

CORRECTED VERSION

LAW REFORM COMMITTEE

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

Melbourne— 17 October 2011

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Witnesses

Ms M. Cummerford.

The CHAIR — Thanks for coming. Were you here for my introductions for the last witnesses?

Ms CUMMERFORD — In terms of parliamentary privilege?

The CHAIR — Yes.

Ms CUMMERFORD — That's fine.

The CHAIR — If you could start with your name and address and then talk us through your submission.

Ms CUMMERFORD — My name is Myfanwy Cummerford.

The CHAIR — What would you like to tell us?

Ms CUMMERFORD — I'm not going to address my submission to the Committee, I'm just going to, if I can, counter some of the points in the submissions that I read. I will counter some of the points that were made in this hearing, firstly.

I just want to make the point that I think was made by Ms Petrovich that donors knew that they were going to father a child — I think you heard from my father last week, Michael Linden. I don't know if he mentioned to the Committee that he wasn't actually aware at the time of donating that his sperm was going to be used to create children, he was told at the time it could possibly be used for medical research, so the first he knew that he had children resulting from his donations was when I made contact with him.

The other point made by Ms Petrovich again was the expectation of family. I think it's fairly common among donor-conceived people, and particularly it was the case for myself, that I had absolutely no expectation that there was going to be any familial relationship between Michael and myself. I didn't expect that Michael would even want to meet me, and it came as a complete surprise that he wanted to include me in his life and considered me equal in status to his daughters that he conceived within his marriage.

Mrs PETROVICH — That was the point I was making. And he's exceptional.

Ms CUMMERFORD — Yeah, he was exceptional. But also that my half sisters, his daughters, consider me an equal as well so they consider that we share a father and I'm equal in status to them as well. A point that came up by Monash IVF, the recommendation made that donor records be managed by clinicians, what assurances do donor-conceived people have that the records will be protected? Maybe it's slightly different with the bigger clinics, like Monash IVF and Royal Women's who have perhaps better record keeping practices, but with smaller clinics we know that records have been destroyed. If those records are maintained by clinics, how can we ensure that donor-conceived people can be assured that their records are not going to be destroyed, are managed correctly, and also the symbolic aspect of it in that if the records are maintained by clinicians they're not maintained by a neutral agency.

I wanted to comment on the concern that clinicians might have about the information maintained in those records. I thought perhaps a good suggestion could be that if it's

information related to practices that occurred at the time, perhaps only the identifying information of the donor, if it exists, could be extracted from those records and passed onto a neutral agency, say VARTA or the central register, if that could alleviate some of the clinicians' concerns.

One of the counsellors mentioned that there's incomplete records and an unknown pregnancy is recorded on their records, because it seems that the number of records where that has occurred is minimal so couldn't that information be cross-referenced with regards to a child being conceived as a result of a donation and then that pregnancy isn't recorded, you know the approximate date? That's just a suggestion. I also wanted to reiterate the point that was made by Lauren and the counsellors who appeared before me that the VARTA service is vital from the service that existed in the previous incarnation of ITA, vital from the donor-conceived person's perspective that we're dealing with a neutral agency and not dealing with the clinic, and also the counselling services that were provided under that previous auspice.

I've got three more points related to the written submissions. I noted that a number of submissions proposed that a suitable compromise would be to treat pre-1988 donor-conceived people the same as those conceived using gametes donated between 1988 and December 1997, in that the consent would need to be sought in order for information to be released. I would just like to say that this isn't a compromise at all and would not effectively change the current position of pre-1988 donor-conceived people. Information belongs to the donor-conceived individual and their family. To require consent for release of identifying information perpetuates the status quo that a donor-conceived person is not entitled to the same freedoms as other donor-conceived people, or indeed the general population. All donor-conceived people must be afforded the same ability to access identifying information. Furthermore, as with the adoption model, there must be a provision that — —

The CHAIR — Just on that comment about accessing identifying information, are you talking about names as well as — —

Ms CUMMERFORD — Identifying information so the person's name.

