CORRECTED VERSION

LAW REFORM COMMITTEE

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

Melbourne— 17 October 2011

Members

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Witnesses

Ms C. Lorbach, National Consumer Advocate,

Ms L. Hewitt, and

Ms G. Hewitt, Donor Conception Support Group.

The CHAIR — Thank you very much for coming. My name is Clem Newton-Brown, I'm the Chair of the Law Reform Committee. This is a Committee made up of various members of Parliament and with me we have Russell Northe, Donna Petrovich, Jane Garrett and Anthony Carbines and we've been given Terms of Reference by Parliament, which you've submitted on, and we will be preparing a report to Parliament which may or may not result in legislative change in the future. Thank you very much for coming.

When you are giving evidence in the room today you have Parliamentary privilege but outside the room you don't, so just be aware that the normal caution should be taken outside the room. We will start with each of your names and addresses, and business address is okay, and some information about the group that you represent, for the transcript.

Ms LORBACH — My name is Caroline Lorbach, I'm the National Consumer Advocate for the Donor Conception Support Group. Our group has been in existence since 1993. We were the first group in the world that supported families of donor conception. We have membership which comes from every state of Australia, and our basic reason for being is to support parents in making a decision to use donor conception; to support them in telling their children the truth about their conception and also to support the donor offspring as they grow. We also have a number of donors in our group as well as counsellors and medical professionals.

Ms G. HEWITT — My name is Genevieve Hewitt and I'm a representative from DCSG. I was conceived through a donor.

Ms L. HEWITT — My name is Leonie Hewitt and I'm the mother of three donor children: Geraldine 28, Kieron 23 and Genevieve 21.

The CHAIR — Do you want to take us through your submission.

Ms LORBACH — I'd just like to start off by making a statement which covers some of the things that we've actually put into our submissions over the last two years. Our group would like to congratulate the State of Victoria for being at the forefront of donor conception legislation starting from the early 1980s, and this was well before any other jurisdiction in the world had even thought that regulation of donor conception was necessary. This is continuing here with this inquiry, which we believe is probably the first time in the world that a government has seriously considered the possibility of full retrospective access to identifying donor information for donor-conceived people, and that is a really big thing and we really do congratulate you for considering this.

Our group's view is that all donor-conceived people, regardless of when or where they were conceived in Australia, should have the right of access to identifying information on their donors. We believe in this that donor conception should be brought into line with adoption. Unfortunately, the Assisted Reproductive Treatment Act has created different categories of people: those who are allowed access to identifying information and those who are actually denied access for that information. Whether this contradicts any specific charter in place in Australia is still being discussed but denial of available information to one group of people based solely on the date of their conception to us is clearly unjust.

Anonymity was never a guarantee given to donors by law, it was a system set in place by the medical profession years ago with no discussion. Donors had to agree with it in order to donate; parents had to agree with it in order to have a child. These people had no idea at the time what the implication of this system could be on any children that were created. Years ago people who gave up their children for adoption in Victoria were also promised that their identity would be preserved but in the debate held about the Adoption Act in 1984 it was accepted that there was a paramountcy of the welfare of the child, and this included access to identifying information on their birth parents. The members of the Victorian Parliament at the time accepted the principle that the right to know about your genetic heritage overrode any concerns about the right of relinquishing parents to privacy, and that it should be applied to all adopted children regardless of when they were adopted.

The arguments in Parliament at the time surrounded the fear of what might happen when adoptees tried to contact their birth parents. What happened in Victoria and around Australia was that adoptees and their birth parents handled things very responsibly. We would ask you the question: why would donor-conceived adults be any different? Of course there is one difference between adoption and donor conception and that's based on numbers. In adoption there may have been one, maybe two, children, it was very unusual to have a bigger number than that, but in donor conception there could be 10 or more children. That's why our group would recommend a more formal contact veto system than the one being used in adoption in Victoria. We feel that a full contact veto system would enable those donors who are fearful a measure of protection from unwanted contact. We would suggest that if this system were to be introduced that a contact veto should be able to be altered by each party at any time. If a donor wished to use a contact veto, it would be of great benefit to donor offspring for that person to be able to give more non-identifying information about themselves than may have initially been recorded many years ago.

