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[redacted]

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Committee Secretary
Legal Affairs and Safety Committee
Parliament House
George Street
Brisbane QLD 4000
Email: lasc@parliament.qld.gov.au

Dear Secretary,

Inquiry into matters relating to Donor Conception information

Thank you for the opportunity to provide a submission for consideration. It's taken me almost 2 months to start writing this as it's a highly emotional topic and leaves me feeling anxious and stressed. The experience of being a DC person has been very traumatic. Nevertheless, I will do my best to convey my story and my thoughts around the necessary changes to legislation to support DC people in knowing their genetic truth.

My story

I found out I was donor conceived (DC) the day before my 13th birthday, in July of 1994. My mother told me in anger after my dad (they divorced when I was 2) came to see me. She said "he's not your real father anyway" and that was the end of the discussion. Back then, there was no internet, no support groups, no information, no answers. I was alone to deal with this catastrophic news. It changed my life forever.

Years later, after riding the emotional rollercoaster that plagues many DC people, I asked for more information from my mother, her treating Doctor and the clinic where that Doctor had set up a permanent place to practice assisted reproductive treatment. In 1996, at the age of 16, I made 3 separate phone calls a few months apart and was told the following lies from the clinics administration staff when I asked whether there were any records about me, my parents or my donor that would help me find out my genetic truth.

- "Sorry, your records were damaged in a flood and they all got destroyed"
- "Sorry, there was a fire and they were all damaged"
- And finally, a very angry medical receptionist told me "There is absolutely no legal requirement for us to have kept any of those records and they were all destroyed after 15 years, they're all gone".

All lies. This is a common theme across Australia and indeed the whole world. Why are clinics telling their staff to lie to DC people about this? Vulnerable, and in my case underage, people who are just seeking answers? People lie when they are ashamed of what they've done and they know they'll get in trouble for telling the truth.

Fast forward through all my teenage years and early 20's, through dark and depressed years asking and re-asking myself "why do I need to know"? I felt alone, invisible, worthless and unsupported. I didn't know how to express how I felt, I didn't know how to deal with what I was going through. It was an AWFUL existence and many times I wished I wasn't alive...despite people saying to me "oh you were SO wanted by your parents, you should be so grateful to be alive"....No, it doesn't work like that.

When the internet became popular in the early 2000's, I managed to find some Australian and international support groups/information. I started to become a little more inspired to connect with others like me (after not realizing there were others for so long) and when Facebook came about it centralised a few support networks and finally, in 2014, I joined an active group of DC people in Australia. In 2015 I joined 47 other DC people at the RUDC conference in Melbourne, where I learned about DNA testing. I decided that I was DONE waiting for answers from clinics and doctors, I was going to find my donor myself.

I returned to Brisbane and asked my dad a whole raft of questions about the DC process he and my mother had gone through. I don't speak to mum anymore and so Dad was my source of information. Dad said he and mum were never offered any counselling, were not given any choice about the donor being anonymous and were told by the Dr to never tell the child, that no one will ever know the truth.

I then had a meeting with the Dr and I asked him 2 pages of questions. His honesty was brutal but appreciated, but my gosh the practices they had and what they got away with is deplorable and should be subject to a Royal Commission. One of the most devasting truths I learnt from him was when I asked about my records being destroyed, and he said they weren't, they were in the back of the office in storage. The file I had been searching for and was told didn't exist anymore, was sitting safely in a box less than 10 metres from where I was sitting. I have included a copy of my file note from that meeting for your information - it's not a nice read in parts, and I'm sure you'll understand why so many DC people feel anger towards these clinics and doctors due to their dodgy practices and abuse of the vulnerable parents who were so desperate for a child they would do whatever they were told.

Armed with this information, I proceeded to do a DNA test with Ancestry.com and received my results a few months later - no direct matches. Not to be deterred, a wonderful DC colleague taught me how to do a "mirror tree", which is a strategy of applying your DNA to different "host" people in your tree to work out, generation by generation, who your relatives are. For the next 5 months, with a screaming newborn baby in my arms, I built out family trees, assigned DNA, ran algorithms, took notes and spent 18 hours a day working on finding my donor - I was an exhausted and anxious mess. By February 2017, I had done it. I had found him. I called his office, refusing to write a letter like most other DC people seemed to do, like a resume justifying my reasons for wanting to reach out and know my true genetic identity. I was not going to be patient anymore. For my own sanity, and my poor husband and children's sanity, I needed it to be over. I just needed the truth. I was physically exhausted from the emotional toll this journey had taken me on and I couldn't do it anymore. It had to stop.

