CORRECTED VERSION

LAW REFORM COMMITTEE

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

Melbourne— 17 October 2011

Members

Mr A. Carbines	Mr R. Northe
Ms J. Garrett	Mrs D. Petrovich
Mr C. Newton-Brown	

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Witnesses

John*

** The name of this witness has been changed to protect his identity.*

The CHAIR — My name is Clem Newton-Brown, I'm the Chair of the Law Reform Committee, and Jane Garrett is the Deputy Chair. We're set up to investigate Terms of Reference that Parliament gives us, we're from both parties, and we report back to Parliament about proposing changes to laws. Russell Northe is on the Committee as well and Anthony Carbines and Donna Petrovich, who isn't able to be here this afternoon.

Everything is recorded, there's a transcript produced, and you have Parliamentary privilege when you're in here, so you can't be sued for whatever you say, but not outside the room so just bear that in mind. So what would you like to tell us?

JOHN — I don't have any prepared statement. What I wanted to do was to give you a bit of background as to how I became involved in all of this and how my thoughts have changed, or not changed. I also obviously will welcome any questions you might have. I think what you're doing is terrific, I think it's a terribly important area. I will explain a bit about how my own thoughts have changed over the last year or so.

I also want to make it clear that while I have sought anonymity, please don't construe that at all as suggesting I'm embarrassed or ashamed or anything like that. There are two factors here. I am someone whose name, if you Googled it, will come up with a lot of responses. And this, of course, has changed since the late 80s so that I'm terribly aware that someone who was trying to track down, say, their donor parent with a little bit of resourceful thinking might find it quite possible to track me down. There are concerns about that, which I will come to, but I did want to give you my input because I suspect that my own experience is probably common to quite a few others.

To keep it simple, I became a donor in the late 80s. It was, I think, in 1988. I think I'm pretty much on both sides of the magic boundary, although obviously I wasn't aware of that at the time. My own reasons for becoming a donor were quite simple: at the time I had been a blood donor for years and years and years and in a rather naive way — and I say that in retrospect — I think I thought that becoming a donor was just one step beyond being a blood donor.

My wife and I had had one child. At the time I became a donor we either just had our second child, or were soon to have our second child. I was basically on a bit of a high in terms of fatherhood, I thought babies were wonderful, so did my wife, and we decided that this was a fairly small thing — when I say small, it didn't seem terribly onerous for me to become involved in the donor program. My aim always was just to try to help other people who were having problems experiencing what we had done in terms of having children and getting some of the joy of that.

Looking back on the period, it does seem very casual. You know, I do remember having discussions with people at Prince Henry's, which of course is no longer there. I was made aware of the legislation. Certainly the privacy thing was very important to me. I had discussed it with my wife, she was happy for me to go ahead but, again, it felt a bit to me like becoming a blood donor. You know, I had never sought or never knew what happened with the blood I donated.

The CHAIR — Similar to donating blood, I might help someone out in a small way?

JOHN — Yeah, exactly. That was my only motivation, there was never any suggestion of money or anything like that. I do remember when I became a donor being rather chuffed to see all around the waiting room there were all these happy pictures of babies and thank you notes from parents and there was a nice, warm, fuzzy feeling to it all. I honestly can't remember for how long I was a donor. Was it a year? I don't know. But that's, again, something of a mystery to me. Since I was a donor I had been kind of in the dark. I do remember getting a letter from time to time saying that the details had been moved to such and such a repository or something, but there was certainly never any great follow-up in terms of: you're still on our registers, you're still part of what we do, etcetera.

I do remember in my own case I stopped being a donor on the very same day I was talking to one of the nurses, or one of the attendants at the sperm bank. And I said something flippant along the lines of: well, I'm glad you're finding this useful. And she said, and I suspect that she wasn't probably meant to say this, but she basically said something along the lines of: Oh, yes, we have had many successful pregnancies from you. That really pulled me up. Suddenly it was not a, you know, just a sort of feel good, giving blood type thing, this was: oh, this has actually led to something very specific.

