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LAW REFORM COMMITTEE

Inquiry into Access by Donor-Conceived People to Information about Donors

Melbourne — 12 September 2011

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Ms Narelle Grech

Ms Lauren Burns

The CHAIR — Thank you very much for coming in. We've heard a lot from people around the whole process so it's great to actually have some people who are part of the process come and give us some information. As you've probably gathered it's pretty casual, we're just interested in your views on things and we'll fire questions at you as we think of them.

Ms BURNS — Sure.

Ms GRECH — Sure.

The CHAIR — I think you were in the room when I gave the initial spiel about the process?

Ms BURNS — Yes.

The CHAIR — All we need to do is get your name and address and then you can start telling us what you want to tell us.

Ms BURNS — My name is Lauren Burns.

Ms GRECH — I'm Narelle Grech.

The CHAIR — Did you know each other before coming today?

Ms BURNS — Yes.

Ms GRECH — Yes. We were introduced through a counsellor, Helen, a few years ago.

The CHAIR — Are you siblings?

Ms GRECH — No.

Ms BURNS — Not that we know of.

Ms GRECH — We might be. I highly doubt it.

The CHAIR — What would you like to tell us?

Ms BURNS — Narelle's going to go first.

Ms GRECH — I've got something here today to say. I wanted to thank you, firstly, for allowing me this opportunity to speak. I'm 29 and I've known about my donor-conceived status since I was 15 years old. I was conceived by an anonymous sperm donor whose donor code is T5, so that's what I will refer to him as; that's what I call him. He donated at Prince Henry's in the early 1980s. Since this time, since learning about my donor conception, I've wanted to access my records so it's been 14 years that I've been seeking this information and it's been quite a journey.

The CHAIR — What happened when you first sought that information?

Ms GRECH — I made an initial contact with Professor Kovacs, who was my mum's treating doctor, and he sent a letter, he accessed support services through VANISH, which is the adoption support agency. They helped him to send a letter to three people in the phone book, I believe it was, with the same first initial and surname. Nothing ever came of that.

I made a further request a few years later for another attempt at contact and that was actually denied. Professor Kovacs said that the Ethics Board from Prince Henry's, which is now Prince Henry's Research, or which sat within Monash anyway, that I know of, they said that they didn't believe it was okay to make more than one attempt due to privacy. I've requested to see the letter that was initially sent but never received that so there's been a lot of inconsistency in my search.

What I do know about my donor, or T5, is that he was a student at the time and he was married. He had brown hair and brown eyes, his blood group was O Positive and I was told his height and weight at the time of donation. I was also able to learn years later that his surname starts with the letter T, and that his surname is most likely of Maltese origin. This would make sense as both of my parents are Maltese and the clinic would have tried to match him with my dad.

I'm not going to go into great detail today about my story, as I've written about it quite extensively in both of my submissions, and I feel that there are certain points I would like to speak to specifically about how donor conception has impacted upon me and why I'm seeking access to my records.

Before learning about my donor-conceived status, I had no idea I was donor-conceived. Although the news came as a shock to me, I felt a sense of relief in knowing the truth, and the news made sense to me in some way. Something that bothers me greatly is that my birth certificate is not true or factual. This concerns me regarding the current legislation as well around birth certificates. I don't feel that anyone should have to question the accuracy of such a document and donor-conceived people are still reliant on their parents to be honest with them, which I don't think is good enough.

I've been actively speaking out about donor conception for a number of years, and it's taken its toll on me emotionally and within my family. It's personally quite taxing to have to recount my story and to have to plead for information that I feel I should already have. The lack of control around this is very disempowering, the secrecy and withholding of information about who I am and my conception leads me to feel like a second-class citizen. I believe that the truth will set me free, so to speak, and I ask for access to my records for this reason. I want answers so that I can move forward in life without these feelings of loss and grief and I don't think anyone should have to endure this, especially when the records do exist. And I do know that my records exist.

The CHAIR — How do you know your records exist?

Ms GRECH — Because Professor Kovacs has told me that he has them, he has access to them, like to do the search initially, and I believe they were at one point held at the ITA.

Ms BURNS — They were held at Monash and then moved to the Public Records Office and the ITA had some access to them while they were there.

Ms GRECH — That's right. Thanks, Lauren.

Ms GARRETT — And your biological father said no?

Ms GRECH — I haven't had any response at all. There was one attempt made when I was 15, and we made that enquiry quite soon after I found out.

The CHAIR — Are you aware whether anybody has considered the ethics of your eight half siblings being informed of your medical condition?

Ms GRECH — Yeah, I'll go on to speak about that. Yeah, I do speak about that, definitely. I'm not only speaking out for myself but also for other donor-conceived people who are unable to make their voices heard for whatever reason. And I feel that if it weren't me, or the small group of us that are doing this, then who would be speaking out? So I feel very compelled to tell my story and this is why I have done so for so many years. I have felt like I don't have the choice and that this has been my path.

I do have eight half siblings who were conceived from the same donor, or so I've been told. I query a lot of information I'm given, to be honest, I don't really know whether I can believe all of it but I'll speak about them more a bit later on.

Donor conception is the reason I decided to go on to study social work. During this time I learnt about a theory called disenfranchised grief, which is a theory that Kenneth Doka put forward, and I wanted to speak a little bit about that because it has some relevance to where I'm at. He defines it as: "Grief that persons experience when they incur a loss that is not, or cannot, be openly acknowledged, publicly mourned or socially supported." I think this theory applies to myself and other donor-conceived people because we can't publicly mourn the loss, or I can't publicly mourn the loss of my biological father and my paternal family as I already have a dad, who society regards as being all that I need.

My biological father is labelled as my donor, and I believe this blurs the true relationship between us. We are socially viewed to have no relationship and therefore I should not feel a loss, but I do feel a great loss for the severed ties for my paternal family. I'd love to know who they are, what we share in common, who I've inherited certain traits from, not only physically but in terms of my personality, and this is knowledge most people take for granted.