So I left a message at his clinic and he called me straight back. I asked if he had donated sperm in the 80's and he confirmed he had. I said "I believe you're my biological father", to which he replied "oh my goodness, hello darling! How are you? Tell me about yourself". He completely understood why I needed to call and get it over with, because he would have done the same.

He came over the next day and we talked for hours. We shared stories about our lives, he told me about his other kids, his parents, his family. MY half siblings, MY grandparents, MY family. He was so happy I had found him, so impressed by my tenacity, so thrilled to have me in his life. We are so insanely similar, we share so many traits both physical and intellectual - it's quite uncanny and makes a strong argument for the impact of nature vs nurture. Since that day we have caught up regularly; we talk on the phone or via text message, I've met his kids, his sister. I've been involved in his life. We haven't defined our relationship as anything other than biologically related. It's amazing, and I'm incredibly lucky.

I've also had 6 other half-siblings pop up on Ancestry, although none of them knew they were DC. It shouldn't be my responsibility to tell them that, so I tell them just enough information about the match we share and why I have done the DNA test and then encourage them to discuss the results with their parents. One of my half siblings had no one to talk to as her mother had died and taken the secret with her to the grave, and her dad refused to discuss it with her as had spent 35 years believing it was a secret to be ashamed of. She had a wonderful life, family, relationship with her parents, and it was destroyed by this secret. For the rest of my life, and my children's life, additional half-siblings and half-cousins will pop up, continuing the trauma across multiple generations. We estimate that we have another 50-60 half-siblings out there, but that could be closer to 100 as my donor donated for so long.

Finding my donor was amazing, and I know I'm one of the lucky ones. It's taken too long to get to this point and it's not good enough that this is still be discussed on a state level when it should be nationally consistent legislation. What is it going to take for someone to take the bull by the horns and stand up for what's right?

For too long DC people have been left behind, been infantilised, been ignored. There are so many of us now, and we grow more vocal by the day.

Please, for the sake of DC people everywhere and our families, friends, and children, please do the right thing and make the necessary changes to the legislation so that we can be treated like human beings. We've been through so much already, and now it's time for change.

It's time to do what's right.

In response to the particular topics being considered in this inquiry, I provide responses below:

Rights of donor-conceived persons, including to know their genetic origins.

We should all be allowed to know our genetic/biological parents. It is not up to a Dr, parent or donor to decide to keep that information from us! It's unacceptable, and thousands upon thousands of DC people worldwide have made it clear that keeping this secret has massive emotional and mental impacts that last a lifetime. I have a right to know my biological parent, my children have a right to know their biological grandparent, and we all deserve to know where we've come from and what our medical history is.

The extent to which identifying information about donors should be given to donor-conceived persons, taking into consideration the right to privacy of donors.

The donor made the decision to make a baby, many of them were told by the clinics it would be anonymous and they weren't given a choice. Many DC people who have found their donors have been amazed by how happy their donors are to know they exist and be a part of their life (like mine). Many donors have changed their mind about being anonymous as well. Anonymity wasn't necessary, and implies that DC is something to be ashamed of. It's not! Anonymity hurts DC people, hurts the parents and hurts families, and legislation has already changed banning it. So if you changed it, you've already acknowledged that it was a bad idea, so making legislation allowing access to identifying and non-identifying information retrospectively is the RIGHT thing to do now.

Access to historical clinical records and implications of retrospectivity

Considering the amount of lies the clinics told to hide their illegal and immoral practices, and the amount of records that have already been destroyed by the clinics/doctors to cover up their malpractice, I think the best thing to do at this point is full disclosure. Victoria have already done this and it's been a huge success. DC people deserve to know the truth, no matter when they were born and in which state.

Access to support and counselling for donor-conceived persons and donors

THIS! Not once, even as a teenager calling the clinic, was I offered any support or counselling to deal with this. I've spent thousands of dollars on counselling for myself and had to stop as I couldn't afford $250+ a session. DC people need free or heavily subsidized counseling with specialist-trained counselors. Donors and parents also should get counselling as the decisions they made have had massive lifelong effects on DC people and they likely feel guilty about keeping the secret. It's not a blame game now, it's how to effectively manage the truth being told.