It was stated some time ago that the intended purpose of the name change from the Infertility Treatment Authority to VARTA and the sending of registers to the Births, Deaths and Marriages was to destigmatise donor conception and infertility. Our response to that from people we have been talking to since that happened is that has not occurred; nothing has changed. We understand the desire to try to normalise donor conception as it's something that our group has been working on for nearly two decades. We also understand the desire to try and prevent a parent's infertility from weighing on the donor-conceived person. The DCSG has spoken to donor-conceived people who have had contact with ITA in the past and none of them expressed any concern that the issues of infertility have clouded their discussions with ITA. Stigmatisation will exist until all donor-conceived people have the right to access whatever information on their donors and half-siblings that still exists. Merely changing the location or names will change nothing worthwhile. Indeed, we feel that it's had the opposite effect. Whereas once donor-conceived people went to an organisation which was created with them in mind — and, yes, we do acknowledge that it also served infertile people and donors — they received help in accessing information from people who had amassed years of experience and now they're going to an organisation that has no experience in donor conception and does not even have counsellors on hand. To put it briefly, services for donor-conceived people, their families and donors have decreased in all respects.

One of the recommendations of the Victorian Law Reform Commission was that the agency responsible for administering the registers should do more to facilitate approaches to donors and help increase awareness of options in relation to providing identifying information. Unfortunately, since the move of the registers to Births, Deaths and Marriages nothing is being done to facilitate approaches to donors. VARTA also provided a much appreciated service of being a letterbox drop so that parties involved in donor conception could communicate with each other without meeting or invading each other's privacy. Since the registers were moved to Births, Deaths and Marriages this service has ceased to exist. As one of our Victorian members wrote: "I think ITA was providing an excellent service and it was completely unnecessary to fragment these roles."

The last thing we would like to make in our statement is about half-sibling information. Information for half-siblings for donor-conceived people is of vital importance; it lets them have just a little picture of who they might possibly be related to. In the past, donor offspring could get access to information on the number of half-siblings they had, what year they were born in and what their sex was, and that could certainly aid them when forming relationships in asking some basic questions, because not all donor-conceived people are told the truth. Unfortunately, they're no longer able to get this information through Births, Deaths and Marriages and that is going to cause an awful lot of distress to donor-conceived people and it needs to be changed.

That's all we wanted to say in our statement but we would love to answer any questions you might have.

Ms GARRETT — If it's okay with Leonie and Genevieve would you mind sharing with us some of your — —

Ms G. HEWITT — Personal story?

Ms GARRETT — Yes.

Ms G. HEWITT — Dad found out he was infertile before Geraldine was conceived and then they turned to adoption first and then donor conception and they wanted to give it a try, and each of us have three different donors, and they told us at about the age of five and six. We didn't fully understand it but at least we were told and growing up with mum and the support group it's been open in our family, it's been discussed a lot.

Mr NORTHE — You're even in the Women's Weekly.

Ms GARRETT — Was this in Victoria?

Ms G. HEWITT — New South Wales.

Ms L. HEWITT — I think an important part of that story is the way my husband was told he was infertile and there is not a lot of support for men. There's a lot of support out there for women who are suffering infertility but Warren was told over the phone, it must be about 29, 30 years ago, that he was infertile in that he had Immotile Ciliary Syndrome, and Warren walked around the city streets of Sydney for two hours; he couldn't go back to work and he came home and he offered me a divorce. And, of course, we didn't get divorced, we've been married for 38 years, since 1973. You know, I think there needs to be a lot more support put in there for men suffering infertility and, yes, we did go down the adoption path that Genevieve talks about but there was a 10 year waiting list.