I can't publicly mourn my loss because, as I said, the relationship isn't recognised. No one has actually passed away so there's no socially acceptable way for me to mourn the loss of my father, his family or for myself, and I'm not socially supported. Generally, as I believe, donor conception is viewed as a positive practice and that serves the interests of the adults primarily who are seeking a solution to their infertility. I feel that the practice of donor conception does not allow donor-conceived people to be of paramount consideration from the outset, even though legislation claims that it does. It's almost impossible for this to occur since donor-conceived people can have no say in their conception or the legislation under which information about their own identify is managed. There has been little information about the long-term consequences of the practice for donor-conceived people.

In voicing my grief I've been met with a lot of negative feedback over the years. I think it was really quite difficult in the early days — I've been speaking about this since about 2003 — and initially I was met with a lot of negative feedback. For example, I must be ungrateful, that I was being disrespectful towards my parents who raised me, and that obviously I was doing this because I had a bad childhood and therefore was looking to replace my dad or my parents. And I wanted to say that this is not the case at all. So using Kenneth Doka's theory, you can begin to see how not being able to know my paternal family and my biological father may have impacted on me over the years.

With regards to my eight half siblings, there are three girls that were born the same year as me. I was able to find out this information a few years later doing some more detective work. Three boys born the year following and two girls born in 1985. I consider them to be my family, and I feel a loss for not being able to know who they are. I recently found out that sperm donated pre legislation may still be used post legislation, it may be used now. I just think that's horrible and, you know, that these people being conceived and born now from this sperm will effectively be in the same position as I'm in. I don't think that's good enough really.

The CHAIR — How did you find out about your siblings?

Ms BURNS — Through ITA.

Ms GRECH — No, I think it might have been Professor Leeton. I can't say that that's definitely the case. I did have to write to another professor, it wasn't Professor Kovacs; it was a number of years ago. Another donor-conceived person was surprised that I didn't know about my half siblings and said I should write to this professor, who I did write to, and it took quite a few months actually to get that information. I think initially I was told there were seven half siblings and then a few years later the ITA clarified that there was actually eight, they had some information. It was through the ITA that I found out their dates of birth, their gender. I think it was date of birth or estimated dates of birth. So just some detective work.

The CHAIR — So the information is held at Births, Deaths and Marriages?

Ms BURNS — Only post legislation information.

Ms GRECH — It's at the Public Records Office.

The CHAIR — What would be the process now if you were to start your search from scratch? I know you went to Professor Kovacs originally.

Ms GRECH — I'm trying to again through Professor Kovacs. He called me today actually, and that was an interesting conversation because he's now saying he has to clarify that my donor code is T5, which I just found ridiculous, to be honest. After all of these years he's now saying he has to clarify — and this is the kind of thing that happens.

Ms BURNS — All the time.

Ms GRECH — So I don't know what's going on and he says he has to contact Freedom of Information. I don't know, I'm getting the runaround again basically and I'm not really clear as to what is the best way to move forward. He says he's going to continue to look into that but it's never very clear, I'm not sure. We fall into a strange category because we were conceived at Prince Henry's, who has obviously closed down.

Ms BURNS — Those records are now officially orphaned records, there's nobody that we can go to who will say they have jurisdiction over those records to make an approach.

The CHAIR — Marianne and Rita, you could be in a situation where donor-conceived children contact you and you assist them with Prince Henry's records; is that right?

Ms ALESI — Yes.

Ms TOME — Not at Melbourne.

Ms ALESI — We have some of Prince Henry's records.

The CHAIR — How would you deal with Narelle's situation if she were to contact you and ask for your assistance?

MS GRECH — I have.

Ms ALESI — I think we locate whether those records exist. If they exist within that particular doctor's private collection, which it sounds like it might be, that's a different issue. So there are some Prince Henry's records that exist within the clinic, that they have access to, and the doctors themselves working at Prince Henry's working at that point in time have kept their private records.

The CHAIR — So the holdup in this situation is the doctor himself?

Ms KANE — What also exists is a file at ITA so I don't know what happened with that. Prince Henry's was people who donated as a result of Prince Henry's treatment. Many of the donor-conceived records actually came to ITA and they include the details of who the donor is but it was not information that ITA were going to act upon because we were advised legally that we were unable.

The CHAIR — Because what, sorry?

Ms KANE — We were legally unable. The information was there but because Kovacs was the private doctor who treated her mother, he had done that before ITA, before the donor registers were actually created, and he'd done that as a private doctor, which was absolutely his right, but ITA had no capacity at all because it was pre-88.

The CHAIR — What would need to be changed for ITA to release that information?

Ms KANE — You would legally need to make a contact with the donor.

MS GARRETT — Which again goes back to the point, is that based on the agreement that private clinicians had with the donors?

Ms KANE — It's pre-88 — —

Ms GARRETT — I know it's pre-88 but we've heard that Monash and Melbourne are now contacting pre-88 donors.

Ms KANE — That's because there's a private doctor to go to.

Ms GARRETT — That's right, so it's about the private doctor.

Ms ALESI — So maybe retrospective legislation for information to be released by someone.

Ms GARRETT — But it doesn't necessarily go to the issue of requiring identification of the donor without their consent but at the very least it would require information to be released non-identifying?

Ms ALESI — Yes.

Ms GARRETT — Or identifying?

The CHAIR — It sounds like there also needs to be some framework around how the manner of invitation or how often you invite people to contact. Professor Kovacs has sent letters some years ago; is that right?

Ms GRECH — Yes, when I was 15.

The CHAIR — How old are you now?

Ms GRECH — 29.

The CHAIR — So it seems like there should be some sort of framework around if you've been contacted three times and five years has elapsed and maybe you've changed your mind and it's appropriate to send another letter.

Mr CARBINES — Just on that, Chair, just asking Narelle, so you made an original enquiry at 15?

Ms GRECH — Yes.

Mr CARBINES — So when you've made a further enquiry, have you done that as an adult?