Whether a register should be established

Of course it should. This should have been done 20 years ago, and we have unofficial registers in our Facebook groups tracking various information anyway. Let's formalize it and control the process properly. I'm not sure how good it will be as the data to include is with the clinics and I don't trust them, but it is a step in the right direction.

Benefits, risks and implications on donor conception practices arising from any recommendations

Anonymity is dead due to DNA testing and all future DC situations should be managed with complete openness from birth (not 18, that's too late) - this includes Australian and internationally sourced sperm/eggs/embryos. Clinics and doctors need to accept that they stuffed up, and it's time to make it right. Their entire business is centered around the creation of babies, and now the babies have grown up and we're yelling from the rooftops that these practices are wrong and should be changed. It's time to listen to the people who live this life! Proper legislation, counselling and honesty is the only way to make DC and ART sustainable into the future, otherwise you will have thousands more DC people born who will be in the same position as us.

In addition to legislation changes, a media campaign addressing DC issues, asking donors to come forward to go on the register, and sharing positive stories of connection will help to make this subject less of a taboo than it currently is. If we don't fix the problem now, it will continue to grow out of control.

Finally, my birth certificate is factually inaccurate as it lists my dad but not my biological father. They are both relevant to my life, however to have my birth certificate corrected, I need to apply to have my dad removed (how offensive to both of us) and then have my biological father added. It would be great for DC people to have an additional box available: "If conceived using donated gametes, add names of biological parent/s here: ________".

It's time to right the wrongs of the past, stop dragging our feet and just get this done properly, with DC people at the forefront of those decisions.

Thank you for your consideration, and best of luck with the inquiry.

Kerri Favarato

REMEMBER! I am a representative of every DC person who doesn't have a voice.

Questions for [redacted] 28/8/15

Firstly, thank you for your time, I do appreciate it. I also appreciate your patience as I work through these questions – I have taken my time writing them and appreciate your time in hearing and answering them. It has taken me 20 years to get here, and I've been told many lies. I'm relying on you today to be truthful and honest, knowing that I'm not here to get mad at you, or to place blame unfairly.

Please give me as much information as you can – any piece of the puzzle, no matter how small, might be significant.

1. **In what year did you begin working with [redacted], and at what point did you start doing donor insemination procedures?** Late 70's/early 80's. Had been doing donor insemination in WA with [redacted] before that.
2. **What was your position/role with [redacted]? What work were you told you would be doing, and how had you gotten started in this field?** He had been in the Kimberley's for a while after having been working in Kalgoorlie with [redacted]. He was registrar in his final year (1979). While he was a student, he had donated sperm himself (he said in his late teens and early 20's). He was in Obstetrics and gynaecology but had gotten involved with some AI stuff with [redacted] and found it fascinating. In Brisbane he started working with [redacted] (now deceased) in his rooms at the [redacted] (essentially as his protégé), but with his own patients. [redacted] screened all the donors (it was actually the Sister who worked with him) and [redacted] and the other 2 Dr's in Brisbane at the time all used the same sperm. [redacted] thinks he might also have used [redacted] rooms at one point but not often.
3. **Who else was involved in donor insemination at the time, and who else was working in the clinic with you?** There was only the 4 of them in Brisbane at the time – [redacted], [redacted], [redacted], [redacted] – were all doing DI at the time, however they all worked on their own, just pooling resources (donors/rooms) initially. He also mentioned [redacted] but I can't remember what he said his role was.

   Note: [redacted] is a scientist at [redacted] who has been here a while – might be helpful for some of the younger DC people, 3015 3000 and they will transfer you.
4. **Was there a lab with staff?** No, just them and their rooms.
5. **How common was donor insemination at the time?** Not common, was just getting started in Brisbane.
6. **How many procedures do you think would have been done per month/year?** Maybe 1 per week in the beginning.
7. **How many pregnancies do you think resulted from those procedures?** He thinks maybe up to 10-15 children per donor.

8. **How did you recruit for donors?** The Dr's were giving lectures at University of Qld and would announce to the men that they were looking for sperm donors and it was anonymous and they got paid $10 or $20.

9. **Where did you find most of your donors then came from?** UQ medical students, maybe a medical researcher.

10. **If uni or med students – what uni/medical facility were they from?** University of Queensland

11. **Did you or anyone else in your clinic ever donate sperm?** No, but [redacted] had donated himself as a medical student (not sure whether he was in Qld or WA?) before he even met [redacted] – he was only in his late teens/early 20's at that stage.