That certainly gave me pause and I think also there was partly a sense of my work here is done, I've done what I wanted to do, which was to help other people achieve conceptions, but I think I also had a sense of wow, that is quicker and more definite and sudden than I had imagined. Again in retrospect, it's interesting that that was my thought. I think that was the first realisation this is something a bit more than giving blood. Essentially what happened since then was we had one more child of our own, so I've now got three. They're essentially all adults now. In terms of what happened to the donor children, I have never actually sought to find out. But what happened over the last year or so, and this might well be due to your own work, I did start to read several articles about this subject, particularly the cries of pain, they seemed to me, by people who were the children of a donor process and they were seeking information about their donor father. Obviously I had a particular interest in this.

None of the articles I read made me think: oh, gee, that sounds just like me. But I did have a sense, I think for the first time, maybe there is something I can do to give these people some kind of assistance. So I think I went and saw someone at VARTA, who was terrific, but, again, I had to do a bit of Googling of my own to try to find out where do I go?

Mr NORTHE — Can you just maybe describe that in terms of timelines when that was, when you went to VARTA?

JOHN — Only a few months ago. It was only a few months ago. It was after reading yet another one of these articles. Someone obviously terribly keen to get information. The problem I took to VARTA, and I think to Amie too when I first contacted you, was I want to help but I'm nervous about to what extent I expose myself. The main consideration for myself is that my own three children do not know that I had any involvement in this program. How they would feel, I'm not sure, but I can see how at least one of them might react hurt. I think they would find it puzzling that there had been this secrecy. I've discussed this with my wife and we both agree that really we don't want to have to face this at this time.

What I have done, though, on the strength of the articles was get myself onto the voluntary registry, giving some information. I have proceeded terribly cautiously with that. Was it you who got back to me and said: you really haven't given much at all? And since then I did actually submit a statement which was meant to be for someone who was seeking some information, just giving them something more than they had.

The CHAIR — The records in relation to your donations, were they all easily accessible by whoever you spoke to, they have got good records?

JOHN — I've had the very strong feeling that, yes, my records are accessible but not to me.

The CHAIR — Do you know how many children?

JOHN — No, no. And that information has not been passed onto me, and I think that's quite deliberate. Nor have I sought that information. Even in my dealings with the registry what I've basically said is: I am not seeking information myself, I do not want to get information about whichever children might have resulted from my own donations. What I have been trying to do, though, is if there are people out there who are specifically seeking information about me, what can I give them to go on?

I'm in a bit of a bind here because, a, you know, I have a name and profession which is easily accessible via Google, so I have to be quite careful about what bits of information I put out. And I think more than anything I am concerned about my children, particularly if they were to find out inadvertently. And I'm aware that some people who were the results of a donation process are terribly desperate to get information, and they're resourceful. And good luck to them, but I can see that it might be possible for someone to put together bits of information and then: are you the man? That's obviously a very big thing.

What I've done in recent months, just by trying to get myself onto the voluntary registry, is just to acknowledge a bit more than I have in the past the significance of what I did and also, and importantly, just trying to help people who might be seeking some information. I suspect it's not going to be as much as they are seeking but it's something.

I guess really all I wanted to say to you was if there are proposals that you change the system as it was, and I think there is no doubt it was flawed, I don't think there was sufficient counselling, I don't think there was sufficient effort made to say to people like myself, who meant well but possibly hadn't thought it through, just think for a while about the significance of what you're doing. I think to change conditions retrospectively is a very serious thing.

If back in 1988 someone had said to me: look, the situation is that all your personal details are kept confidential but down the track they may change and the results of this program may come looking for you. I've got very little doubt that I would have said: sorry, but I can't help you. That strikes me as a shame because my intention all along was to help and I think it would be upsetting if this led to dramas down the track.

The CHAIR — One of the ideas we were discussing before lunch as an option would be to require donors to provide non-identifying information.

JOHN — As in donors now?

The CHAIR — No, donors from pre-88. What would your view be on that? You've come forward voluntarily but how would you feel if a year ago, before you had come forward, you were contacted and compelled to provide non-identifying information?

