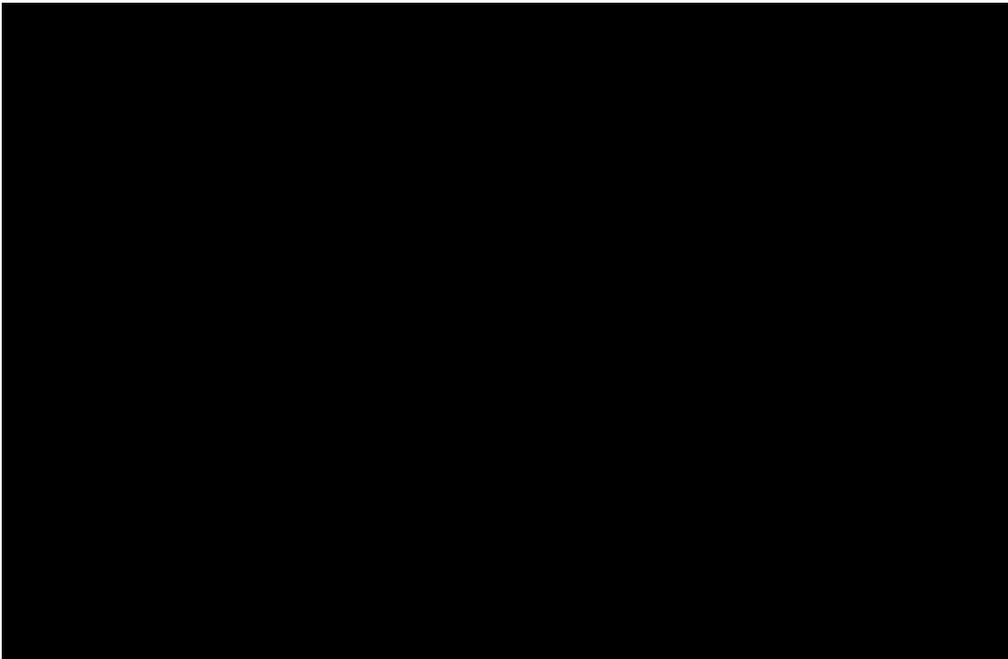
I was born in 1986 in Perth to a couple that found themselves unable to naturally conceive a child as my dad is infertile. I have an older sister, born in 1983, who has a different donor as the clinic that my parents received treatment from promised to reserve enough sperm from the same donor for a subsequent child, however they did not stay true to that promise. My parents, after great debate and angst, went against the stern recommendation from the clinic doctor, and decided to tell my sister and I the truth about our conception when we were in our early teens. We became an active family in the WA chapter of the Donor Conception Support Group (DCSG), attending support picnics and assisting with various donor conception rights movements. From as young as 12 years of age I have written opinion pieces for DCSG booklets, spoken at WA Reproductive Technology Council (RTC) seminars, and provided quotes for books. In the early 2000's the WA DCSG drifted apart, as too did my parents' marriage. My dad wasn't close to me and I feel that my parents' decision to tell us girls about our donor conception placed a big strain on their marriage and made my dad feel less connected to us.

My mum sought to find as much information for my sister and I about our donors as by this stage she and a lot of other parents had realised that it was a normal human desire to want to know their heritage, and that the unregulated industries' underlying theme of instructing parents to "go home, make love and pretend that none of this happened as no one needs to know" was actually quite a dangerous way to proceed with life. The clinic that my parents were treated at stuck to their story of only have a few minor pieces of non-identifying information available to provide to us, and would not inform us of how many other half-siblings there were for either of us. I joined the WA Voluntary Register in 2007, when I was 21, and was only provided with the same minor pieces of non-identifying information, including blood type, height, hair colour and build. My sister has a few extra details, although it also came to light that the clinic had initially lied to my parents regarding the blood type of her donor, and if she wasn't told about her donor conceived status it would have come out at some stage as she could not have her blood type if our dad was her biological dad. This was either a mistake by the clinic that they should have come clean about, or this was done on purpose so that my parents went through with paying for a treatment that day, as they did not have any sperm available from a donor that had matching blood type.

In 2011 my life shattered with the passing of my mum from breast cancer at the age of 49 after a very full on two year battle. I then had to start battling the government regarding the rights genetic testing for the breast cancer gene for my sister and I, as most of the females in my mums family have died from breast cancer, and they were dying younger with each generation. I have also now become a mother myself, with two gorgeous healthy children. Although I was already very passionate about donor conception rights, since the passing of my mum and the birth of my own children, I have been longing to find out more about this mysterious other half of me even more. Ever since I had known of my donor conception status I have been full of wonder- wondering whether I have met one of my half siblings, if my donor father is still alive, if he or my half siblings are more like me personality wise (I am the black sheep of my family), and if I share any physical features with him or them. However when wondering such things, I was always brought back to that same lump in the throat feeling that it was very likely that I would never be able to have these questions answered. This is such a huge part of me, not to mention never having information on my medical history for myself or my children. I have already inherited an autoimmune disorder from him amongst other medical things, so I wondered what other important medical information I would not know of that may be of importance.