Ms GRECH — Yes. I did when I was about 21 and Professor Kovacs said that he consulted the Ethics Board of Prince Henry's Institute of Research and that they decided that not more than one attempt at contact could be made, and that's what I had to deal with.

Mr CARBINES — I just want to clarify then what your thoughts are beyond what you've provided around pursuing information as an adult when perhaps obviously it may have resulted in an inclination, a decision to make an application to seek information when you first knew, which in many examples might be when people are necessarily an adult and maybe thinking differently about how they would want to pursue that information and not being able to do so?

Ms GRECH — Sorry, what was the question?

Mr CARBINES — I suppose as an adult being able to again wanting to seek that information if there is any different context as to when you first thought about it?

Ms GRECH — I've always had the same curiosity, always wanted to know, always felt that it should be information that I should have, you know, especially seeing that it exists. Speaking about it has become a lot more important for me to know now in terms of health concerns, it was never something that I wanted to know alone, it was always a matter of curiosity about other things, more kind of social implications and if it's genetically inherited, but now it's become reignited with becoming unwell.

Mr CARBINES — Do you feel that when you've been refused on subsequent occasions that it's been particularly based on different principles than not having a response in the first place?

Ms GRECH — I don't agree that only one attempt being made is enough.

Ms BURNS — We don't even know if the letter was sent to the correct person.

Ms GRECH — I did ask Professor Kovacs to see a copy of the letter because I would even query as to what he'd written, whether he consulted a counsellor even, that the letter itself may have been, I don't know, off-putting. I query whether he actually did that search. I don't have a lot of trust in the doctors, I don't have a lot of trust in the system. I've been lied to from the time of my conception so why should I believe that anything has been done now? I feel a big lack of control and mistrust.

Mr CARBINES — Narelle, the follow-up question for me is it sounds like a donor-conceived person having some confidence in what sort of approach has been made regardless of what the outcome of that approach might be that's been done on your behalf is important in giving you some confidence about it?

Ms GRECH — Yeah. And the other thing is when I found out, I wasn't at all offered any counselling, there were no provisions for that, and I had to deal with it on my own, and I did for quite a number of years. I think I saw a school counsellor but they had no idea about donor conception. I think I did end up seeing one counsellor, fertility counsellor, when I was about 18, but I was the first donor-conceived person she had met, she'd only ever spoken with infertile couples. She helped me a little bit but I had to support myself through it.

Mr CARBINES — I was hoping to try and understand the circumstances that you're trying to think through and grapple with as to why the information cannot be provided. As you say, it's one less aspect that you perhaps concern yourself with if you had some confidence in knowing this is the content of the letter that's been made and the approach and that's one less aspect you might be thinking about.

Ms BURNS — Or it's been handled by an independent authority, not by a doctor who maybe the donor was his friend, we just don't know.

Ms GRECH — Yeah.

The CHAIR — Do you know if the doctor has contacted the siblings?

Ms GRECH — No, I don't think he has. I have put my information onto the voluntary registers in hopes of finding anyone, be it the donor or the half siblings, I would be interested to know them or meet them, or even exchange information through the register.

The CHAIR — Half siblings would have to have done what you've done and gone back to finding the treating doctor.

Ms GRECH — Exactly. And they would have to know they were donor-conceived. I'm relying on the fact that their parents have told them and I'd say that most of them don't know that they're donor-conceived because it's not reflected on the birth certificate, and that makes me very angry. I could go my whole life without knowing any of them. I could meet them in the street, I could have met them already. I do go on to speak about that, if I can continue with my submission.

So during my time at university, speaking of my half siblings, I made posters in the hopes that I would find my half siblings. The posters asked my peers to think about their place in their family, for they may be donor-conceived and not know it. They may be my sibling and not know it. I felt, and still feel, very strongly that all donor-conceived people need to know the truth about their conception. I never did hear anything from a potential sibling but hoped that it got people thinking about this injustice. I also have concerns about genetic sexual attraction, which is real. Melbourne is a small place and the risk associated with meeting and having a relationship with a relative is possible.

I've gone to other strange and great lengths to search for T5. This is a little bit embarrassing. I had a dream years ago that T5's surname is Aberdeen. I was so moved by this dream that I sent letters to all the Aberdeens in the White Pages in Melbourne asking if they had donated sperm at Prince Henry's. Unfortunately, I only received letters back stating that they were not who I was looking for. You might think this is a very strange thing to have done but when you have little or no information you're forced to follow your heart.

I've been forced to be my own detective, so to speak, in my search for answers. None of the information has really ever come easily, besides the few pieces of non-identifying information that Professor Kovacs gave to me initially. There's been a lot of inconsistency in support and assistance provided to me and other donor-conceived people, especially those of us born prior to legislation. Like I said, there was the one attempt made and the second attempt was denied. You often have to know who to ask, who to phone, where to write before any information is given to you. You're lucky if your records exist, you're lucky if you're offered counselling. Maybe lucky isn't the right word but it feels like some of us need luck on our side before we're assisted. I feel like I've been dealt a dud hand for so many reasons.

Not only do I not have access to my records, earlier this year in May I was diagnosed with Stage 4 bowel cancer following an emergency surgery at Royal Melbourne Hospital. The first thing the doctors and surgeons asked me was: is there any family history of cancer in your family? You can imagine how upsetting it was to not only be told of this diagnosis but to then have to wonder whether I've inherited this from my paternal family. I must say that my sister and I both were really angry and upset and in tears about this at the hospital. I'm sure there was no family history of illness at the time that T5 donated but who is to say he simply did not know this at the time? What if he or someone else has developed cancer since 1981? What if he died from cancer himself? What about mental health implications? I'm not sure that the questions around health in the early days were as thorough as they are now. What if my eight half siblings are also at risk of cancer? What if they have children whose aunty has bowel cancer? It's really quite important that they should know this if they're at risk.