JOHN — I think that would have concerned me. I like the feeling that it was up to me. I basically responded to the information I had seen in newspaper articles by people and I thought, well, I will voluntarily respond. I think if I had received a letter, as you outlined there, I would have thought, gee, that's a big hard line. And also, you know, you would have terrible problems, exactly what kind of identifying information? It might be easy to say: let's just use a first name only but, you know, if you've got a not terribly common first name, or a name that can be put together with other things, along with other identifying information, that changes everything. So I would have reservations about that.

Mr NORTHE — But you're saying non-identifying information?

The CHAIR — Yes. Not a name, just information that a child may have some comfort from knowing what sort of work you do — —

JOHN — I think you need to be more specific. If it's couched like that, even in what I've gone through recently, I didn't have any problem giving sort of basic information about likes, dislikes. I certainly understand the desire for people to have some health history, is there any incidence of this or that. I think that kind of thing can be offered up without too much trauma.

The CHAIR — If one of your offspring do seek that information, are you open to the idea of being contacted to review your views as time goes by?

JOHN — The last I heard was that there had been no specific request made matching mine, and this surprised me because I thought someone had said to me: yes, we do have a couple of people basically looking for you. Although when I submitted the most recent information the answer I got was no, there has been no one specifically but we've had a couple of enquiries that might be yours. That's a bridge I'm waiting to cross. If I were to be contacted now by someone from the registry saying someone is specifically seeking more information than you have offered, I would certainly take that very seriously and I think it would depend on what kind of information they were looking for.

I've read the stories by people who essentially have gone public, and good luck to them, and I know there's stories about people who have met their donor-conceived children. I'm not sure that I'm ready for that but if there was a specific request I think I would do what I could to help, bearing in mind though that it might not be as much as they were actually seeking.

The CHAIR — Are you happy that you donated back then? Would you do it again?

JOHN — That's a very good question. I think, yes, I am happy I donated. I'm particularly happy that I didn't do it because someone was offering $20 a go, or whatever it was, that was never the system, but I'm glad that I did it for altruistic reasons, and especially glad that I did it with the green light from my wife. That would be a really difficult thing now. I can't imagine why I wouldn't have shared that knowledge with her.

I do believe that more counselling should have been offered. Even if it were as simple as saying: you've basically passed all the health checks, etcetera. I remember that was done. I think it would have been a good idea to say: look, you've passed all the health checks, from our point of view you're a suitable donor, but we suggest you go away for a couple of months and just think a bit more about this. I think that would have been a good idea. I say that only because I remember how shocked I was when I was told essentially, yes, we've kicked several goals; thank you. And the fact that I then stopped.

Ms GARRETT — It was very real.

JOHN — Yes, it was very real. And also in retrospect it's interesting that there was never any follow-up at all, there was never any follow-up from anyone at Prince Henry's saying: we notice you're not coming in. Why? Is there anything you want to talk about? Again, I do think it was odd that, apart from one letter maybe from someone at mission control saying: your details have been transferred because Prince Henry's shut down, and even when Prince Henry's shut down I had a sense of: oh, I've lost my contact with the people there. So I think that was badly handled but, again, I do think it's good what's being done now to try to, not right the wrongs, because I don't think it's a matter of right or wrong, but just to acknowledge the seriousness of all this. The bottom line is you're dealing with real people and that has to be taken terribly seriously.

Ms GARRETT — I really appreciate you coming in, we all really appreciate you coming in and sharing your story so candidly, thank you. And certainly I think the most compelling evidence has been from people directly affected — donor-conceived children, donors — and, you know, it's obviously an extremely complex issue.

JOHN — I do remember just recently when I went to see the woman in VARTA, whose name I can't remember, I was a little early and I had time for a quick coffee but it was a real moment of: gee, this is very big. This is 23 years ago. You know, my life has changed, I have children I didn't have then, but it was a real sense of: gee, something I did 23 years ago as a much younger person with a lesser sort of world view, if you like, is still something I have to deal with. Not in a bad way.