My story took an interesting turn when in December 2014 I was contacted by the WA Voluntary Register and provided with new information regarding my donors code- that there were 7 other confirmed offspring born from this donor and this included 5 other girls and 2 boys, all born either in the same year as myself (1986) or in 1987, with one of the boys born in 1990. Once I had attempted to deal with the anger, confusion and other emotions I was experiencing I would then start to get excited about it. This information to me was more than a million Christmases and birthdays rolled into one. This information could look to others like just a list of facts but to someone who had come to terms with never knowing this information, then accepting that my donors code was not found on any other paperwork (so there were no other offspring to him), then bam I have 5 other half sisters and 2 half brothers! It was overwhelming to say the least! And that isn't all, one of them had also signed up to the WA Voluntary Register and was wanting to undertake information sharing with me in the hope of meeting up. To do this we both had to undertake a mandatory counselling session with one of the RTC's approved counsellors, of whom only 1 would meet with me as the rest turned down my requests for a session as I was not a patient of theirs receiving fertility treatment. I then decided to attempt to get this counselling session subsidised, as money is not something that I have just lying around, and if this is a mandatory part of a government process then surely it could be funded to some degree too- but no, every response I received from politicians was a dead end. For some reason donor conception is still put into a separate category to other parallels such as adoptions and we are not afforded the right to have counselling sessions such as this covered, even though the reproductive technology industry is a billion dollar industry.

I eventually had to concede defeat on that and proceed with the counselling session if I wanted to meet my half sibling. Thus, I met my half sibling, Simone, in August 2015. She is 6 months younger than me, and went to the same school as me. If I was born in January instead of December then we would have been in the same grade at school and would have known each other. She shares many physical traits with me and we both have so many similar interests. We both felt an instant, indescribable bond, one that we know will last the rest of our lives. How lucky that not only did we both have parents that told us the truth about being donor conceived, but that we both felt the desire to find out more and discovered the WA Voluntary Register, and that we had some records still in existence from the clinic that were able to be used to link us. We are trying not to think of the years that we have missed out on knowing each other for and are just concentrating on the now and the future. We feel blessed that we at least found each other- something that the extremely far majority of donor conceived people do not get to do.



Myself and Sim when we first met (August 2015).

As you are aware, the Victorian government made history in 2015 by passing Narelle's Law (the *Assisted Reproductive Treatment Amendment Bill 2015*), legislation which now affords all DC people in Victoria the same rights in regards to accessing their donor's identity regardless of the year in which they were conceived, due to the retrospectivity of the legislation. This legislation was the result of an inquiry with experts who considered the issues and implications of the recommendations that they made so thoroughly, and that is why it will work. The legislation has a great balance of a right to information for DC people and privacy provisions for donors. Prior to such legislation donors actually had no protection, and it is known and appreciated that with the advances of online genetic testing that DC people are actually able to find who their donors are, and the new legislation provides donors with protection via the implementation of contact preferences and vetoes. However, it is known that such measures were never found necessary with the retrospective adoption laws; they were found to have such great success with the practices used by agencies for information sharing and arranging for contact between adoptees and biological parents. Speaking of, there was scepticism regarding retrospectivity for those adoption laws when that was changed however it was decided by the government that those adoptees' rights needed to be put first and when implemented the legislation was very successful and no one has debated it since? So why on earth are DC people still being put in a separate category, and many years later we are having to fight so hard for what should be our right- to know the identity of our biological father and to access information regarding our medical history, and the potential to more if both the donor and the DC person both consent.

In December 2016 Sim and I both took a DNA test through the online company Ancestry.com. Other DC people that we knew in Australia were having some good results with either finding half siblings or working out who their donors were from doing a DNA test and working through the results. We weren't hopeful of similar results, however figured that in the very least we'd find out more about our ancestry like what region of the world we descended from. When we received the results we were able to isolate which matches we had in common, which were the matches from our donor's side. The highest match we had was a 3<sup>rd</sup> cousin match, which was a lady in the US. This lady's husband found the little snippet of information we needed to get the race started- her Great grandparents immigrated from England to Melbourne on 24/10/1856. We were able to track down this record easily and then it got tricky. He married twice, having 13 children to the two wives. They seemed to travel a lot for it being the late 1800's and early 1900's- I was very surprised to see that the children were not only born all over Australia but all over the world! They travelled to South Africa, Sri Lanka (then called Ceylon), eventually moving back to Australia- this time to WA where they set up the town of Nyabing and were also noted as being a pioneering family in the nearby town of Katanning. Here his first wife passed away and he married his second wife. To her he had a few more children who lived and died in WA, so it looked like these lines would be promising in the search of finding out who my donor was.