It's believed that in most cases where a person is diagnosed with bowel cancer under the age of 30 that there is a genetic link. There's no cancer on my mother's side of the family. Everyone has been shocked that someone of my age could have such developed cancer. It's metastasised to my liver and my lungs. I'm responding really well to treatment; however, I still have a big battle ahead of me. Had I known about this possibly inherited disease I could have been screened for it at a much earlier age; for instance, when I found out I was donor-conceived. Perhaps it could have been caught earlier, giving me a better chance of survival. At it stands, the doctors are saying that the cancer is incurable and the chemotherapy treatment I am currently undergoing is not to cure me but to prolong my life expectancy. If the doctors are correct, I have five to 10 years left to live, if I'm lucky.

So it's really important to me now that I can know who my paternal family is. I would like to meet them or know of them before I die. I want to be able to say that I truly know myself before I die. I do not want to leave this earth without this knowledge. Having to know my genetic history for health reasons was, like I said earlier, truly one of the last reasons I ever felt the urge to find my donor, and now it's probably the most important thing.

For this reason I feel very strongly that not only should thorough medical information be collected from donors but that this information should be updated at least every five years and that there's some kind of provision made for that. Broadly speaking, I feel that the practice of donor conception has always been too far ahead of any ethical consideration given to the human implications of this medical treatment. I view donor conception primarily as a money-making industry that is mainly focussed on enabling adults to have children at a price. I do not feel that the doctors have any true vested interests in the emotional or social consequences of what they do. In my experience with them, I feel especially strongly that the doctors who began this practice in the late 70s here in Melbourne did so with their own interests at heart. They were eager to make history and went ahead and did so without properly considering what that meant to people like myself who they were helping to create.

I was going to say, for example this afternoon my conservation with Professor Kovacs was just shocking to me and I was quite upset. I think it was quite unprofessional of him to say he has to now check that my donor code is T5 when for me that's been a huge piece of information. I'm sure it is T5 but it's very hard to hear that your treating doctor is now saying he has to double-check that.

The CHAIR — Was the phone call related to your appearance here today?

Ms GRECH — Yeah, just this afternoon because he had a meeting with Births, Deaths and Marriages to try and access my information again because since finding out that I have cancer now he's willing to help me.

Ms GARRETT — Thank you for making the submission here today and we are most impressed with your courage and wish you absolutely all the best.

Ms GRECH — Thank you.

Ms GARRETT — There is the ethical obligation, the doctor is now saying that he should, so initially a visit to the Ethics Committee about only once, it's going back to the Ethics Committee now?

Ms GRECH — I don't know. I can't say for sure that he did approach the Ethics Committee years ago. I don't really believe everything that he's telling me. I would like some more searching to be done, some more attempts to be done. I'm seeking access to my records for many of the reasons I've spoken about today. I'm seeking fair and equal treatment and feel that all donor-conceived people should have access to their records no matter where or when they were born. Much like the access granted to adopted people in this state, I'm asking that we are awarded the same rights and I don't believe anyone should have to question their own identity. I feel very strongly that I should be able to have the opportunity to know my whole genetic history and ask the Victorian Government to allow me this opportunity in the near future.

I would like to thank you for your time today.

The CHAIR — Before we move to Lauren, if I could make a comment. As a committee we will come up with a report which we will make recommendations to Parliament and the whole process grinds along very, very slowly, which is obviously not ideal in your situation. There has been a lot of interest in this inquiry with the media and I'm just wondering whether it would assist you if you would want me, in my discussions with the media, to suggest that your story might be a good one for them to profile and perhaps going into the detail of the Maltese origin of your father, that it may prompt that person to come forward?

Ms GRECH — Sure.

The CHAIR — Do you want to have a think about it and maybe contact me later?

Ms GRECH — I'm happy to do that. I've done a lot of media over the years; I've lost count of how much I've done. I'm happy to do more. I did Channel 10 News recently, The Age, the Women's Weekly comes out at the end of the month so, you know, I've always done it in the hope that he would see and come forward. I feel quite defeated. Lauren and I were speaking earlier just about I used to be quite angry and really passionate when I spoke and I feel quite defeated. I should be at home looking after myself and getting well but I feel so compelled to do this, but I'm also quite tired of having to continuously beg for this information and it's really soul destroying.

Ms BURNS — Can I just say, because Narelle probably won't bring it up herself, she's undergoing chemotherapy once a fortnight, she's got no energy, she's nauseous, and she should be concentrating on getting well but she's spent a lot of time writing this submission and she's still actually diverting that energy, that should go into her health, into this inquiry.

The CHAIR — With the media that you've done so far has any of that included the Maltese origin?

Ms GRECH — I can't remember.

The CHAIR — It seems to me that that would be a key thing to get out there. There's probably 1,000 donors out there that might read the Sunday Age and say: that could be my daughter, I don't know. But if there is some publicity around the Maltese origin, that might prompt T5, if he reads it, to come forward.

Ms GRECH — Yeah.

The CHAIR — It might assist in some way. Okay, Lauren.

Ms BURNS — I would like to also begin today by thanking the committee for giving me this opportunity to provide evidence at this public hearing. I found out I was donor-conceived when I was 21, without ever suspecting that my dad was not my biological father. After that I spent about three years in shock, before meeting up with other donor-conceived people, such as Narelle, and realising it was actually normal to have these feelings of anger, grief and loss associated with withholding of information about my genetic father and siblings. Without this information, I didn't feel like I could be a whole person and I ask: can you imagine what it was like for me to know that the information actually existed but it was being withheld from me? It was especially painful when a supposedly socially progressive Parliament passed the Assisted Reproductive Act back in 2008, and this reaffirmed that it is illegal for me to truly know myself. I don't think it is wrong to want to know who my biological father is but the fact is the law still says that it is.

Initially I was told my donor would have forgotten about me, definitely wouldn't want to know me; in fact, finding out about my existence would have negative impacts and potentially even ruin his life. There is a perception that donors must be protected from donor-conceived people, such as myself and Narelle, and the way the debate is framed about potential impacts on past donors suggests the very existence of donor-conceived people is somehow toxic and an embarrassment, which is quite hurtful to us.