12. **A few years ago, I spoke to a donor named [redacted] who told me about a [redacted] and a [redacted]. He was quite certain that if you didn't know who my donor was, that these 2 doctors would, or would know the few people were that were donating at the time – do you know these Dr's and their involvement?** He said [redacted] was a lecturer "not a quack" (referring to a Dr) and then later was doing some research with [redacted]. They did some work with the Professor of [redacted] (who is now living in England) – they were doing more advanced testing on the sperm to find out why men were infertile. Dr [redacted] didn't work with [redacted] though – he is the Head of Fertility at the [redacted] Hospital now he thinks. Can't remember much about their involvement at the time but doesn't think they would have known who the donors were (worth checking whether I can speak with Dr [redacted] however!)

13. **Were you or anyone else in your clinic, asked to donate due to low donor numbers in the early stages of donor conception?** No.

14. **How many donors were you using in those early years?** Between the 4 Dr's maybe 30 total, although Dr [redacted] believes he only used about 6-7 different ones in the early days. Dr [redacted] was the one who screened all the donors though which was fine with the other Dr's – less work for them to have to find them and do the testing/screening themselves.

15. **How were donors screened and for what medical conditions?** Hepatitis B, syphilis, gonorrhoea, not much really. Sperm was checked to see if it was good. No donors were tested for AIDS until the mid 80's when there were about 10 kids in Sydney that got AIDS from a donor that was infected. He said "we were lucky to not have had any issues with that".

16. **How and how often did the donors donate?** Donors would donate a few specimens maybe every month or 2. Would donate either at home or in the rooms (in the toilet) and would bring the cup to the Dr. It would then be used that day and if it was a “good sample” it would be used multiple times. He said the cup of sperm would just sit on the desk for the next Dr to use. He said there could have been 2 or 3 patients per Dr some days although he never usually had that many, maybe 1/week.

17. **Were donations frozen or used fresh?** Until about 85 the donations were all fresh. Didn’t have the technology in Brisbane to freeze donations at that time (not sure about other states). When they say ‘fresh’ he said they would have a donor come in that morning, donate into a cup, the cup would be left in the rooms on the desk and if it was a good sample it would be used by possibly all of the doctors who had patients to inseminate that day.

18. **How were the donations stored?** They weren’t, no frozen donations at that early stage. Not sure when that technology became available in Brisbane but he thought about ‘85.

19. **If frozen, were donations sent elsewhere in Australia?** Not in the early years no, they do now though.

20. **Was a record kept for each individual donation?** No

21. **How long would each donor donate for?** 6 months tops, maybe occasionally someone would donate for longer, but that was a rarity (when I found my donor he confirmed he had donated 2-3 times/week for 5 years).

22. **Sometimes parents wanted more babies after the first one, and they were often told that they could have the same donor so all kids were genetically related on the paternal side. Did that actually happen?** Not a chance, donors got sick of it, and couldn’t be bothered anymore”. He said that a donor might give a total of 8-10 samples in their time and that was it.

23. **How common was it for a donor to be donating over many years?** Very uncommon.

24. **How were donors codes assigned? Ie. Last names initial and a number?** It was initials. He used the examples of [redacted] but said he didn’t remember of the codes. [redacted] assistant (the Sister) would assign the codes. She would record basic physical info but that wouldn’t go into their actual records, just on the donation. Maybe height, hair colour etc. They didn’t do blood types back then either, too hard to match a donor like that.

25. **Do you remember any of the donor codes?** No

26. **Do you know who my donor was, or a few people who it might have been?** No, he may have seen a couple of donors walk through the doors but didn't know their names and wouldn't recognise them if he saw them. He didn't screen the donors; that was [redacted] job.

27. **What information was on the donor record?** Not much information to be honest, not in those early stages. It was medical history and occasionally some physical characteristics - he mentioned the Sister that worked with Dr [redacted] and how she would sometimes write on the donation what the physical characteristics were to 'match' with the recipients, however it wasn't a case of pick and choose! No names would have even been recorded on the donor record.

28. **What information was on the recipient's record?** Donor code was usually put on the mother's record.

29. **How were donors assigned to a family?** We have sperm – here you go. There was no choice, they would only try to match donor statistics if possible. If they only had 1 good sample that day, it was used for everyone that came in. He said they were all 'white/Caucasian'.