I remember it was not a small thing for me to sit down with my wife over a coffee and say: look, some things are happening that you should probably know about. But, again, I was very gratified that her response was essentially do it. She was very cautious, she said to me that we shouldn't tell the children, but she was certainly very encouraging in terms of: yes, go to the registry, talk to people. She knows I'm here today. That was terrific. But, again, I can see how that might not be the same with all couples. It's a very tricky thing, as you well know.

Ms GARRETT — We've had very powerful testimony from donor-conceived people. Is the transcript public now? Parts of it may be. Anyway, the theme has been people feeling very — I think the words of one of them today was: I felt completely disenfranchised and disempowered knowing that people were holding information about my biological identity and I was not allowed access to it. It's a very strong theme and it is so difficult. It's been talked about competing rights, competing ethical responsibilities, all of these things. And I take your testimony very, very seriously obviously.

If there was a proposal along the lines as Clem had identified of providing non-identifying information and a period of time to which donors can come to terms with that, and if there was a proposal that if the donors did not consent to being identified that that information would be released anyway — and I'm not suggesting that's the case but that's part of the Terms of Reference, consent or otherwise — would you be comforted in some way if there was a non contact veto possibility that you as a donor were able to say: I don't want any contact with the donor children. Or is it the fact that your identity would be known?

JOHN — No, I think that would be comforting. I think that if there was a sense that there might not be the knock on the door, that would be a comfort. I'm absolutely in favour of those who are quite happy to make contact of whatever kind they want to be able to do that, but I think it would be unfortunate if the situation changed so that I, for example, had no choice.

Ms GARRETT — Of contact?

JOHN — Yes. If someone said: well, sorry, the law has changed, I have been able to put two and two together and I believe you're the person responsible and can I see you? That would be very confronting. I also think it would be a kind of a betrayal of why I got involved in the first place, but I do think if it were a situation where contact was made with me through one of the agencies and the situation was put: this is the situation, a person has come forward, they're seeking more information than you have already offered, is there anything more you can offer? And I think particularly it would be useful if it was put to me specifically. If someone was saying: look, we're actually not too fussed about knowing your name or your profession, but can you help us with these sorts of things? Because it might be fairly innocuous things so I suspect that's rather fuzzy. I think that would be how I would respond.

Mr CARBINES — Chair, following on from that question. You've clearly thought very deeply about these matters over a long period of time. If there were people who might have sought information and you were contacted, even under the current arrangements, I suppose as much as you've thought about all the different possibilities and implications, would you feel that it's hard to emphasise — with your circumstances do you feel that there's still a thought process there to be had when you're confronted potentially with someone you might know is seeking that information? You can't have that conversation with yourself, even as much as you've probably tried to think about that?

JOHN — You know, even when I was having a coffee before seeing the woman at VARTA, I was thinking: why exactly are you doing this, John? If you're basically wanting to keep yourself private, why are you doing this? And I think the answer is because I had seen not one, not two but several really raw articles with people wanting to know where they came from and thinking: well, I'm trying to do a bit to help. But, again, there's that sense of it's possibly not as much as they want. If there was a specific enquiry made to me, yes, I would still have to do a lot of thinking, and I would do that with my wife, but from the discussions we've had already that's a big leap. That's a big leap.

The CHAIR — If there was such a thing as a no contact veto, what length of time do you think would be reasonable for somebody to come back to you and say: look, five years ago you had a no contact veto, do you want to review it? Or 10 years? Or never?

JOHN — It's hard to put a time-frame on it because immediately when you started asking your question I thought: where he's going with this is after your death, can information be revealed? Say in my own situation, even if I were dead, if my children were to discover did you know your dad had however many donor children?

The CHAIR — That would be worse than you're allowed to discuss it.

JOHN — Yes. One of the people I talked to said: we recommend you do tell your children. And I can see the arguments as to why you would do that, but certainly in my own case we've decided no, not at the moment. Again, it's awkward because you think: why are you being so secretive? Are you ashamed of this? No, I'm not but it would be a really big thing to spring on the children. We know they're adults, they understand these things, but that would be a shock to them. It's a big thing.