The CHAIR — If I could just interrupt there. We've had a fair bit of submissions to this inquiry and I think the overwhelming evidence from everybody in the process is that donors are actually quite inquisitive about their — —

Ms BURNS — Exactly. My point is that that was a myth. Despite the negative response of the clinics and the law, I believed I did have justice on my side so I went through a long process of trying to obtain this information, including two newspaper articles, an appearance on the breakfast show, Sunrise, engaging a lawyer pro bono through PILCH, endless letters to politicians and the previous Attorney-General before I made a breakthrough.

After meeting with the then Governor of Victoria, he agreed to write to my donor on my behalf and in fact my donor responded within days. I was really lucky to have the resources of some fantastic donor linking counsellors — Helen Kane here and Kate Bourne — in making those first tentative steps and I want to publicly thank them, and also David de Kretser, for their assistance. I'm really glad that I made this approach back in 2009 because if I did it again today I would be completely on my own, because the Assisted Reproductive Treatment Act effectively dismantled donor linking services and personally I can't fathom why this was done, and I really hope that one of the outcomes of this inquiry is the restoration of the management of the donor registers and the counselling services to VARTA, or basically to the ITA model.

Anyway, finding out about my existence didn't ruin my biological father, Ben, and his three children's lives; in fact, they responded in the opposite way to which I had been warned. They were very welcoming and after writing letters and speaking on the phone we all met in person and have been in touch since that day. Before we met I was extremely nervous and on the day it was quite overwhelming to be surrounded by people that looked like me. Afterwards I think my overarching feeling was one of relief, relief to finally be able to trace the origins of my looks, personality and interests and this had the effect of soothing the endless whirring of questions which had been like a splinter in my brain.

I've written about my story quite extensively so I will leave it up to the committee to ask any more specific questions about my experience in getting to know my genetic father. Now I would like to highlight some key issues regarding the polarisation of viewpoints within the medical community, draw on some legal arguments and help provide some clarity regarding the so-called donor contracts.

Reading the submissions which were put up on the website it became apparent to me that opinions are divided upon quite clear lines so on the one hand donor-conceived people, our parents and faith-based organisations believe that it is crucial for the health and well-being of donor-conceived people that we are all treated equally and provided with access to information about our genetic identity regardless of when we were born. Or, to put it another way, the rights and interests of the child should be considered paramount, as enshrined within the Assisted Reproductive Treatment Act which, as I mentioned, ironically takes away those rights for those of us born prior to 1988. On the other hand, peak bodies representing health professionals, the Fertility Society of Australia, the Australian Medical Association and individual doctors believe that under no circumstances should donor-conceived people have information about their biological identity without the consent of the donor.

I think it should be noted that the experience and expertise of these doctors is with patients wishing to fall pregnant. They worked analytically on what was seen as a purely medical problem in that if the problem was defective sperm, logically this could be fixed by bringing in healthy sperm. Then the gametes were prescribed like medicine, without thought for the social issues involved in re-engineering these intimate family relationships. For example, when I met with Professor David de Kretser, he told me that I was the first adult donor-conceived person he had ever met. So for those doctors, when a healthy baby is born they congratulate themselves on a job well done and what they may not realise is this is not the end, it is actually the beginning of the story of our lives. Unfortunately, the doctors don't stick around to see what happens next so they don't see this smiling, bouncy baby grow up and begin to think for themselves about what it all means, struggle with identity formation and knowing who they really are, or begin to feel somewhat hollow inside through feelings of loss and grief associated with separation from their biological family.

None of this is an infertility doctor's area of expertise and because this inquiry is about donor-conceived people, doctors actually have very little expertise to comment on these issues. They are not ethicists and so we must remember it was these exact same people who decided it would be a good idea to have anonymous donors in the first place. Today we recognise that this is a mistake, anonymous donation is banned in Victoria. Doctors were mistaken then and I believe they are mistaken again today in recommending that we do not deal with and rectify the wrongs of the past.

To illustrate what I mean, I want to read a short passage from Gab Kovac's personal submission: "Retrospectively removing the anonymity makes liars of the clinicians who recruited these donors, including such eminent clinicians as Professors Carl Wood, David de Kretser, John Leeton, Doug Lording, Gordon Baker, Mr Ian Johnston, and myself." Clearly for Gab Kovacs, this inquiry is very much about Gab Kovacs and potential loss of reputation.

In my opinion, the last thing we should be worrying about is the reputation of doctors. This inquiry is about donor-conceived people and at long last the focus should be on us. In his submission Professor Kovacs does not acknowledge the hurt and harm caused to donor-conceived people and, somewhat bizarrely, doesn't actually even mention potential impacts on past donors. He doesn't have experience dealing with the long-term effects of donor conception from either the donor-conceived or the donors' perspective and it's for this reason that I think his submission should not be given much weight.

Personally, I think that he and some of the other doctors are afraid, they're afraid of acknowledging complications caused by their actions, so instead they trivialise the testimony of donor-conceived people, such as Narelle and myself, as not being important enough to require attention or indeed action. I hope that this committee has more courage and this is not yet another inquiry that goes nowhere but recommendations for real change are made. Reputation is one reason why doctors, and the peak bodies representing them, oppose this reform.

There is potentially another reason, which was raised by Kate Dobby who maintained the donor registers at the Infertility Treatment Authority from 2005 to 2009. I'm not sure if you asked her about this at the public hearing on Thursday, but this quote is from her submission number 33 from the interim report. She said: "Some clinics, hospitals and doctors may oppose the granting of equal rights to access information for the donor-conceived, not only because it exposes the weaknesses and inadequacies of past records, but because of what is revealed about past practices. Egg swapping, sperm mixing, donor's identities not being verified or donors being encouraged to donate under pseudonyms, offering free vasectomies and sperm storage, STD testing and university course credits in exchange for donating, knowingly creating up to 30 separate families or in excess of 40 children from one donor, using anonymous donors imported from interstate without paperwork, recoding donors, the practise of on-donation, utilising patients as donors whilst they are still in treatment and using donors for whom valid consent could not be verified are just some of the practices that I know to have occurred in Victoria — even after the introduction of legislation."