The CHAIR — What if they're going onto the right to contact them and have a relationship?

Ms CUMMERFORD — I'm talking about information, not necessarily contact.

Mr NORTHE — Through the Chair. I guess just in my own head for clarity, the term identifying information is used quite often. I'm not sure that we have a real description of what that means so, in your view, how far and wide ranging is the identifying information?

Ms CUMMERFORD — It's information that's maintained on the records, which identify the donor. For example, I was entitled to receive from the Royal Women's Hospital non-identifying information so it was information regarding Michael's height, hair colour, marital status, previous children, occupation, very basic physical description basically. The final part to that point that I wanted to say is that there must be provision that if the donor cannot be found following reasonable attempts to contact them, as was the case with me, then the identifying information — this is a provision in the adoption model — or whatever information exists on the record, should be released to the prescribed applicant. I recommend

that that could be the donor-conceived person or one of their family members, so for example in my case my son, say if I'm deceased, and if I didn't know who Michael was and he wanted to seek information about my biological father that he would have the ability to do that, as is the case with adopted people.

The second point is I would like to dispute the Fertility Society of Australia's assertion in their submission that the requirement for anonymity reflected community views at the time. Anonymity was a condition of donating, and I note that this was also pointed out in the DCSG's submission and there wasn't an option to be identifiable. I submit that the environment of secrecy was in fact instigated and promoted by the clinics, for example by telling my parents that they should go home and forget about it and not tell me that I was donor-conceived.

The CHAIR — When were you told?

Ms CUMMERFORD — I was told when I was 20, following my parents' divorce. I would like to counter the argument submitted again by the Fertility Society of Australia that section 13 of the Charter of Human Rights and Responsibilities Act, the Victorian Act, which refers to the privacy and reputation section is an effective legal instrument to trump the interests of donor-conceived people, and for the record section 13 states:

"A person has the right (a) not to have his or her privacy, family, home or correspondence unlawfully or arbitrarily interfered with."

The case of *Rose v Secretary of State for Health and HFEA* in 2002 was a case brought to the English High Court by Joanna Rose and another minor on this very issue of retrospective access. Justice Scott Baker ruled that a case could be brought under the Human Rights Act challenging the rights of donors to remain anonymous. Of note was his comment in that ruling that a donor-conceived person has a right to establish a picture of their identity as much as anyone else and, more importantly, that to uphold donor anonymity contravened the donor-conceived person's right to respect for private and family life as guaranteed by Article 8 of the European Convention which states:

"Everyone has the right to respect for his or her private and family life, his home and his correspondence and there should be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary."

You will note that Article 8 of the European Convention is almost identical to section 13 of the Charter of Human Rights and Responsibilities.

The CHAIR — Myfanwy, you've obviously had a very positive experience with your father. Had you sought him and found that it wasn't a positive experience, would your views be different in terms of kids having the right to obtain that information against the wishes of the donor?

Ms CUMMERFORD — Absolutely not. You're talking about contact. As I said before, I didn't expect that I was ever going to have a relationship with Michael; it was enough for me just to have his name. It came as a complete surprise, as I said before, that he actually wanted

to have contact with me so that doesn't change my view with regards to retrospective access at all.

The CHAIR — So your main point is just having that information?

Ms CUMMERFORD — It's your choice to access it if you want to access it.

Ms GARRETT — Thanks, Myfanwy, and I know it's personal issues that you're talking about and we appreciate you appearing and speaking frankly. Can I ask for you to go even more personal and frank, and you found out when you were 20, could you describe to the Committee how it felt and the importance for you, as you've obviously identified in your submission, of knowing your biological father, knowing who your biological father was?