That article where it says the doctor sat me down, that's not right. I went to see him when I was expecting Geraldine — Geraldine's 28 — and I said to him, his name is Dr Graeme Hughes and he doesn't get a lot of publicity, he's not one of those big IVF flyers out there in the media, and I said to him: if you had donor children would you tell them that they were donor children? I had been raised as a State Ward of Victoria, I knew about the loss of identity, and so I didn't want to replicate that for my children. I had been searching, I was struggling, I had been raised by nuns to tell the truth, the whole truth and nothing but the truth, so help me God. So I wasn't going to tell a lie to my children so I went to Dr Graeme Hughes and said: if you were going to have donor children would you tell them? And he said: yes. So that really just supported my own thinking. I came home and I said to Warren: well, if Graeme Hughes can tell his kids, why can't we? That really does need to be acknowledged because in the secrecy surrounding donor conception all those years ago, he was a voice that was speaking out in the wilderness — well, he didn't speak out, that was an individual conversation. Many doctors advocated secrecy all over this country and it's had a devastating effect on tens of thousands of families.

Ms GARRETT — To continue, did you know who the donors were?

Ms L. HEWITT — No, we didn't get to choose; they were chosen for us. Geraldine has four half-siblings and nobody says they've destroyed them but they have destroyed them — his records. Kieron has 27 half-siblings, 20 in South Australia because the donor was in the Army and he moved around, so there are 20 children there, and one of them even has the same first name as my son. I've met them. Then there are four half-siblings at the Royal Hospital for Women at Paddington and then the donor has four children of his own. If you count Geraldine and Genevieve, that's 31. He raised another child of his first wife, so there's no biological link there.

That's an awful lot of children that you're related to. It's totally different for adoption, and these children need to know who they are related to and who they are not related to so that they don't form a relationship with their half-sibling, or even their donor. You can't say when Genevieve reaches 25 or 30 that she doesn't have a relationship with a man in his 50s. It could happen.

Ms LORBACH — Currently at the moment the donor's children have more rights to information than donor-conceived children in that if the donor applies to get information about how many half-siblings there are, he can get that, so therefore his children will be able to know that, they will be able to know how many boys and girls there are and what years they were born in, but the donor-conceived people can't know that. So there's definitely a real disparity in that.

The CHAIR — Any questions?

Mr NORTHE — Caroline, in your submission you talk about a national register. Can you maybe just elaborate on your logic and thinking behind that and how it might work in a practical sense?

Ms LORBACH — A reason for pushing for national legislation and a national register is partly because of the reluctance of some states to actually do anything about this issue, and there are still a number of states who haven't addressed this issue — Tasmania, Queensland and the two Territories have not addressed this issue at all. South Australia has done to a certain degree but don't have any registers, they have a facility to have a register but haven't put one in place. I think they're waiting in the hope that the Federal Government will do something. Also the fact that we're a very mobile population so people move around, so it seems quite logical for this issue to be dealt with as a country, not in the way it has been done around the states so that people have very different abilities to access information depending on when they were born and where they were born. It just seems very logical that we should be dealing with this on a national basis, and I think the Federal Government probably has more resources than each state in order to do this properly because it's going to be a very big undertaking.

Also for the fact of keeping track of where and when donors donate, because there is no system of checking on whether donors have even donated at another clinic in most states. As Leonie says, her son's donor donated in more than one state, so we need something that will keep track of where donors are donating. Most donors are very responsible but some aren't, and not all clinics will even ask the question of whether a donor donated at another clinic.

Ms L. HEWITT — Especially that semen that was being transported from Western Australia to Victoria in the early 1990s.

Ms LORBACH — Queensland has regularly imported sperm from other states over the past number of decades; it's been quite well-known.

Mr NORTHE — Just digressing a little bit. So I'm very clear on your views with respect to donor-conceived persons accessing information of the donors, but conversely — and it's distinct from what Leonie and Genevieve have been through with being upfront with each other — if the donor wants to seek information on their offspring but the offspring might not be aware that they're actually a donor-conceived person, how does that play out and how should the system work in your mind with respect to that?

Ms LORBACH — I firmly believe that all donor-conceived people should have the right to know how they were conceived; it's their information. Victoria has addressed this to a certain degree in the extra information that will be available in the future when donor offspring access birth certificates. But that doesn't apply to already conceived children. My husband and I told our three children from a very young age, starting at about the age of two, so they grew up always knowing how they were conceived. I don't think that parents have a right to withhold that information from the person. Perhaps as parents when their children are growing maybe some people might say they have the right to withhold that information, but once that person becomes an adult it's their information, it belongs to them, it's about them, and I don't believe that anyone should have the right to say: you don't need to know this.