So can you imagine what might happen when people believe they are protected by an absolute cloak of secrecy and that their actions will never subject to scrutiny? Perhaps some of the donors themselves are from the medical community and this may be just another reason for strong resistance to transparency from the medical associations. So having seen that the donor-conceived people and doctors are in conflict, who else is there for the community to listen to? I believe a more balanced and objective viewpoint can be ascertained from accredited fertility counsellors, because they have regular experience dealing with the main players, that is the donors and the donor-conceived people. Even better, some of them have rich personal experience at the coalface of dealing with the whole donor linking experience. Fertility counsellors such as Helen Kane, Kate Bourne, Merrilyn Mannerheim and Jo Moffat. These are fertility counsellors who made individual submissions to the committee endorsing retrospective access to information. Indeed, Gab Kovacs admits that Monash IVF’s submission endorsing retrospective access to information was written by a infertility treatment counsellor.

Another independent person is Dr Sonia Allan, who is a Global Health Law Fellow at Georgetown University Law Centre. In considering the balance of rights and interests of all parties, she concludes that the possible injustice to one party — some donors — is acceptable in correcting a manifest injustice to others, namely donor-conceived people, donors who wish to share information and parents who want their children to have access to information. This is the principle upon which retrospective access should be recommended and is the identical argument that underpinned retrospective access to adoption records which occurred in Victoria in 1984, after which all states in Australia, New Zealand and the UK followed suit, despite protests from a small number of birth mothers who argued they had a right to privacy.

The CHAIR — As far as the access goes, the actual information that you think should be provided, are you talking about the actual name of the person and their contact details, everything, or just relevant information that doesn't identify them?

Ms BURNS — I'm not saying that the information should just be released to the donor-conceived person, I think the Committee should make a broad policy decision that we have a right to access this information and then come up with a system which is sensitive to donors based upon things like the adoption precedent, so you have counsellors acting as intermediaries and things like donors and the donor's family being able to access counselling about what it all means for themselves and their families, and that there should be a process; it's not just a question of releasing information.

The CHAIR — I understand that but my question, putting aside the actual process, obviously it has to be done properly, do you think that someone who doesn't want to be identified should be obliged to be identified to a donor-conceived child?

Ms BURNS — I think that there should be a distinction between an information veto and a contact veto. I think donors who don't want contact, that's absolutely within their rights, and I respect that, and every donor-conceived person I've ever spoken to also respects that and is very conscious of not wanting to intrude upon the donor or invade their life in any way. As I said, I think the Committee should make a broad policy decision that we should have access to this information but in coming up with a system that is also sensitive towards donors perhaps we may look at things like a contact veto, for example.

The CHAIR — So if there's a contact veto, does that mean that you would be provided with as much information as can be gathered without providing the contact details?

Ms BURNS — No, no. The way a contact veto works, if you're looking to, for example, the Adoption Act in New South Wales, the identifying information is released to the person after they sign a stat dec stating that they will not make contact, or they will not have a person make contact on their behalf. But there are also issues with contact vetoes, for instance if they are revoked, I think that the person should be informed, if in the future a contact veto is revoked, so there are still issues to consider.

To answer your fundamental question, yes, I think we should be able to obtain the information based on the principle that the rights of the child are paramount. As you can see, it potentially can drive us crazy for the rest of our lives not to have that information.

The CHAIR — If a donor-conceived child was to receive the information but also got the information that the donor doesn't want anything to do with them, is that circumstance a better outcome than otherwise?

Ms BURNS — Yes.

Ms GRECH — Can I say personally, I've always felt being in a position where I don't know anything, it would be better to know something. I've thought of all of the potentialities of finding my donor, or even learning his name, but like I said in my submission he could have passed away. I don't imagine that he's only a really nice person or a nice man, I don't put him on a pedestal, he's a person, so he may not want to know me but as long as I knew that I'd have something to then move forward with and I wouldn't continue to have this longing. It's the curiosity of not knowing, like if a child goes missing or if someone you love went missing, you would just want to know where they are, even if it's that they don't want to come back. It's having the answers and, you know, it being your choice or their choice as to whether that contact is made.

The CHAIR — So you're not aware whether T5 is still alive or not?

Ms GRECH — No idea.

The CHAIR — Do you know whether Professor Kovacs has had any contact at all since — —

Ms GRECH — No idea.

The CHAIR — He's told you no?

Ms GRECH — I know nothing. So to know something, even if T5 said: okay, here's my name, here's a little bit of information, I can't for whatever reason know you or have you as a part of my life. At least then I would know that and I could move on. Or maybe at least do a little bit of ancestry research myself without having to sit down with him. I can understand that time has changed, he's perhaps got his own family, but he may be passed away, he may be living in another country; it would just be nice to know anything. It's just disempowering not being able to know.

Ms BURNS — I think it's worth noting that this inquiry, including the Interim Report, has been going on now for about 15 months and you would think that this inquiry in particular would attract responses from donors who do not wish to be contacted. It's my understanding that so far the Committee has received such a response from only one donor, which I think is quite significant because it's only one over the course of the 15 months it's been advertised. Unfortunately, I think a weak point of this inquiry has been the lack of donors actually responding to the call for submissions. It's not a criticism of the Committee, I understand it's very difficult to reach these men because they don't have their own networks. I believe there has been only four, which is not enough to draw strong conclusions; however, we can look to other evidence.

For instance, I looked up, as of June 2010, 143 donors have registered with the voluntary registers in Victoria. The Committee may be surprised to learn that donors actually currently outnumber donor-conceived people on those voluntary registers. We also got some submissions from donor linking counsellors such as Merrilyn Mannerheim and Jo Moffatt who drew some general conclusions from their dealings with many donors in their own submissions.

