CORRECTED VERSION

LAW REFORM COMMITTEE

Inquiry into access by donor-conceived people to information about donors

Melbourne — 5 December 2011

Members

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

Chair: Mr C. Newton-Brown
Deputy Chair: Ms J. Garrett

Staff

Executive Officer: Dr V. Koops
Research Officer: Ms A. Gordon
Administrative Officer: Ms H. Ross-Soden.

Witness

Alex*

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

The CHAIR — The Law Reform Committee is a joint parliamentary committee made up of members from both parties. Parliament gives us terms of reference to look at, we gather information, look at evidence and then provide a report to the Parliament, which may or may not enact changes to the legislation to address some of the issues that we have discovered or that we think need addressing. We record everything. Obviously your anonymity will be preserved. You will get a transcript of today's hearings, and if there are any inaccuracies, you can let us know and we will correct the transcript. If you just launch into your story, we will ask questions as they arise.

ALEX — Yes, good. I am a donor. My donations were made at Prince Henry's Institute over a period of a year or two in the early to mid-80s.

The CHAIR — How old were you then?

ALEX — I would have been in my 30s. My wife and I had just had our first child, and we had some friends who were having difficulty conceiving. That was the way I became a donor — because of having experienced the miracle of birth and the difficulties that other people were having. That was my motivation for becoming a donor. I cannot recall much by way of counselling happening at that time from the point of view of thinking through the consequences of what I thought at the time was helping in the process of other people conceiving. Certainly the understanding was that it was entirely anonymous and there would be no contemplation of responsibility or contact with the children. I think that was the philosophy at the time.

The CHAIR — How was that communicated to you?

ALEX — In an introductory session that I had with one of the people organising it.

The CHAIR — Do you recall if there was a written form or anything that you signed?

ALEX — No.

Ms GARRETT — Was it a one-on-one session?

ALEX — Yes. I think donors are fairly thin on the ground. You would be doing well to get a group session. I suspect that they are thinner on the ground now than they were, I do not know. Obviously things have changed. My understanding is that the counselling now is much better and disclosure is one of the central ideas of the process now, which I think is good. I suspect the reason why you are here is that things have changed, and so you have a bank of people who want to know, or may want to know if they knew about their background themselves. As to how to wade your way through the difficulties that arise through people being told that there will not be disclosures and people now wanting some kind of disclosure or contact, it is a difficult task. There is no problem now with what is happening, but with children conceived as a result of my donations I guess there is lots of difficulty because of the inconsistencies in approach.

I then stopped donating, I heard nothing and then — I think as a result of some publicity — I got in touch with the Infertility Treatment Authority who were encouraging donors to say whether or not they would be prepared to have the information shared with the donor-conceived people, so I registered. I thought at the time, and I still do, that it is important for children to know their parentage. I think that is very important, so I registered. There was then a silence of some months or years; I am not quite sure how long. Then a letter arrived, 'Dear Alexander' — only my mother calls me Alexander — 'You have 15 children'. I found that rather stunning for a variety of reasons. It is rather a lot. I do not know how many children people here have, but I suspect if we added them all up, it might not be 15. But I have 15 children as a result of donations and another 3 as a result of my wife and I, so that is 18 children.

The first thing I would say is that 15 is rather a lot. I do not know if it is a good idea for people to have 15 children conceived naturally or with several partners or through donation. I do not know if the terms of reference extend that far, but all of the difficulties that come out of donor conception are multiplied significantly by the numbers. I think it is daunting, and I think as a practice it is not a good idea for people to have so many children.

The CHAIR — How does that impact on you if you do not have contact with them and have no direct responsibility for them? Is it just that the thought of having 15 is a burden?

ALEX — That and I have three children conceived naturally. The odds increase substantially of them coming into contact or having relationships with a half-brother or half-sister. I think it is illegal. You would all be familiar with the Crimes Act. I do not think you are allowed to have sex with your half-brother or half-sister. If there are 15 people out there who you do not know, then that increases the risk in that fashion. I have not had any contact, and apparently none of the children have sought to have any contact. I am comfortable with that. If people do not want to have any contact, that is fine. Imagine if they all did, though? I struggle to give my three natural children appropriate time. Imagine if another 15 turned up on the doorstep? I guess it impacts in that way, but you are quite right — if there is no contact, then what does it matter? But it matters from the point of view of wondering whether or not my children's partners are related to them.

Mr NORTHE — This is a statement rather than a question, but I would imagine it is probably more that some of the donor-conceived children may not know that they were actually donor conceived.

ALEX — I think that is probably right, and that is also a problem, isn't it? With 15 children, and there are 12 families — I was provided with a bit of information when the letter came — my expectation is that you are right and their parents have not told them. One of the things I was intending to say is that parents ought to be encouraged to tell them. It is now compulsory, so you have a situation where different things apply to different people, and they really should not. The way I would deal with that would be to encourage the adults — well, I know all these children are also adults now, but the parents and the donors — to perhaps get together via a counselling process, so the parents have some reassurance that the donor is not a maniac and is not going to assume some role as a parent or interfere with the relationship.