Ms CUMMERFORD — To find out that I was donor-conceived at age 20 was absolutely devastating. I cannot describe a more traumatic experience to go through because by the time you reach age 20 you've got through that angsty teenage period of wondering who the hell am I, that sort of growing up stage, and you seem to be developing a better idea of who you are and where you fit in the world, and then to have that completely demolished is, like I said, absolutely devastating. There was only a really short period of time between me discovering that I was donor-conceived and then actually coming into contact with Michael, but during that period I went through stages — it's described frequently, people talk about grief and loss, it's a process of grieving, what I knew to be who I thought I was, and then redeveloping a sense of identity with this new information that I had. So knowing that people who I thought were my family members were no longer my biological family members, so attributes that I thought I'd inherited from my dad's side of the family I could no longer rely on that position. I also felt like a bit of a fraud, to be honest. I had been overseas and visited people who were my dad's family members and stayed in their houses on the basis that I was their relative, and I felt guilty that, you know, I felt like they'd been duped because I wasn't related to them. I mean, in some sense I guess that's sort of a bit nonsensical but that was my feeling at the time.

After a period of time I began to accept that I probably was never going to know who Michael was, and I was beginning to reach that point at the time that Michael and I came into contact with each other. But even now, I'm not completely okay with the way that I discovered that I was donor-conceived; I really don't want to ever do anything like this ever again so I hope you guys do something about it. I find it really stressful. Does that answer your question?

Ms GARRETT — Yes.

Mr NORTHE — Obviously you're a very strong woman and well done; it takes a lot of guts to do what you're doing. Just in terms of that period of time when you did find out, are you able to advise the Committee, did you have any counselling and support available during that time and who provided them, how did you get through that particular period, and what we could potentially do to enhance it, or were they good at the time?

Ms CUMMERFORD — When I discovered that I was donor-conceived the ITA was I think established at the time but with regards to its support services they were really in their infancy. The first thing I did was to do a Google search and discovered the Donor Conception Support Group who played a key role in Michael and I meeting. I think even the first day that I discovered I was donor-conceived I made the decision that I wanted to do what I could to

discover who my biological father was so I went back to the Royal Women's with my mum at the time. The Royal Women's policy was like a briefing/counselling session where I was handed the non-identifying information. I think I had a number of sessions and then after one or two sessions I was given the non-identifying information. I felt that the service at the time was a bit ad hoc. The Royal Women's agreed to do a search on my behalf for Michael, which was unsuccessful. Once I'd exhausted that, even though I also appealed to the Ethics Committee of the hospital at the time to take my search further, which was declined, once I had exhausted those options I was sort of basically, not told explicitly but that there was nothing more that they could do for me so that was the end of any support from the clinic; and if I wanted to take my search further I'd be on my own in that regard, not that I could really do anything with the information that I had.

Mr NORTHE — So you would advocate then, from your experience, a central body such as VARTA?

Ms CUMMERFORD — Absolutely. I think it's vital, like I said before, that a central body and not the clinics are responsible for conducting searches, mediating between parties and sensitively handling the information.

Mr NORTHE — A subsequent question, if you don't mind conveying, the next phase from there? Obviously you were at a junction where you don't think it's going to happen, the contact?

Ms CUMMERFORD — Sorry?

Mr NORTHE — You're just relaying the story now of where you're at and you haven't quite made contact. Did you feel after that experience you're still not going to make contact with Michael so what did you do after that period of time?

Ms GARRETT — Just if I may — sorry, just before we get there — you knew that the clinic had his details?

Ms CUMMERFORD — That's right.

Ms GARRETT — But they couldn't tell you?

Ms CUMMERFORD — That's right.

Ms GARRETT — How did you feel about that?

Ms CUMMERFORD — I felt really disempowered and disenfranchised and I felt like a second-class citizen because I knew that that information was sitting in a filing cabinet and I wasn't entitled to access it. That made me incredibly angry, and still makes me angry today to hear from counsellors that they've got this information and it's on the computer and that my friend Narelle, who is associated with that clinic, isn't allowed to do anything with that information.