The last thing I wanted to talk about was I wanted to clarify what I think is a very important point which is crucial for the investigations of the Committee. In the submission by the Australian Medical Association, they assert that "Contractual assurances were given to those who donated prior to 1 July 1988 that their identities would not be revealed to donor recipients, nor to donor-conceived people and that they would be able to remain anonymous."

Closer scrutiny reveals that on the best evidence that is available this is actually complete rubbish. TangledWebs have been collecting donor statement and consent forms, which are the so-called contracts, from all Victorian infertility treatment clinics offering donor insemination prior to 1988. I tabled three of these for the Committee covering Prince Henry's, Royal Women's and Queen Victoria hospitals and none of these statement and consent forms provided an assurance that donors would remain anonymous, or that their details would not be passed onto the donor-conceived children or a third party such as a donor register. They simply prohibit the identity of the donor being revealed to the recipient woman and vice versa. Maybe the doctors did talk about anonymity or maybe they didn't, I don't know, but we know that they didn't put it in the contract and if they thought that perhaps they should I think it shows a lack of forethought as to the long-term consequences. The fact that the donor-conceived child doesn't actually even make it into that donor statement and consent form shows how little they actually thought about us.

The myth of the existence of these contracts has been an unchallenged assumption that is a key issue for the Committee, since it goes to the heart of what was promised and implications for breach of contract — we talked about legal implications and things like that. I would be very interested to know if the Committee has actually seen any evidence of contracts guaranteeing the identity of sperm donors will not be revealed to donor-conceived people. I don't know if you can answer that or maybe later.

So I put it to the Committee that the existence of contracts guaranteeing donor anonymity is a myth that has been perpetuated by several inquiries without the strength of any evidence. Even if such a contract could be produced, how could such a contract between two parties, the donor and the clinic, be seen to be binding towards a third party, the donor-conceived person?

In truth, there's a bit of a subtext that sometimes the relationship between donor-conceived people and the doctors and the clinics is actually quite dysfunctional, and I believe that some doctors view us as essentially Frankenstein's monster rebelling against our creator. For example, the AMA bring out an old chestnut that I often hear brought up in the context of this debate. They said: "It should be noted that the donor-conceived child may not exist but for the agreement in question." The implication being that if we are happy to be alive, we don't have the moral authority to criticise what happened in the past. And to that I say that we don't ask children conceived from rape to endorse rape because otherwise they wouldn't exist, and it is similarly absurd to expect donor-conceived people to endorse anonymous donor conception in order to pay back a perceived existential debt.

In summary, donor-conceived people believe we have a right to information, while doctors don't support that position according to the submissions. As individuals, fertility counsellors provide a more objective viewpoint and the evidence presented to the Committee from these individuals who have worked as donor-linking counsellors is they believe that on balance donor-conceived people should have a right to information, with the appropriate support available to all stakeholders. Doctors may oppose transparency due to worries about loss of reputation and scrutiny of past practices. As far as I'm aware there is no evidence to support the existence of contracts guaranteeing donors anonymity.

Clinics have been peddling a golden fairytale of assisted reproductive technology for four decades and this inquiry is one of the first opportunities that donor-conceived people such as Narelle and myself have had to express the full reality and complications of these procedures and the long-term effect they have on our lives. I hope the Committee will focus on the two most important groups, the donors and donor-conceived people, and will not give much weight to the mouthpiece of the medical establishment who presume to speak on our behalf.

And at its heart, I believe this inquiry is about people. It is not about forcing people into unwanted relationships, it's about giving people like Narelle or myself the knowledge we need to complete our sense of identity and normalising the rights of older donor-conceived people to match the standards we set for other Victorians, such as adopted people or younger donor-conceived people. I urge the Committee to make a commitment to the broad policy outcome that donor-conceived people deserve to know the identify of their donor and use the experience from the adoption precedent to create a sensitive system that enables this right and is respectful of donors. Please have the courage to not let this be another inquiry that goes nowhere. I ask you: what is the point of not facing up to the past wrongs? Be brave enough to rectify the mistakes of the past and dismantle the antiquated and inhumane system of denying donor-conceived people knowledge of our genetic heritage, with the assistance of appropriate counselling services as were previously provided by the Infertility Treatment Authority. Thank you.

The CHAIR — Thanks, Lauren; that was really good.

Mr CARBINES — Lauren, just picking up on some of the examples of the donor consent form that is part of your submission. As a Committee we will have to make broad positions on our views of those forms, but to take one as an example that is included here, and a couple of the statements in one of the consent forms, just to quote from it it says: "I understand that the identity of any recipient shall not be disclosed to me, nor shall you voluntarily reveal my identify to any recipient." Then when you go down further it talks about: "I agree never to seek the identity of any child or children born following upon the artificial insemination of any recipient of my semen, nor seek to make any claim in respect of any such child or children in any circumstances whatsoever." The two statements seem to refer to recipient and — —

Ms BURNS — The recipient is the woman undergoing artificial insemination.

Mr CARBINES — People who are trying to make an argument or construct around consent forms, your view is a donor-conceived person isn't covered?

Ms BURNS — It's there in front of you, in black and white, we're not mentioned in the contract. It's not just what I'm saying.

Mr CARBINES — If they were making a virtue of the consent forms to hold a certain position, your view is?

Ms GARRETT — I suppose the context was also that the couple receiving the donation were told not to tell the child.

Ms BURNS — Yes.

Ms GARRETT — So presumably there is a view the child would never know.

Ms BURNS — There was. But secrets of that magnitude don't — —

Ms GARRETT — I'm not saying it was right, I'm just saying it seems to have been that perhaps the child wasn't even contemplated because the prevailing wisdom was you would never, ever tell.

Ms BURNS — I think it shows how little the child was actually considered.

The CHAIR — The problem, as I see it, regardless of what is in this contract, your exclusion from the process is covered not by this but by just doctor/patient confidentiality. If I was to go to a doctor and say: tell me about my mother's medical history. The doctor would rightly say: sorry, we can't give it to you without consent. To me, that seems to be the real problem that we've got.

