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LAW REFORM COMMITTEE

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

Melbourne — 21 November 2011

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The CHAIR — Clem-Newton Brown speaking. Can you hear me okay?

Dr ALLAN — Yes, I can hear you really well.

The CHAIR — I'm the Chair of the Law Reform Committee and this is a joint parliamentary committee which is set up to investigate matters to do with law reform and this is one of the references that we're looking at at the moment. Also with me today is Jane Garrett, who is the member for Brunswick and the Deputy Chair; Russell Northe, who is the member for Morwell; and Donna Petrovich, who is the member for Northern Victoria. Also on the committee but not here is Anthony Carbines, who is the member for Ivanhoe.

We're fairly informal here. We would just like people to talk us through their submission and we will ask questions as they arise. Everything is recorded here so when you start if you could just start with your name and your professional address and who you represent. Anything you say today is protected by parliamentary privilege but not outside the hearing room. If you could start with your name and address and then launch into your submission, please.

Dr ALLAN — Okay. My name is Sonia Allan, my professional address is Deakin University, Burwood Highway, Victoria but I'm currently based in Washington DC at Georgetown University Law Centre.

The CHAIR — Do you want to talk us through the main points in your submission that you want to highlight?

Dr ALLAN — Okay. Where do I start? I've put in two submissions to your inquiry, the first was a general submission just advocating for information release for donor-conceived people generally. I think Victoria is well placed to lead the way in that sense; we already have registers for a number of donor-conceived people to be able to access information. Subsequent to the national Senate Committee report I thought that it was important to actually focus on the issue of retrospective release, so perhaps it's worth me concentrating on that today.

My starting point, the first issue is whether or not we can legislate for the retrospective release of information. When I researched that question there doesn't seem to me to be any impediment to the legislature actually deciding to do so if they see fit, but I think that it's a question of then asking whether it would be okay to do so given that there are some people who would argue that releasing information retrospectively would contravene people's rights to privacy or confidentiality. So then for me the question becomes if we're going to legislate retrospectively that you need to balance the interests of the different parties involved because it is acceptable to pass retrospective legislation even if an individual or a group of people suffer an injustice, if the result is addressing a manifest injustice suffered by a larger group of people.

I would submit that the manifest injustice is the one that is currently being suffered by not just donor-conceived individuals but their parents, the recipient parents, and also donors who actually want their information released. So it goes beyond the donor-conceived individual themselves by not allowing access to information, it puts

the recipient parents in a position where they may not be able to give their children information and so may choose not to tell them about their donor conception at all. Also I'm aware of a number of donors, some of whom are in Victoria, who actually want to share their information but don't have any avenue to do so. Do you have any questions on that?

Mrs PETROVICH — No, not at this stage.

Dr ALLAN — Then what I did was actually looked at the different arguments about why we should release the information as opposed to the argument put forward by people who say that we shouldn't. Again, it would be my submission that the arguments for release actually far outweigh the arguments against release of information and it goes beyond wanting to know medical history and the risk of hereditary diseases and, again, we're seeing some donor-conceived people who actually have hereditary diseases but can't access information about their donors. They are aware that they have siblings, genetically related siblings, that they can't contact them and share the information about them being ill, so that's a pretty salient argument for release of information but I think there are a lot of other arguments that also support the release.

The CHAIR — The contact between siblings, is that a different issue to between a father and child in terms of how would we go about facilitating contact between siblings where potentially one sibling knows and the other doesn't? Are you suggesting that it should all be out in the open so that everybody can contact everybody or is it more defined when you expand the family relationships?

Dr ALLAN — Perhaps I shouldn't have used the word contact. Mostly what I advocate is that information be held somewhere on a central register. We already have that in Victoria but it stops at a certain date, so if the information was on the register and then there was a way to counsel people, match people, so you could have donor linking. To answer your question, I suppose the first issue is where a donor-conceived individual knows that they're donor-conceived and they want information about their genetic parent, and I think that's definitely the first point that needs to be addressed.

It is a slightly different issue to say they also want information or to be able to exchange the information with their siblings, I don't know whether that would be possible at the forefront because, as you've recognised, there are many donor-conceived people who don't know that they are donor-conceived so it would be very difficult to have that information and contact them without them knowing that they were donor-conceived. I suppose the focus should be, at least primarily, on the donor-conceived individual knowing the donor or information about their donor.

In terms of my submission, I would stress that I don't equate information release with contact, I think contact is something that would need to be determined between the parties and probably would have to take place with extensive counselling and preparation for that sort of contact, but I think the information about identity and also to non-identifying information should be out there. Does that answer your question?

The CHAIR — Yes, thank you.