If I were asked for my opinion — and opinions are not necessarily so helpful; information I guess is what you are seeking — that would be the way that I would do it. The central agency in most cases knows the donor and the parents. I know with some donor organisations that is not the case, which is appalling. There are no records, and people are in limbo. I would put people together, not the children but the adults, and have some information and perhaps some meetings properly organised with appropriate counselling and support so that perhaps the parents of all of these children can say, 'Here is the truth'. Children are entitled to the truth, I think. So that is what I would do with it.

Mrs PETROVICH — Alex, you have another complicating factor. You have subsequently found out that your dad had a medical issue.

ALEX — Yes.

Mrs PETROVICH — Obviously once you had your letter with notification of 15 offspring — has that been taken any further? Has there been any further attempt to identify and inform those children?

ALEX — No, and there are a number of reasons. The main reason for that is that I am still making some inquiries. When my father got the condition, we were all advised to get tested. I saw a doctor and had some tests. He said, 'You don't have it; don't worry about it', but in more recent times I have been advised to have some genetic testing to find out what the prospect of passing it on is. I have had some more testing, and I am awaiting the results of that. That is important. When I get the information and am sure of it, I will contact someone and tell them. What do they then do with that information? I suspect that they may have no obligation to do anything. They might be prohibited from doing things, but the parents and the children ought to know.

That creates a problem with secrecy, doesn't it? In some way or another kids find out in an inappropriate sort of way. They find out by accident because people know and some people, as the publicity increases, feel it is more and more important that children know. Once you have a separation or a divorce sometimes agreements that children not be informed change. Children are informed in inappropriate circumstances. The best way is for them to be told by their parents. If the parents will not do anything, that leaves the children at risk.

I guess that is another point. The deliberations and decisions that you have to make really in the end need to focus on what is in the best interests of the children. It is all very well for the donors to be concerned about what is going to happen. I read a submission from one similarly anonymous donor who was awfully frightened about the effect on his family. It was sad to read that. He was saying, 'I couldn't possibly have any contact: it would ruin my life and my family'. I think it is unlikely that is going to happen, and with good counselling and support and a proper process it need not happen. I suspect that most donors are not mad and most children are not troublesome, or no more troublesome than everyone else's children are.

Mrs PETROVICH — What is expected, perhaps.

ALEX — Yes. Those medical issues arise. It is fairly common, and children should know those things. I have not done what I need to do yet, but I will shortly be in a position, when I get the genetic testing back, to follow that up.

Ms GARRETT — Just to go back to your initial discussion about getting a letter advising that you have 15 children, am I right that you said that you rang up the ITA and said you were a donor and you were interested in finding out what had happened and then months later you got a letter out of the blue? Is that what happened?

ALEX — That is my understanding of what happened.

Ms GARRETT — How did that make you feel? Would you have preferred a different process to that?

ALEX — I guess it is hard, isn't it? There is really no other way than being blunt about it. What do you do?

Ms GARRETT — Would you have preferred to have been invited in and talked to?

ALEX — Possibly. It is certainly a fairly blunt sort of process, but most people are sufficiently robust. I had not thought of it much because I did not have any idea that I had any children, let alone 15. I think a better process now would be that donors are told at the same time as the natural parents are told. I did not have any choice in it. Perhaps it would have been nice to come in and have a cup of tea and a barley sugar.

Ms GARRETT — The other thing is that — and I think the way you are handling it is to be absolutely applauded; it is not an easy thing, and I think you are approaching it with a great sense of openness, and I respect that — if some people were at all concerned, such as that donor who said he was frightened, I imagine receiving a letter like that might compound those feelings if they had questions that could not be answered upon receiving that letter.

ALEX — I agree with that. While we are on the subject of openness, I have not told anybody about this, including my wife. That is not very satisfactory really because our relationship is a good one, and she should know. The impact of that would be very substantial on a relationship. She was perhaps understanding but not particularly supportive. She knew of what I was doing but was not particularly supportive of it. I am yet to tell her. I will, but I am yet to tell her. I guess I can get away with it at the moment because there has not been contact with the children.

The CHAIR — She knew that you were donating at the time but does not know what the outcome of that was?

ALEX — No.

The CHAIR — That is one of the things which this committee is considering. One of the hardest questions for us is the issue of retrospectively releasing identifying information. We have heard stories such as yours from donors and then we have heard kids who have come in here and are desperate to get some information about their parents. We are grappling with that at the moment. From your perspective, how would you feel if there were a right for your offspring to know, firstly, non-identifying information about you, and secondly, identifying information about you?