Ms BURNS — That's up to you guys. The Privacy Act says that exception is made for legislation so if you pass legislation then that problem disappears.

The CHAIR — In weighing up essentially the rights of the donors, the donors against rights of the children. Would a middle ground of a legislative requirement for people who hold this information to at least make contact on behalf of donor-conceived children, would that go far enough to satisfy children do you think?

Ms BURNS — No, I don't believe so. Currently we have a system where in an ideal world clinics would make an approach on our behalf but I think you've heard from our testimony we have to fight tooth and nail for that and for clinics that don't exist anymore the records aren't accessible.

The CHAIR — But if there was a process whereby, for example, Narelle was able to be assured that, yes, a serious contact had been made and it's been five years since the last one, or whatever the period is, and now another one is going to be made because that's in the rules as we suggest, would that satisfy you?

Ms BURNS — Are you talking about from a central authority or from clinics?

The CHAIR — Wherever it may be and we have to consider that what is the most appropriate way of records being held. But if we were to come up with something, wherever the records are held, that there is that requirement that is consistent regardless of where your records are held, that if an approach is made from a child that this is the process that must be followed and it goes as far as a serious attempt being made to contact the donor and to let him know that there's an offspring looking for further information, does that go far enough?

Ms BURNS — I think that that would help a lot of people. I guess my problem with that is it doesn't fulfil the equality aspects of we give these rights to younger donor-conceived people once we make a decision that they deserve this information; it just doesn't make sense to only apply it to a certain population. It's the same in adoption, they could have unsealed the adoption records from the point in time that the legislation was passed but instead they chose to make it retrospective back to 1928 because they thought it wasn't fair to create a two-tier system where you essentially have first class citizens who have access to information and then second class citizens who don't automatically have that information. I think, for me personally, there is a kind of almost an ethical thing in knowing that the law says that I don't have a right to access this information, for me it just seems morally wrong to have that in a state such as Victoria, which is supposed to have removed all forms of discrimination from its books.

Ms GRECH — We're the only group of people who can't access our own information.

Ms BURNS — I don't understand why we have to make these arguments over and over again through different law reform, through adoption, through donor-conception. To me it's extraordinary that we actually don't have the information, that we're still going through this process.

Ms GRECH — The Adoption Act is a blueprint for what we're going through now, that was 20 years ago, and the people that were arguing for that access to the closed records were actually in touch with the fertility doctors — funnily enough we know some of them personally — who have said that they were speaking to the fertility doctors at Prince Henry's and other such clinics saying that the same problem will be faced by donor-conceived people born by anonymous donation. So there's many reasons why we feel that we're entitled to this information, I don't think the doctors should be that shocked that we're asking for this now; it was thought that this may be the case from the outset. I think it's about time.

Ms BURNS — I think it's the methods that the donors have to be protected from us. Donors essentially did this for altruistic reasons and I think that altruistically they will be happy to help out once again, to provide information that the people need, just to be able to make sense of themselves.

The CHAIR — From what I've heard so far, that would be my expectation that if there is that contact made, and it's done properly, it would get a positive outcome in most cases. Just in terms of balancing it up, if we go that step further where basically these people are being forced to be identified — —

Ms BURNS — But it's not about forcing people into unwanted relationships. We're all adults, and in other spheres of adult life, you know, without the government interfering in your personal relationships you just say: look, I don't want to speak to you. I mean, if you felt like you had to add some extra protection for the donors, you could consider things like a contact veto. I know that in New South Wales it actually has never had a breach of a contact veto, it's worked very well there. I just think that it's morally wrong.

The CHAIR — Contact veto in the adoption — —

Ms BURNS — In the New South Wales Adoption Act. I just think that it's morally wrong to deny us this information.

Ms GRECH — We're not seeking anything material, we're not seeking to intrude on their lives. I think if T5 turned around and said, like I said earlier, I can't know you, I can't meet you, here is some information, these are the reasons why I can't meet you, these are the reasons I donated, that would satisfy me. We don't want to intrude, we really don't want to intrude. I've never met a donor-conceived person who has pushed for that. I understand that T5 probably did it for money, or that he probably had no real idea what he was doing; if he was a young person who was just married, maybe he did it for some extra cash, I don't know. I'm fine with that and I understand that it was done in secrecy.

Ms BURNS — We're not asking the Committee to break new ground, this has already happened in adoption, there was the question of what are we going to do about the birth mothers who want to remain anonymous? When they relinquished their child they were assured they would remain anonymous and do they have a right to privacy? These are the questions that were considered. It's a very complicated situation but on balance, transparency and truth is the best way forward, just to minimise the harm from the whole situation.

As happened in the 80s, Victoria was the first, Victoria was ground breaking. I think we have a proud history of having some really good law reform in Victoria, a socially progressive state, and it was actually followed suit all around Australia. I think it's the same thing here. I don't know if you're aware there was a Federal inquiry by a senate committee in constitutional affairs who said they are going to leave the question of retrospective access up to the states and I believe that the other states are watching Victoria and that if this proceeds I think that very quickly some other states will follow suit.

The CHAIR — Anything else?

Mr NORTHE — Only a statement. Full of admiration for you both. You've presented extremely well, articulated your case just wonderfully well. I know we've gone way over time but it's just enlightening to listen to you both.

Ms BURNS — Sorry.

Mr NORTHE — Don't be sorry at all. I think I can speak for us all, it was absolutely enlightening and well done to both of you and wish you all the best.

Ms GRECH — Thank you.

Ms BURNS — Not always easy. We were talking just on the phone, we almost just feel like bursting into tears. We've said this so many times, we've told our story so many times, but we know that for you guys this is the first time you've heard it. This is the last time we have to essentially go through it.

The CHAIR — Thank you very much.

Ms GARRETT — Thank you very much.

The CHAIR — You've certainly given us a lot more to think about. When things were starting to become a bit clearer they've suddenly become a whole lot murkier so you've done your job well.

Ms GRECH — Thank you.

Ms BURNS — Thank you.

The CHAIR — Well done.

Committee Adjourned.