Dr ALLAN — In my submission I've listed a number of other arguments so there's the argument about genealogical bewilderment and a sense of identity. There's quite a bit of research that supports the fact that the later people are told about their donor conception can lead to all sorts of psychosocial or social problems or issues about identity, there's fear and risk of forming consanguineous relationships and this again goes to knowing about genetic siblings.

I don't want to make it a secondary issue because I think for the donor-conceived individuals that I've met over the years they want as much information as they can possibly have, and for them they're real issues, so they fear that they could be attracted to somebody because they're related to them. I suppose that could happen just as much with a donor as it could genetic siblings.

I think there's inconsistency, and this comes to a kind of issue of equity in the law, about allowing some donor-conceived individuals to have information and not others, and that that is determined based upon when in time the donation was made. In that sense, I suppose it's difficult again when you have adult donor-conceived individuals who are the ones that are calling for information the loudest, it seems that as people become adults or start having children of their own it's them that actually want to be able to not just have information about themselves but impart information to their children about that genetic heritage. I think these are pretty salient arguments in terms of the donor-conceived.

As I mentioned before, I think there are also arguments about recipient parents wanting to be able to give information to their children and currently not being able to. Before the law was changed in Victoria about access there were a number of women who were travelling interstate to undergo assisted reproductive treatment and then they come back to Victoria and have children in Victoria and those children don't have access to information because the other states that the mothers attended had anonymous donations or didn't have the registers in place that Victoria has. I think there are a lot of recipient parents who would actually like to see the information released and, as I said before, there are also donors who are strongly advocating for information release.

When I went through the national Senate Committee's report and the submissions, it seemed to me that the strongest voices against the information release were not in fact donors but it was the clinics and the Fertility Society of Australia.

The CHAIR — Why do you think that might have been the case?

Dr ALLAN — I've had many conversations with many people about why that might be the case and we can only suppose because we don't really know. They seem vehemently against retrospective release. One possibility is because the donors in the 70s and 80s were medical students; there seems to be some consensus that in fact a lot of donors were recruited in class, I really don't know. I don't know if it would expose inconsistent record keeping, I don't know if it would affect their practices; we can guess but nobody really knows. They seem to accept, and we've got some clear

statements that from now on donor-conceived individuals should have information, but talking about the past is the bit where they close the door. Sometimes they use the argument that it would be against the donor's privacy and confidentiality but then I don't see an abundance of donors putting in submissions saying that they don't want release. I do see a number of donors putting in submissions saying that they do want release, so I could only guess at the motivations of the clinics and the people engaged in the practice of assisted reproductive technology but I suppose what I do notice is that they seem the strongest voice of opposition and that to me then, when you're weighing up the arguments and you say okay, so I've got donor-conceived individuals, I've got recipient parents and I have donors who are saying that they want information release, and then I have the clinics who are saying they don't, I think we should think of the people who are actually affected by not having information.

The CHAIR — On the issue of retrospectivity, you make the point that it's somewhat analogous with adoption but then also note that you concede that it's not similar in all ways. Could you just talk us through your thinking on that as to if we're assessing whether we follow the adoption model or not, what are the things we need to think about in terms of the differences?

Dr ALLAN — I would not start by saying that a donor-conceived individual's situation within their family is necessarily the same as an adopted person's situation within their family or their relationship with their birth parents. Perhaps with adoption there might even be an increased desire to have contact with the first parent, depending on the circumstances in which the child was given up. I think there's a difference between adoption and donor conception in that some would argue that donor-conceived individuals, because they're not relinquished by another parent but rather they're in fact very wanted by the recipient parents who have them, that they're in quite different positions. I have, however, had other donor-conceived individuals who say the donor is relinquishing them before they even have them, but that's not necessarily my thinking.

The difficulty is to say that they are the same in every way, I don't think they are, but I think where we can draw the analogy and the point was made — I think it was accepted in *Pratten* in Canada, a case currently on appeal — where we shouldn't negate donor-conceived individuals' feelings about wanting information about their genetic heritage and perhaps they are actually more similar in that sense to adopted children because the desire to have information is the same regardless of what their family situation is or whether they were wanted or whether they were given up for all sorts of other reasons. Perhaps it's just that then, that the psychological and social issues differentiate between the donor-conceived and adopted people at a certain point, but I think with the desire for information we can draw a very good analogy.