After working through a few lines we ended on the youngest girl's line. Girl lines are always that little bit more complicated as they marry and you have to get lucky in finding their married name to continue the search on their line. We were able to find her death record which said she died in 1994 in Como which is a suburb in Perth. This was looking promising as this line was now appearing to have moved to Perth which is where we needed it to be. We found her married name and from this were able to find out amazing links of their family and the history of Perth. The first of their family in Perth came over as a convict but he was pardoned after only 4 months and given a plot of land from St Georges Terrace down to the Swan River where he set up Perth's first nursery. There is a laneway in Perth today which still has a sign acknowledging that it marked the boundary of his property. He was appointed to be the first gardener for the City of Perth and there are stories of him whacking kids over the head with a stick for stealing the fruit from the Supreme Court Gardens (which he planted for people to utilise but not for kids to steal and sell!).

It was 2.30am on 3<sup>rd</sup> November (we had been doing insane hours on this for 3 days straight at this stage) when my husband very excitedly announced to me that he had found the name of the daughter of this person, and very quickly we were able to work the electoral role records down to discover her married name and then found a son who was listed as being a student. We found him quite fast just by googling his name. He studied medicine at the University of Western Australia (UWA) and

graduated in 1983- moving on to specialise in gynaecology/obstetrics in 1984. I knew that my donor started donating in 1984 through 1990 (I was provided this information over the phone at the Keogh Institute, formerly the Reproductive Technology Institute- where the donor donated, not the clinic that my parents used for the procedure). This appeared to be a pretty strong connection and was exactly the type of person we had always thought the donor to have been. We thought this was it- he fit perfectly- THIS WAS HIM!!!!

However, after only a few minutes my husband discovered that there were three brothers, all of who studied in the Faculty of Medicine at UWA over the same time! Can you believe it?! It was now becoming obvious that it may be a lot harder to narrow down who of the three brothers was our donor. Over the next day or so we were able to find all three brothers- the second eldest travelled all over Australia continuing to add letters behind his name whilst practising in various remote locations, finally settling down in NSW in 2001 where he now works as a clinic as a GP. It was exciting to learn that he is also a cartoonist as I draw cartoons, always have and can't draw anything but cartoons. The eldest brother became a dentist and opened a practice in 1989 a few suburbs away from where I live now. The youngest brother was a GP who resided in Perth. It was exciting to see on his facebook page that he was into "birding" and he was actually on some of the same facebook pages that I'm on for bird photography and bird spotting. I'd actually "liked" a photo he posted only last week where he had made a humorous caption about the bird and the way it was getting the nectar from a kangaroo paw. From the photos on his page we worked out that he had a daughter and a son with his wife. I was actually quite blown away with the photos of the boy whom I definitely saw physical similarities to myself. Up until this point I hadn't really felt there were any strong physical similarities between any of the brothers and Sim and I. There was another set of photos which really solidified the physical resemblance thing for me- photos of his daughter as a toddler in 1990. The face is so close to mine at that age, and my son's. I didn't look like anyone in my family as a baby/toddler- and my son looks very similar to me at that age too. When I showed a few friends these photos they instantly were wowed about how much this little toddler looks like my son and like the photos of me at that age.

So what did we do next? To narrow it down to only one of the brothers and work out who our donor is we decided to write identical letters to all three brothers. From this process we were able to find our donor, an amazing man named John. The relationship was extremely awkward at first, as could be expected, and we all did not know what the appropriate way to interact was. This was amplified by John and his wife having to tell their children about John being a donor (as they had not known) and about us making contact. Over the year that has passed since finding John I can happily say that I know who my biological father is, I have a great relationship with him, his lovely wife and their daughter (who is 7 months younger than me, and only 1 month younger than Sim). I would not have been able to imagine when we first met that a year later we would have the relationship that we do now. We all have such common interests and have found interacting one on one and in a large group just so natural. My children and husband also have amazing and natural relationships with John, his wife, their daughter and her husband and little boy (the little cousins playing together is just perfection to watch!). I admire, trust and value my relationship with John so very much and have learnt just an immense amount about myself through knowing him. Life makes so much more sense and I feel so much relief and a sense of completeness and just amazement that I actually have found him!