To go on from your point about what I did from there, I didn't really feel like I had any option with regards to taking my search any further so I was coming to terms with not ever knowing who my biological father and half-siblings were, and I still am at that point because I know I

have three other half-siblings out there somewhere. I have dreams every now and again that I'm going to get a phone call one day and be told that one of my sisters wants to know who I am but I've pretty much accepted that that's never going to happen.

The key thing for me in making contact with Michael was that I was a member of the Donor Conception Support Group at the time and Leonie Hewitt, who is appearing after me, organised a meeting of — I forget, it was a couple of dozen donor-conceived people in Sydney, and as part of that she organised some media which resulted in a story in *The Australian* on election day, November 2001, when John Howard got back in again. Michael, my biological father, was reading the newspaper at the time and my story appeared on the front page after the election results and so he was reading the newspapers and primarily saw my picture in the paper but also saw the non-identifying information about me, and then he contacted the DCSG and his details were passed onto me.

Then what we did was we tried to sort of follow policy by communicating through letters via the clinic, so he sent a letter to the Royal Women's and I sent a letter to the Royal Women's, which were supposed to be sent on but they weren't sent on; for whatever reason they were withheld. I forget the period of time but Michael and I were sort of wondering — both of us were actually thinking that we didn't want to have contact with each other because we hadn't received any information. So what we did, because we both had each other's details, we circumvented the whole clinic counselling process and just made contact with each other that way.

Ms GARRETT — Did you make the contact?

Ms CUMMERFORD — To be honest, I can't really remember. It was an e-mail, I think, was the first contact that we had. It was e-mails and then I made the first phone call to Michael, and I got his answering machine.

The CHAIR — What about the circumstance where had you not been told and your biological father had tracked you down and you had no idea at all, do you think it should be that the fathers have the access or the rights to track down their offspring or not?

Ms CUMMERFORD — It's a really difficult situation to negotiate, I think, but to speak very personally I found out in really traumatic circumstances, it was really distressing for me at the time to discover in the way that I did. I would still rather know, no matter how I found out, that I was donor-conceived than not know that I was donor-conceived. We've got a mess, we have to fix it, and I think the only way forward is to provide people with the right to access the information otherwise we're still treated as children.

The CHAIR — Including the donors?

Ms CUMMERFORD — Yes.

The CHAIR — And what about the siblings, should you have the rights to find information about siblings, if they exist?

Ms CUMMERFORD — I don't think it's going to be possible, to be honest, but I would like to know who my half-sisters are. Honestly, I couldn't say that if I got that information

whether I would make the approach. I think I would rather it came from them, but I would like to have the ability to know who they are.

Ms GARRETT — Again, and sorry I know we're on personal terrain, but do you have some advice or some thoughts about, to use the phrase, the 'time to tell', what would help families who have raised donor-conceived children to tell their children? Obviously your experience wasn't ideal, do you have a thought about what role a central agency could play in that?

Ms CUMMERFORD — Counselling and vital information on how to do it. It's never going to be easy. My mum told me that she wanted to tell me for a very long time but felt that she couldn't because she felt that my dad was reluctant for us to know that we're donor-conceived; my dad has differing views on that. I think support is going to be the key thing in getting people to tell their children. From my family's experience, once the secret was out in the open there was so much relief and my relationship with my dad is closer now than it ever had been before I found out that I was donor-conceived so I view the whole thing as nothing but positive. I recognise that it's difficult but I think support counselling by a central body would be absolutely vital and mediation between the parties is absolutely vital. Does that answer your question?

Ms GARRETT — Yes, it does; thank you.

Ms CUMMERFORD — I'm not really an expert in counselling.

Ms GARRETT — From your personal experience.

Mrs PETROVICH — Mr Chairman, thank you. Myfanwy, thank you for a very powerful presentation today. You said a moment ago that "we were donor-conceived". Have you siblings in your family?