That's what we were told by the first doctor we went to see, that nobody needed to know how our child was conceived. And he meant the child. And we just couldn't do that because our whole society is based on truth being so important. Relationships are based on truth, on honesty between people, and we could never have envisaged lying to our children because if you don't tell them the truth about how they were conceived you're lying to them because you're letting them believe something that is not true. I think people should have to tell their children the truth about how their children were conceived.

Mrs PETROVICH — You made a comment before about the Assisted Reproductive Treatment Act and the fact that it's created, in your view, different categories of people. What's the way forward? How do we address this scenario that we have some people who know, some people can know, some people who will never be able to be identified?

Ms LORBACH — By becoming the first jurisdiction in the world to give full retrospectivity as you did for adoption. As simple as that. If you did it for adoption all those years ago, and that was so right, why is it not right to give the same access to information to donor-conceived people? What makes donor-conceived people different to adoptees?

Mrs PETROVICH — Just one follow-up. How do you explain to a two year old and how do you couch that with a two year old, about their conception?

Ms LORBACH — You need a sperm from a dad and an egg from a mum to conceive and in our family dad didn't have any sperm so we had to go to a clinic where the doctors would find men who were willing to help families like ours to have a child, and they would give us their sperm. We never got any questions about it for a number of years; it was very simple and you repeat that message to them so they know it's something that's open for conversation and discussion. You add little bits as they grow up, you make it a little bit more detailed, and it's a very gentle way. Very few children will ask questions when they're very young, they will ask questions as they get older but then they grow up always having known it's part of their identity for as long as they can remember.

My eldest son, who is 22 now, doesn't remember a time where he didn't know. The other two were told probably from an even earlier age and it's part of their identity. I remember having an e-mail conversation with a donor-conceived person from Great Britain who was told when he was 12 how he was conceived and he said: it was like being hit by a truck. And he said: I had to then start rebuilding my identity. And that is what some donor-conceived people have had to do at much later ages because they've either discovered or been told in the heat of arguments, separations — and we've had numerous people like that come to our group — and they wish they had been told right from the word go so that it becomes part of them and they don't have that sudden time of being told where they then start wondering: who am I? How is that donor linked to me? What am I if I am not a child of both my parents who raised me? And I think that is an awful thing to discover at a later age.

Mrs PETROVICH — We've had submissions around that particular issue.

Ms LORBACH — Yes, because I think the issue then becomes one of much wider importance in the family. Once you feel you haven't been told the truth about one topic, you will then start wondering about everything else in your life that you may not have been told the truth about. So parents need a lot of support in how to tell the children and a good education campaign, perhaps working with sex education in schools, so that people feel that this way of forming a family is perhaps more 'normal', if you want to put it in inverted commas, and parents feel that they can tell their children.

Victoria is definitely a lot further down the track than any other state in Australia, and in most jurisdictions around the world as well. My son, who is 22, doesn't like telling people how he was conceived. He has a girlfriend he's had for a couple of years now, who is absolutely lovely, he didn't tell her for six months because he was afraid that she might view him differently because of how he was conceived. But if he'd grown up in a world where this was very open and talked about, he probably wouldn't feel that way.

Ms GARRETT — And I think that society has caught up in a sense, now obviously people conceived here will be able to identify their information at 18 so that changes the dynamic in the family unit and hopefully those sorts of conversations are taking place. With respect to what's happened pre-88 here and the issue of retrospective access to identifying information, the culture, the people who are told that they would remain anonymous; in fact it was better that the whole thing was kept under the rug — we've heard a lot of evidence about that — in your role, both personally and professionally, all of you I suppose, is it your experience that those donors who gave donations under that set of circumstances are in the main open to being identified?

Ms L. HEWITT — Since the group was formed in 1993 I've probably spoken to 1,500 donors across this country and I could count on one hand how many don't want openness, don't want their identity used. Most of them, when they understand the issues for the donor-conceived person, are quite prepared to have contact. I could probably name the five people that didn't want to, and one is a doctor who lives in Melbourne, trained in Sydney, and he didn't want his identity released. Another guy was from out near Blacktown, so there are very few that don't want their identity released. These are people who did it for altruistic reasons in the main, they wanted to help infertile couples, and it just stands to reason that they'd make that step further to help the donor-conceived people.