The CHAIR — I suppose my question was aimed at querying whether your view is that people's attitudes change and that you may have a different view in five years' time.

JOHN — I would have no problem in the question being put, I would have no problem at all with a letter coming out, as you said, saying: five years ago, 10 years ago you said this. Has your situation changed? It might simply be a matter of saying: no, I'm sorry it hasn't changed. Or it might well be: well, actually, for whatever reason I don't have a problem now. I think that could be a worthwhile way to go. But, again, I think what's important is to respect — I mean you're dealing with claims from very real and legitimate cases, but I do feel that my rights and the rights of other donors like myself do have to be respected, particularly going back to the situation in which we did offer up donations originally, completely voluntarily.

Mr NORTHE — Do you think your position might change — we've heard some evidence from donor-conceived persons who have maybe a genetic illness or hereditary issues, and it works both ways, I'm talking about the donor-conceived person trying to contact the donor and vice versa, it might be you as a donor who has realised that some time in life you had a genetic issue and you want to contact your offspring that there may be a problem. Do you think that would change in terms of divulging information or an obligation upon that exchange of information?

JOHN — I think what's happened already is positive in the sense that the information has come out, information about the voluntary registry in how to access it, I think that would have made other people rather than just myself think about these things. So that, yes, if I had something like you were suggesting I would want to put that information out there. Again, if there was a question put to me by one of these donor-conceived children, I've discovered that I have this condition or I have the possibility, can you help me, is there a history there? I think I'd certainly want to answer that question. Again, I think if it were put to me on the basis of: can you offer someone some peace of mind on this? Certainly you'd try to help.

Mr NORTHE — I guess it's the point of where the requirement to divulge that information voluntarily or it would be an obligation, and I guess that's the types of issues that we have to deal with as a Committee.

JOHN — Again, you might inadvertently stumble onto some identifying information. If it were, for example, a fairly rare condition and information came out saying: there's a person here whose name is Bob, he's from the US, and he has this rather unusual Huntington's or something. Someone out there could go: hang on, Bob, US, Huntington's. Isn't that you? Again, the world has changed, Google did not exist in 88. You can punch all kind of keywords into Google and come up with astonishing things. So that's where potentially benign information could actually be the last bit of the jigsaw. But certainly in my own situation if an enquiry was made regarding an illness or a hereditary or a genetic thing, sure.

Ms GARRETT — There was also a suggestion that if the Committee or Parliament was so minded to make changes including, at the last stage of the process, providing identifying information regardless of consent, that perhaps there could be a mechanism for a review or Patient Review Panel type thing where the donor could raise his concerns and a decision would be made. Would you see that as an important protection or you wouldn't want it to be at that stage?

JOHN — Are you saying that if the law is changed to basically say: sorry, the donors' identities are going to be revealed but we'll have a Committee that can examine these things. No, I wouldn't react well to that at all because I think in the same spirit in which I voluntarily became a donor I would like to feel that I was still given some choice in this rather than being told: sorry, you are now compelled to have your identity out there. You can, of course, appeal or go to our Board of Review but essentially the decision has been made. That to me seems like a rather rough way to treat someone who was acting out of altruism initially. I acknowledge that the altruism may have been a little naive but that was how it was done.

The CHAIR — Any further questions? Thank you very much for coming, your evidence has really been invaluable, having donors who are positive and out there, and we've had a few of those and that's been great. I suppose the nature of it is that donors who don't want to be out there are unlikely to be contacting us to give evidence.

JOHN — That was why I also wanted to make the point about it, it's not out of shame or embarrassment or anything like that, it's a bit more complicated.

The CHAIR — Now you've given us a very good perspective for us to put into the mix. You probably haven't made it any easier.

JOHN — Okay. I do think it's a fascinating area but I don't envy you trying to — —

Ms GARRETT — As you said, it's real people's lives.

JOHN — Exactly.

The CHAIR — Thank you.

Committee Adjourned.