Then I used the adoption analogy in the sense of looking at a clear example in the law where people have said: I want information about my genetic heritage. And Australia has said: we recognise the need, we recognise that information about your genetic heritage is important and we are happy to legislate retrospectively even though some people may not want that to happen. I think it was early in the 90s the New South Wales Law Reform Commission stated clearly that there was this balancing of all the

interests of the parties, so the adoptive parents, the adoptee, the person who relinquished the child, and that they in balancing those interests decided that the interests of the person who had been adopted should prevail. So there I would draw the analogy with donor conception and say, again, we potentially have competing interests but whose interests ultimately should prevail? I think it should be the donor-conceived, the recipient parents and the donors who want to exchange information.

I think too I used the example of the potential for contact vetoes so if we want to differentiate between making information accessible as opposed to them moving to relationships that it would be possible to place contact vetoes so the donor-conceived individual could have information but the donor could protect their privacy by saying: 'okay, I don't want contact with any of the donor-conceived individuals that are in existence as a result of my donation', to balance the interests. There may be donors out there who donated in their 20s when they were at school and have moved on to have their own families and their own lives and they don't want that interrupted, and that's a fair argument. So it's not to kind of move in to say that you made this donation when you were 20, you didn't think about it, sorry now you have to have contact with your seven donor-conceived children and how that would impact on them because they might not have even told their families that they donated sperm in the 70s, so I think we really do need to balance the interests and so the adoption analogy is actually quite good in providing a model to do that because we can protect the donor's privacy by saying you can opt out rather than opt in if we pass retrospective legislation giving donor-conceived individuals access to information, you know that your information is going to be on the register, that donor-conceived individual may contact you unless you opt out. If you opt out then the donor-conceived individual is not allowed to make contact and is not allowed to breach that person's privacy. I think that model actually works quite nicely, noting that Victoria doesn't actually have contact vetoes for adopted people, it's one of the states that hasn't done that in that circumstance, so perhaps if you want to differentiate between the two, contact vetoes could still be possible.

The CHAIR — Jane Garrett has a question for you.

Ms GARRETT — No, I wanted to ask you about contact vetoes, so thank you.

Dr ALLAN — The other thing on that would be in the paper that's coming out in December, and I've given you a copy of that. Queensland had information vetoes as well so you could opt out of the system and say: I don't want my information released. But they actually retrospectively took that away as well because they were concerned that there were 3,000 adopted people born prior to 1991 that were being denied information. If you look at the numbers of donor-conceived, or possible numbers of donor-conceived individuals, if there's a state doing that for 3,000 people then maybe we should be thinking about the thousands of people that potentially are being denied information as a subset of the Australian population.

The other thing that I wanted to talk to you about is one thing I noticed that the clinics also argued a lot about was this contract for anonymity. Over the years I've come across the argument about the contract and I thought perhaps we should go and actually try and find these contracts and have a look at them. From what I could see,

and I was given contracts by donors, recipient parents and donor-conceived people, they're not really contracts, they're consent forms that were signed at the time of donation. I can see that it says that the recipient parent won't seek out the donor, and the donor won't seek out the recipient parent or the child, but none of them actually prohibit or say anything about the donor-conceived individual looking for information so I don't think that the contracts themselves stand the test of being a contract that protects the anonymity if it is actually the donor-conceived person seeking information.

Another fear perhaps that the clinics have is that they could be sued for breach of confidentiality if they were forced to release information. I think that could be quite simply addressed by something in the law saying how this information is to be made available and that there would be no liability for breach of contract, because I think perhaps that could also be an explanation why people are fearful of seeing information released. Again, I am supposing; I really can only second-guess because it's not clear to me what lies behind some of the clinics' argument.

Mrs PETROVICH — Sonia, in your submission you talk about a national and even an international model for registration — we're focusing very much on a Victorian register — but can you explain the benefits perhaps of a national register and what work has been done on that? You talked about a Senate committee previously.

Dr ALLAN — It starts well before the Senate committee. In about 2007, myself and another — well, he's now a graduate of Melbourne Law School but also a donor-conceived individual, we made a submission to the Attorney-General for a national register and we suggested at the time that it be voluntary. The Senate committee then obviously went further. Their first recommendation was that there be a centralised national register. I think the reasoning that lies behind that is that ultimately there's a push to say everybody in Australia who is donor-conceived deserves the right to be able to access the information and if it was all held in a centralised register then that might enable smoother flow of information, there may be donors that have donated across states, there may be siblings that are living in different states, so it might facilitate the kind of sharing of information a bit better.

This was a question put to me by the Senate committee when I appeared before them: where does the power lie in terms of being able to pass legislation and what powers does the federal government have to be able to set up a national register and where would it be held? So although we could start with the ideal by saying a centralised national register might be the best way to disseminate information across Australia, ultimately I think in the Senate Committee report they recommended that each of the states take it on board and set up a central register within the states. I'm hopeful that Victoria will lead the way because I think if Victoria doesn't lead the way it's going to be much harder for the rest of Australia to do so. But if each state had a central register perhaps they could then link in with each other so that sort of information sharing could be a possibility in the future.