Ms GARRETT — Just to follow on a further question when you mentioned once they become aware of the issues for the donor-conceived people, in your experience how has that best taken place? Obviously through an awareness campaign, etcetera. We had evidence from donors here, one Mr Smith who said: it was when I had my own children that I realised the complexity of what had happened and what I'd created. Would you think a change in legislation would assist that process as well, that people would be — I suppose force might be the wrong word, but required to look at this in a different light and if there was accompanying education and awareness, your experience has been that that would then shift thinking if perhaps it was one way it would shift it in a different direction? That's a long question, I'm sorry.

Ms LORBACH — Yes, I think you're right that it would, because any legislation of this type would have to be accompanied by a fairly extensive education campaign to explain the reasoning behind it. But it's strange, people have talked for years, especially doctors, about how donors don't want to be identified but there's been research done in the 1980s in Australia, very little research on donors since then, but in the 1980s they were quite happy on the whole to have their identity stored on a register. A good proportion of them were happy to have their identities known and, surprisingly, most of them really didn't want to be paid either.

Ms L. HEWITT — I think in that campaign we need to encourage past donors to come forward and also I'm just thinking of that child psychiatrist in Orange who came forward to the King George V Hospital because he had been a donor when he was a student, and he'd had his subsequent family with his wife and that started to raise the issues for him. I gave him the number of the counsellor to speak to about his donations, to see if there were any children. There were no children as a result of his donation yet he'd been left wondering all those years if he'd created children so you've got to put some of these blokes' minds at rest that there may not be any results from their donations. That's a really important point.

Ms LORBACH — It was surprising how upset that man was.

Ms L. HEWITT — He was; he was very upset.

Ms LORBACH — That he'd imagined these children over the years and had never thought he could actually ask for the information but when we encouraged him he actually went back and found out and, unfortunately, there wasn't any children and he was quite distressed by that, that he hadn't been told beforehand.

Mr CARBINES — Chair, I would just like to ask whether you have a view as to why the voluntary register that exists there aren't perhaps more donors and more people who have chosen to take up the option to have their names listed there?

Ms LORBACH — I was led to believe that there are actually more donors on those registers than other people. I think part of it is probably because a number of years ago a lot of parents weren't telling their children, and also the number of donor offspring who may believe there is no point, that there isn't any information so what's the point? They don't want to take that step forward to ask for information and then be told that there is nothing because they know for a lot of them that records are either very minimal or may well have been destroyed. So we do need more education around that.

Mr A. CARBINES — Just as a follow-on, you can empathise more than we can around parents of donor-conceived offspring, what do you think they're thinking about in terms of say there's greater disclosure, what sort of mechanisms and supports do we need to potentially have in place, and what's going through people's minds, is it purely around advice they might have had from a clinician at the time? What are the sorts of things they're thinking about, do you think?

Ms LORBACH — And the fact is the longer you keep a secret the harder it is to tell because then other issues come up: why didn't you trust me with this information years ago? Why didn't you tell me the truth?

Mr CARBINES — I'm trying to think if there was a greater disclosure and you are the parents of donor-conceived children, and the support is available to you, what might potentially be your thinking at that point because I suppose there's a time pressure potentially around how you choose to deal with that situation.

Ms LORBACH — VARTA has been doing a very good job in the last number of years with their Time to Tell campaigns. I think they've only been holding one meeting a year but they're very well attended, so there needs to be perhaps an enlargement of their role in helping with public education campaigns, meetings where parents can get together with like-minded people, and help that way. Unfortunately, we really feel that the move of the registers to Births, Deaths and Marriages was not of benefit to donor-conceived families at all.

Mr NORTHE — You haven't been alone in those comments either.

Mrs PETROVICH — We've heard a number of submissions that have stated that there are more donor-conceived children out there who don't know that they're donor-conceived. And we've also heard about the devastating effect of that, finding out through anger or in a period of time perhaps going through difficult life changes when you're 15 or 16 or even in your early 20s. If these people don't know, is honesty still the best policy?