Ms CUMMERFORD — Yeah, I've got a full brother who was conceived using Michael's donation as well. Sorry, I didn't — —

Mrs PETROVICH — That's fine, I was just clarifying. Should access to identifying information be retrospectively provided to parents to know who their donor-conceived children are, and should donor-conceived people have access to identifying information about their donor-conceived children's siblings, is that something that would make life a little bit easier, do you think?

Ms CUMMERFORD — So you're saying should parents of a donor-conceived person have the ability to access — —

Mrs PETROVICH — I'm saying should the donor have access to understanding who their children are, if they seek it?

Ms CUMMERFORD — Yes.

Mrs PETROVICH — And you suggested that you have a desire to meet your siblings if they're out there?

Ms CUMMERFORD — Yes.

Mrs PETROVICH — How do we do that? Do we need an intermediary to assist with that? I know you said you rang Michael and got the answering machine initially, that in some sense might have been a relief, I suspect, because it's a fairly difficult thing to do.

Ms CUMMERFORD — It was a relief but then I had to ring him again.

Mrs PETROVICH — So you're prolonging the agony.

Ms CUMMERFORD — I don't envisage the situation where you would just be handing over information to individuals, I don't think that that would be a good way of doing it at all. Like I suggested in my submission, I think the adoption model is the ideal way of dealing with this situation. An intermediary is the key, I think. I did feel at the time when I was trying to find Michael, I felt incredible frustration in dealing with the clinic as an intermediary, but I think that came from the fact that these were people who I felt had created this situation that I found myself in, and there was also an element of distrust as well because I had no idea whether they were actually doing the things that they were saying that they were doing, and I had no way of ascertaining what kind of searches they were doing, how far they were going with that. In particular when I asked, because I wanted to have my information released to VANISH to do a search on my behalf because I knew that they had done that for another donor-conceived person at a different clinic, and when that request was denied that increased my level of distrust with the clinic because I felt I know you can do this for other people, why can't you do it for me? It felt completely arbitrary.

Mrs PETROVICH — Do you think there would be more clarity of information if it was at arm's length from the practising doctors and the clinics at the time, if we had that intermediary service would it assist?

Ms CUMMERFORD — I think it would provide a sense of security for donor-conceived people and their families in knowing that the government or an agency is handling this information, that it's secure and safe and not subject to people who are concerned about releasing that information. The thing that I was reading from the submissions is that clinicians are very concerned about releasing information, I'd like to know exactly what they're concerned about, to be honest. I mean, I've always regarded this information as mine and I find it really disenfranchising to have somebody else holding this power over the information, removing that information from the clinics and holding it in an intermediary body is really important.

Mr CARBINES — Chair, can I just go back to a couple of points. With regard to the Royal Women's, did you pursue any explanation from them at the time that Michael and you were trying to pass letters for communication, or did you move on and not ever bother following it up?

Ms CUMMERFORD — We just moved on. I have to say that I believe the counsellor who I dealt with wasn't involved in that letter being withheld; she was really good in terms of dealing with my distress. I really don't know what happened there.

Mr CARBINES — It wasn't like Michael got yours or you got Michael's, neither was progressed?

Ms CUMMERFORD — Yes.

Mr CARBINES — Just the other question, in relation to donor-conceived people and other siblings, is it reasonable to assume that under the current arrangements you might not know who some of those half-siblings are because they might not know they're donor-conceived but with the broader array of information it could potentially be available under changed arrangements that some of those links might be more likely to occur?

Ms CUMMERFORD — Yeah, I fully expect that they don't know that they're donor-conceived but I'm hoping that if retrospective access is enabled that it might encourage their parents to tell them that they're donor-conceived. I mean, that's really the only option I've got. Yeah, that's my hope.

The CHAIR — Any other questions? Thank you very much; that was really helpful.

Witness withdrew.