I think if we focus on Victoria, we already have some great examples — in fact I would argue some of the best registers in the world — and when they were run

previously by the Infertility Treatment Authority I think the earlier model in terms of donor linking, they have a great model for the way that they counsel everybody involved, they exchanged letters, there's a process, the information is held and I believe that the record keeping was quite comprehensive in terms of the way that they could link people with their information. Although that national ideal could be a possibility, I think the more realistic option is that Victoria looks at the registers that they have and where they're held and how they could function. We're already in a position to actually facilitate release of information, and I think the Senate Committee recognised that, so their recommendation was if in the event a national register couldn't be set up that it should fall to the states and then hopefully what would happen is that the states would pass uniform legislation. So if Victoria passes the legislation and sets up a central register that operates to give information to all donor-conceived individuals, and New South Wales has an inquiry on foot now asking similar questions, potentially they could then look to Victoria and say, okay, this is how they're doing it, and maybe we would get a domino effect and it would happen around Australia.

Mrs PETROVICH — Sonia, we've heard in our inquiries that in pre-1988 the records were very poor. What makes you think that Victoria needs to be the leader in this role and what makes you think that Victoria is in a better position than other states?

Dr ALLAN — There are issues about the records being poor and the record keeping and I imagine there are some records that have been destroyed. The other thing that the Senate Committee recommended was that there be not only the register where any records that are in existence be put on that register but alongside that a voluntary register still operate, and linked with that would be a DNA bank so people could be genetically matched if they were willing to come forward. It's not an ideal situation because the records are sparse or were ill kept or have been destroyed but, again, I think Victoria is in the position to lead the way because they are well experienced in maintaining registers. Being at the forefront they were the first state, the first place in the world to actually pass legislation saying that donor-conceived individuals had a right to information, and have moved forward that way ever since. They're in the position to lead the way because they always have in a sense.

They also have the expertise sitting there at VARTA in terms of people who have been working in the field. Kate Bourne is an example, she's a counsellor at VARTA. She, I believe, worked at the clinics for a long time counselling people, linking people. She now works for the Victorian Assisted Reproductive Treatment Authority. We have some real experts in Victoria that place us in a really good position to actually work out how this should work. In doing that, I would also stress that I don't see it as a quick fix, I don't see it that overnight we would just release all the records, I think that there needs to be a lot of structure in place and in that sense we have the people in Victoria that can be consulted that are probably worldwide the people with the most experience in releasing information and managing these relationships or helping donor-conceived people accessing information about themselves.

Ms GARRETT — Thank you for your submission and for doing it from the other side of the world. I had a question regarding contact vetoes and, should the Victorian Parliament go down the path of giving retrospective access to donor-conceived children, and certainly you're not alone in your suggestion that there could be a possible introduction of a contact veto. Given there is complexity around donors having had their own families after donating when they were very young, as you've pointed out, and having other donor-conceived children out there, what's your view on contact vetoes extending to members of the donor's family? Is that what happens in New South Wales, do you know?

Dr ALLAN — I would imagine that a contact veto would not only protect the donor but would protect their immediate family.

Ms GARRETT — Donor's children.

Dr ALLAN — In Western Australia there's some quite stringent penalties for breaching a contact veto.

Ms GARRETT — In regards to those and in New South Wales, is it from your research that the New South Wales system has operated effectively the contact veto system in the adoptive context?

Dr ALLAN — I couldn't actually answer that off the top of my head; I could take that question on notice and look into it more. I believe that the contact veto system actually works quite well there but that's me positing an opinion rather than a researched opinion on how adoptees and the people involved actually view it. I do believe that the contact veto system works quite well, provided there is counselling. It's not enough just to be able to say: well, if you don't want to be contacted you place a contact veto and that's the end of it for everybody. Because, as with adoptees, donor-conceived individuals would need to be counselled about the fact that you can have this information only on the basis that you cannot make contact with the donor or the donor's family, you can't show up on their doorstep. I think for donor-conceived individuals that's actually quite unlikely that they would do that. I think the boundaries need to be quite clearly set but then the support systems also need to be in place. I think that does happen in New South Wales and I'm sure that it happens in Western Australia, they have to see a counsellor before they're actually given the information if there's a contact veto in place. I would say that you would need to see a counsellor even before you're given information, regardless of whether there's a contact veto.

The CHAIR — Anyone else got any questions? No. Sonia, thank you very much for your submission, it's a very detailed submission and it's been very helpful to us so thank you very much.

Dr ALLAN — Thank you.

Witness withdrew.