Ms LORBACH — I guess you've got to think of what do those people think about themselves because the number of donor offspring that we've spoken to over the years who haven't been told until their late teens, 20s, up to their 50s, who actually did think there was something different about themselves, who either thought they were adopted. One man thought his mother had gone out and had an affair because his older brother was adopted and he was convinced and thought he was not his father's child. We don't know what the effects of donor offspring not being told the truth is, what effect it has on them psychologically, so it's a very hard question to answer. I think if it was me, I would want to know the truth. I would want someone to sit me down and say: this is actually how you came into being, this is who you are related to, this is the truth about your identity.

Ms L. HEWITT — There's a family in the same suburb where we live in Georges Hall and our two eldest children went to school with these two children, they were conceived at the same clinic. Geraldine, when she was in Grade 6, gave the big spiel about egg and sperm, that she was a donor-conceived offspring, and this boy was sitting in the classroom and went home to mum and told her that Geraldine had given this spiel. Those children don't know. When the parents have died — I won't know about the father but when the mother has died — I am going to disclose to those kids because I believe they have a right to know. She actually hid in my bathroom one day when I had a social for her to come and meet some donor families and somebody came knocking on the door, she didn't want anybody to know that she was at my house because I was so out of the closet out there, she didn't want to be associated with me and anybody discovering that. She still hasn't told her children. She says she hasn't lied; she just hasn't told the truth and they haven't asked.

Ms LORBACH — I had an e-mail recently from a member of our group, who has been a member for a very, very long time, whose son is in his 20s. He recently formed a relationship with a young woman and after a few months of going out, and he's donor-conceived of course, she was told by her parents, in a not particularly nice way, that she was also donor-conceived. And they'd formed the relationship and she didn't know. That's in Queensland. They say the chance of them having the same donor is virtually zero because he was conceived in Western Australia, but she doesn't know who her donor is, she has no information about him because her parents won't talk about it anymore. They said they've told her the truth and that's the end of it.

Mrs PETROVICH — There was a difficult point that you raised earlier about relationships and there are numbers of offspring out there. You talk about that scenario with two donor-conceived people in a relationship. Is it somebody's responsibility to actually offer them some testing to make sure that they are not related in any way?

Ms LORBACH — I think it's the responsibility of the whole of society that we deal with all of these issues, it's the responsibility of the doctors who facilitated these births, it's the responsibility of us as parents, and it's the responsibility of governments and the whole of society that we do have to look at these issues and do something as soon as possible.

Ms L. HEWITT — I think they should be able to get a DNA test free of charge. Genevieve shouldn't be made to pay for that test if she wants to check that the man she wants to marry isn't genetically related to her; she didn't create this problem. The Australian taxpayers pay an awful lot of money through Medicare for us to have families — mind you, Caroline and I never, ever went through IVF. The figures through the IVF perinatal statistics for donor children, our children are not counted in that because it's only if you're an IVF baby.

Ms LORBACH — Until a few years ago when they started collecting figures on donor insemination as well.

Ms L. HEWITT — So we haven't used any taxpayers' dollars to create our families through IVF, but I think there are plenty of other families who have and I think that the Australian Government should show leadership on this and should introduce a national register because there are eggs coming from Greece and Albania and where else, everywhere. It's a really international issue, it's huge. And semen from — what's that bloke in Denmark from the Danish clinic? It's just a real industry and it's got to be regulated and controlled and these people's human rights are important, just like your human rights are important to know your identity, so do my kids.

Mrs PETROVICH — You've just raised an issue that I don't know that I've actually heard, and others on this Committee may have, that there is international material. We knew that there were possibilities of national material moving around but I think you've just thrown a whole other — —

Ms LORBACH — Well, they would have to get permission to bring it in from overseas into Victoria because you've got good regulation in that area.

Mrs PETROVICH — So it is protected?

Ms LORBACH — Yes. The same as bringing in material from other states, you have to get permission to do it here as well. But it's happening on a regular basis in other states.

Ms L. HEWITT — It's hard enough to find Australian donors, let alone overseas donors.

The CHAIR — Thank you very much for coming in today. Does anyone else have any final questions? It's been really helpful. Thank you.

Witnesses withdrew.