ALEX — I think that they should have that right really, notwithstanding the difficulties it might cause for donors. I have read some of the submissions from children who find it difficult not knowing or, worse than that, knowing that the information is there but not being able to get it. That is much worse than a situation where a child is conceived, the relationship is brief, the father moves on, the mother does not want to know him and that parent is gone. It must be enormously frustrating for a child to know that the information is there but they cannot have it. I imagine that would have a very significant effect on people.

It is a balancing act. I know retrospective legislation is a no-no, but it is unfair for people to be treated differently. That is highlighted by a case where they send the letter to a family where there are two children. In my case, family no. 4 has two children who were born at different times. One is covered by the 1984 central register but the other child is not because they were born earlier. It strikes me as enormously inconsistent that one member of a family has different rights to another family member.

Mrs PETROVICH — Do you have a numbering system for offspring? In your letter you talk about 15 offspring. Each of those is explained in a set of codes; is that right?

ALEX — No, there is no code. I have a code — but the children do not. There is no code.

Mrs PETROVICH — There is no identifying scenario there as to — —

ALEX — There is the month and year of birth and the gender.

Mrs PETROVICH — Presumably at that point enough records were retained, those prior to 1988, such that you actually have the information.

ALEX — I do not want any information. I am not here searching for my children. If they want to have some contact with me, I am happy for them to have some contact with me, but I do not need to contact my children.

Mrs PETROVICH — The point I am driving at is back to the medical issue. If there is sufficient information to tell you how many there are and the dates of birth, one would hope that other information is passed on at least to the parents.

ALEX — My expectation would be that the registry or the ITA would now have all that information or be able to track it down. They would know who the parents are and have some means of contacting them. It is not hard to find people these days.

Mr CARBINES — I have a couple of questions. Taking it back to the process by which you were making the donation and talking with health professionals at the time, while you are saying today that it was not an issue for you about offspring knowing that you had been the donor, was it presented to you that there was a choice in that matter at the time you were offering to make donations?

ALEX — There was no choice. In fact there was the reverse of that. There was an affirmation not to worry about it and that it was done on the basis that the children have no right to contact you. That was the way it was presented at the time.

Mr CARBINES — Following on from that, while obviously you chose to be a donor to help others conceive and have children, was there any expectation or thought or information presented to you to give you any comfort as to what sort of contribution that was likely to be?

ALEX — I cannot recall that happening. I think there was a different philosophy at that time. I expect the people who ran those programs were very interested in bums in cribs. They were different times, and less thought was given by those people and certainly by me about the consequences. Things have changed. We all know in other areas the stress and difficulty people have in not knowing those things in the adoption area, with removals and the stolen generation and people from overseas. There is an enormous effect on people in not knowing their background. I think that is something the committee needs to take into account very strongly.

Mr CARBINES — I have one last question. Knowing what you know now, which is not a lot of information, but you do know of donor-conceived children you have played a role in, and knowing potentially that there may be a medical condition you want to be able to provide information to them about through an intermediary, however that might be done, does it trouble you if there is not a process by which to do that?

ALEX — It troubles me enormously. The genetic disorder is a pretty mild sort of complaint, but imagine if it were something serious. Imagine if it were, as is often the case, something that could be passed on. I think it is an appalling situation. It bothers me a great deal.

Mr CARBINES — I assumed it would, but I want to pick up on the issue that there are donor-conceived children who may not necessarily know that they are donor conceived and therefore not be able to access the information via a voluntary register. However, we are hearing from people who were donors — whether or not they want to have interaction with donor-conceived offspring — that there are other matters that might arise that still leave a donor in trouble.

ALEX — They leave a donor in trouble, but they leave a child vulnerable. Yes, I agree with that completely. How do you deal with that? It would be a brave committee that made a recommendation that it would be compulsory for parents to tell their children or that there would be a system where children get a letter, as I got mine. If parents make the decision never to tell their children, I wonder whether the state can really then decide that it knows better. I think a better way of doing it would be through a process of at least firstly educating the parents and then perhaps introducing them in some form or other to the donor and having some guidelines about what information is passed on.

What is identifying information and what is not identifying information? That is interesting, isn't it? If you provide my name to my children, they will find me in 5 or 10 minutes or less with their computer skills. Some people are more anonymous than others, I suppose. They will not have any trouble finding me, including my address. If they were going to turn up in a minibus on my doorstep, that would be a shock.

The likelihood in the overwhelming majority of cases is that people are civilised and the end result of disclosures will be positive, I think, for all concerned. That is my feeling. I do not think you will get stalkers and people turning up on your doorstep. I think people will be respectful. But there needs to be a good process, and I wonder about the issue of compulsion, particularly from the point of view of parents being required to tell their children, because you will not get anywhere unless the children know. That is the reason why out of 12 families I have not heard a word. There must be 12 families who are determined not to tell their children anything, I suspect.