John would not have joined the WA Voluntary Register and I believe he will not in the future either; however he very clearly does enjoy the relationships that he has with Sim, myself, our husbands and our children. John also does not know his donor code, so if he had joined the voluntary register then he would not have been able to be matched to any offspring as in its current format the voluntary register only work via matching donor codes up. John would not be able to find his donor code out from the place where he donated as it has been stated to me many times by the staff at Keogh that when Dr Keogh passed, the files that he kept on the donors were put into another filing system therefore making them unable to be easily identified as being donor files, and Keogh have not since this time been able to locate them.

Current legislation in WA recognises that anonymity in DC is not appropriate, and the arguments of donor numbers decreasing etc were found to be completely unfounded, just alike the debate of "but the donors wanted to remain anonymous"- how do we know this unless we ask each individual donor? From the studies that VARTA undertook, ¾ of donors from the anonymous era said that they'd be open to some level of information sharing when asked recently if they wished to still remain anonymous. This is either because there was no option back then to be identifiable (they were forced to be anonymous), or that after all of this time they are now open to releasing some information to their DC offspring, sometimes due to them simply reflecting on their own natural offspring and their rights, or just their own personal curiosity about their DC offspring. So if the majority of donors appear to have no issue with no longer being anonymous, and if the new legislation actually gives protection to donors that they currently do not have, then why is there even a question as to if this type of legislation is appropriate or not?

Well done Victoria, with all of the research and consultation with stakeholders that they did, they passed Narelle's Law. This was the obvious and right decision and the giant step in the right direction that they took has now set the precedent for the rest of Australia. Every other State and Territory (in the absence of Federal legislation which was deemed not appropriate by the Federal Government even after the unanimous recommendation of the Senate Inquiry of 2011 to have it dealt with at a Federal level) needs to follow in Victoria's steps and enact identical legislation. Anything less is not appropriate and in this age of human rights a government who chooses to do anything other than attempt to rectify the past inadequacies with similar legislation to that of Victoria will be ridiculed and shamed for doing so.

I am quite sure that there will not be many submissions made from DC people in WA, and if you're ever wondering why there isn't as much pressure for the issues surrounding DC and the anonymous donor era, it is estimated that there are 60000 DC people in Australia and only 10% have actually been told that they are DC. This is something that basically cannot be fixed, as only education programs to remind parents to tell their now adult children the truth, as well as DC people finding out by accident (either medical means or from doing an easily accessible online dna test), are really the only ways that more DC people from that era can learn about their actual true identity. So that's already a mess. On top of that mess is the fact that even with such progressive and appropriate legislation like Narelle's Law, for a large proportion of DC people from that era we have no hope anyway as we either have had our records destroyed by clinics, doctors and hospitals (I remind you here of how after 3 women died after being inseminated with HIV+ sperm in the mid 80's which set off a chain of mass destruction of DC records nationwide, which doctors have admitted was because they didn't always do the necessary and available tests such as a HIV test and they didn't want to get caught out if another case came up), or names of donors were never recorded as it was not deemed "appropriate". The very least the WA government can do is attempt to fix the massive problem that they have allowed to occur and to remain, for those DC people for whom records still do exist. The situation is shameful and one that I believe, from experience, everyone in the public would actually agree with if they had the details of Narelle's Law explained to them. Yes it revokes the donor's anonymity, but it affords them privacy, and recognises that despite those DC people being born before legislation was introduced that made the industry operate correctly (by putting the DC child's rights above all others), that they deserve the same rights and that any right to anonymity that the donor may have, the DC person's rights trump that. We (DC people) were not privy to any decision made about our creation yet we are the ones being made to suffer through the consequences. Not on. Fix this insane mess.

I have written to Premiers, Health Ministers, Attorney Generals, etc throughout the years regarding my concerns and troubles. Despite this I have not got anywhere with the issue here in WA. I am blown away by how the Victorian government lead the way with the passing of Narelle's Law in 2015 and applaud them for doing so. Legislation that mirrors Narelle's Law is what we in the other states of Australia need in order to attempt to get our slow, dark age states into gear. This is WA's chance to do just that. Please do not waste this opportunity to provide myself and many others with these basic human rights. Using my own personal experience as an example- knowing who my biological father is, my half siblings from his marriage, and also 1 of the estimated 7 half siblings I have through the DC process, has had such an amazingly profound effect on my life.

Please do not hesitate to contact me to discuss further any of the issues raised in this submission.

**Points that need to be considered:**

- Mirror the legislation that Victoria passed- Narelle's Law
- Access to information by donor conceived people
- 'One door in' service model encompassing search, information, donor linking and counselling services provision- complete with funding these services
- Information disclosure and contact processes
- Locating and verifying records to be collated by one central register
- DNA testing to remove doubt on matches and for people whose records have been destroyed
- Retain records indefinitely
- Mandatory inclusion of donor conception information on Birth Registration

Best regards,

Bridgitte Reynolds

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