30. **Were the donors offered anonymity or were they told that was how it was?** They were told that it was anonymous – no questions asked. Most of the donors were in their late teens/early-mid 20's and so were worried about the impact on their future families. They thought they were giving a great gift.

31. **Were contracts signed or consent forms?** Not contracts, maybe consent forms but he can't remember exactly.

32. **What was the wording of those?** Words to the effect of "we are proceeding with AI treatment using donor sperm as discussed".

33. **Was there any mention of the rights of the child to find out information about the donor father?** No. Dr [redacted] doesn't believe that the children should know, as long as no one else knows and that information isn't going to be sprung on the child causing emotional/mental harm. If only the parents know, and they agree to keep it a secret, then he thinks it should be kept from the child.

34. **Was consideration given to the donor changing their mind about anonymity down the track?** No

35. **What were the reasons for anonymity – what was everyone afraid of?** He recalls that the donors just wanted to do something nice for people who couldn't have kids. The donors were young, single and were concerned about the impact on their future life and family. They were worried about 'children' coming back and "trying to get their hands on the Porsche" or other financial things.

36. **Was consideration given to the child ever wanting to know their genetic history, both for ethical and medical reasons?** No

37. **Where were the donor and recipient records kept – initially and long term – and how long were they kept for? I know my parents records were destroyed but do you remember anything that would have been in it?** Initially kept in the rooms, but then when they get their own space it was kept in their rooms. Dr [redacted] kept his in his office, had water damage in the office at one point and some records were moved to his home garage. There was later a fire in the garage and some of the records were smoke damaged but no records of his got destroyed. Some of the records are now in a storage room at [redacted], others at his home, but most are upstairs at his office. He had his wife [redacted] look around at home last night and she couldn't find anything relevant. He said I was more than welcome to go through the files at [redacted] and his office to see whether I could find anything. Said he wasn't sure what the legal ramifications of that were but he didn't see what harm it could do. Said he would have one of his staff come with me to make sure I wasn't reading anyone else's records. At the time records were kept: General gyno 7 years, obstetrics 21 years. Dr [redacted] never destroyed any of his records, however during many moves and shuffling of storage space he's sure things have been misplaced.

38. **Who decided when to destroy them?** The Dr's decided. Dr [redacted] destroyed all his records when he retired.

39. **How were they destroyed?** Chucked in the bin

40. **Was any of the information retained and transferred to a computer or other system?** No

41. **What criteria were recipients required to meet before receiving donations?** Qld didn't do police checks, so it was just the Dr having a chat with them and he got their basic history, general health, any medication, did an exam and checked the woman's tubes (flushed with dye) and that was it.

42. **Was counselling offered before, during or after the process to the mother, father or donor?** No

43. **Was support offered during pregnancy and after birth?** He would see some patients initially but would usually send them back to their normal Dr. He did say he did deliver quite a few babies though.

44. **Do you believe that the donors should have been anonymous?** Yes

45. **Do you think their views might have changed about maintaining their anonymity, given recent documentaries involving donors who want to know their offspring?** He said he wasn't sure, couldn't answer this for others. He knows his view hasn't changed and he intends to remain anonymous.

46. **Do you think that the child has a right to know their genetic information?** Can't say whether children don't have the right to know. He said if there is not a strict code of silence between the parents then this news can rock the boat.

47. **The NHMRC guidelines state that clinics should work with relevant professional organisations and should use forums for public information to encourage people who were donors before the introduction of these guidelines, and those previously conceived using donated gametes, to contact the clinic and register their consent to being contacted by their genetic children or genetic siblings and half-siblings respectively.**

    a. **What are you and your clinic doing to contact donors?** Nothing, we don't contact anonymous donors, only discuss things with them if they call the clinic first.
    b. **How do you encourage them to come forward?** Wouldn't do this for an anonymous donor, would not put this type of pressure on them. Who knows what type of impact this would have on them?
    c. **What about the pressure put on the child born of that donation? What about the impact on them?** Dr [redacted] couldn't answer me.
    d. **How many have come forward voluntarily?** None.

The NHMRC Guidelines emphasise the right of donor conceived people to be entitled to information about their genetic heritage. They also provide for information release and proactive engagement by ART providers.

According to the NHMRC guidelines, "persons conceived using ART procedures are entitled to know their genetic parents" and "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.

The Human Rights convention/charter enshrines the rights of the child to know its parents.