Mr CARBINES — When you are starting to go down this process of potentially having information that you would like to be able to pass on, do you feel you have had any clarity around how any of that process might work, or you have not perhaps had those discussions yet with a more central authority about, 'Well, I'm going down the path of getting some information that I think might need to be passed on. What is the process for that'? Or has nothing really been communicated to you as to how that next step might happen?

ALEX — The answer to that is not a lot. It really happened quite accidentally. I do not have a perfect recollection of what I did initially, but I am pretty sure what I did was, as a result of publicity, got in touch with the Infertility Treatment Authority and said, 'I'm happy to be on a register of people who would pass information on', and that was it. I was not asked to provide any information or profile or whatever. I think all I did was be placed on a register so that if there was a child who was told, he or she could get some information. What information God only knows. Then I contacted one of the staff at the ITA and went in. She told me about the inquiry, which I guess is the main reason why I am here. I was encouraged to attend because donors are thin on the ground and you were interested in hearing from them. But she suggested, 'Well, what if you die? What if you get run over by a bus, why not do a profile and lodge it?'. I have not done that yet. But I am thinking of writing my memoirs, publishing them. What do you do? Or a videotape perhaps — 'Hello' — from the grave.

Mr CARBINES — It would seem perhaps that there is not necessarily a different process by which you can provide information to donor-conceived people than if you purely just wanted to be available to connect with someone as opposed to providing information that might be clinically important to their livelihood.

ALEX — I am not quite aware of there being any precise process. I think it is all hit and miss, but I may be just poorly informed in relation to that. I do not know. But nothing has happened for me so I do not know. No one has — —

Ms GARRETT — Contacted you.

ALEX — — contacted me. If that happened, as I say, I do not need to contact my children. I am in enough trouble. I have got three children and they are more than enough for me. But, if they did, I would be happy to have some contact, but it would be really helpful if that was regulated, done carefully and done sensitively with some liaison between trained staff so that you can get an idea of who people are and what level of involvement you want to have. There are people out there who might be disagreeable. I suspect if they have got my genes, they will not be, but you never know. The hammer of environment and the anvil of heredity — environment is important. So to have a go-between in relation to that and what information would be disclosed. My wife would be enormously curious if the minibus arrived with 15 of them.

Mrs PETROVICH — I would like to thank you for your presentation today. You have been incredibly honest and very thoughtful about this whole issue. Obviously it is very confronting in your circumstance. You have obviously made some attempt to have a register, or put your name on a register, but would the option of placing a contact veto, prohibiting contact with you and perhaps members of your family, allay some of the concerns that you have around your donor-conceived children? They can still actually have that profile, they could still actually have an understanding of perhaps some key information but almost non-identifying information. Is that really where you are at?

ALEX — I think it is helpful. Some people would be aided by that, and in some circumstances I might be, depending on the person and personalities involved. You might find that there are some needy people out there. I do not know that I have got an enormous amount of time for needy people. So there might be a circumstance where you might want to have a veto. If there was some kind of compulsion, then the poor man who sent in the submission, which I am sure you have all seen, he might get some assistance from having that safeguard in the end. So, yes, I think there probably does need to be some kind of veto about meeting people if you do not want to.

Mrs PETROVICH — I suspect that is probably a choice thing, and various donors may have different views about that, but I think it is something that people perhaps need the option.

ALEX — I agree with that, and you might need it in some circumstances, depending on the personalities involved. In the end I think people need to be truthful about their children and where they have come from, and there needs to be a good and consistent process for providing information. At what level of information and identifying information is another matter, but I think that there needs to be some consistency and the children should be the focus rather than fretting too much about retrospective legislation and people being promised anonymity and the consequences and should children know?

Mr NORTHE — I did want to ask, Alex, how you received your correspondence or that information in the sensitive and, I guess, discreet manner — how that was received about your family?

ALEX — Sorry, how — —

Ms GARRETT — Registered mail or — —

Mr NORTHE — Did you receive that through registered mail?

ALEX — I do not recall. It was a couple of years ago.

Mr NORTHE — One of the issues that we are dealing with as well is if we do open up contact, how do you do that in a discreet manner without upsetting other family members of the donor?

ALEX — I have got a business, so when I provided my details I was able to provide a business address. So I was lucky in that respect, but some people are not going to be so lucky. I guess there will be some spouses like my spouse who do not know either. That is not very satisfactory. Here I am advocating openness but not going out into the open with the most important person in my life. There is some measure of hypocrisy there, but timing is important, or at least that is my excuse.

The CHAIR — When we release our report in a few months time that might be good timing.

ALEX — Yes, I will send her a copy of the transcript, and she will not have any trouble picking it up I wouldn’t have thought!

The CHAIR — Thank you very much, Alex. That was really informative.

Witness withdrew.