CORRECTED VERSION

LAW REFORM COMMITTEE

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

Melbourne — 12 September 2011

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Witnesses

A/Prof Rosalie Hudson, and

A/Prof Nicholas Tonti-Filippini, Ad Hoc Interfaith Committee.

The CHAIR — Welcome. My name is Clem Newton-Brown, I'm the Chair of the Law Reform Committee. You are probably aware this is a cross-party committee which is set up by Parliament to investigate various terms of reference, this being one of the three that we're looking at at the moment. I've got Jane Garrett, who is Deputy Chair, Russell Northe and Anthony Carbines. Basically what we've been doing is going through, asking you to orally present the main points you want to emphasise in your submissions and if you don't mind we will jump in when we have a question or an issue that needs further clarification.

One thing to be aware of is that you're protected with parliamentary privilege here but not outside the room so if you are contacted by journalists to make further comment you don't have that protection. If we could start with getting your name and address and what capacity you're here, who are you representing, and that's being recorded as we speak.

A/Prof HUDSON — My name is Rosalie Hudson, and I'm here as one of the members of the Ad Hoc Interfaith Committee.

A/Prof TONTI-FILIPPINI — I'm Professor Nicholas Tonti-Filippini, I'm from the John Paul II Institute. I'm also a member of the Ad Hoc Interfaith Committee but I made my own submission and what we've decided to do is that Rosalie will speak for the Interfaith and I'll speak for my own.

The CHAIR — Perhaps before you launch into it, if you could explain to the Committee what the Ad Hoc Interfaith Committee is.

A/Prof HUDSON — It was set up two or three years ago mainly to respond to the issue of abortion as we believe that it affected a lot of people from various interfaith perspectives so at the invitation of Nicholas Tonti-Filippini and his institute, probably eight or 10 people from a variety of faith backgrounds were called to an introductory meeting, very informal, and it's called an ad hoc committee because we meet from time to time when there is an issue that emerges so we represent most of the main Christian dominations plus Muslim, Jewish, Hindu. We try to reflect a variety of faith perspectives but basically it's drawing together a people who have a common interest in the particular subject.

The CHAIR — So I presume it's an antiabortion — —

A/Prof TONTI-FILIPPINI — No, it's social issues basically and abortion was the initial issue but it wasn't formed for abortion, it was formed just to respond on social issues so it's a whole range of issues. If you remember around that time there was a long range of things in terms of equal opportunity legislation and reproductive technology through 2008, there was a whole range of social issues.

The CHAIR — Do each of the churches nominate a person to be on the Ad Hoc Committee?

A/Prof TONTI-FILIPPINI — No, it's ad hoc.

A/Prof HUDSON — No, it's far less formal than that.

The CHAIR — The position of the Ad Hoc Interfaith Committee, is that representative of the churches that have members in the committee?

A/PROF TONTI-FILIPPINI — It's representative of the people who sign the document. Sometimes when we put out a document we've had almost all the church leaders sign it.

The CHAIR — But not necessarily?

A/PROF TONTI-FILIPPINI — Not necessarily. This time we didn't have time to approach them so we just met with those who were informed. But other times on the abortion issue we put out a statement that I think had every church leader except for the Uniting Church on it, and similarly on reproductive technology, so it just depends on what happens. We put it around through the churches if we've got time.

A/Prof HUDSON — I'm a member of the Uniting Church in Australia but I don't represent the Uniting Church.

Ms GARRETT — Thanks for clarifying that.

The CHAIR — I will let you launch into it.

A/Prof HUDSON — I've just prepared 10 points as a summary for our submission, which you obviously have. First of all, I would like to thank you on behalf of Nicholas and myself for inviting us to present in person at the inquiry and for an opportunity to speak to our original submission.

As I said, the purpose of the Ad Hoc Committee is to use reasoned argument, informed by our various faith perspectives, on issues of the day and this is one issue of the day that we were very interested in responding to. Our basic position is that we do have very grave concerns about donor-conceived people who by the very nature of their origins are disadvantaged, we believe, compared with children born naturally of a father and a mother. We believe that it is confusing to have parenthood fragmented into genetic, gestational and social roles, raising the question particularly for people so conceived of who are their real parents? Is he or she their genetic parent, their social parent, their nurturing parent or their substitute parent? So the very nature of this issue has, in our view, fragmented parenthood just because there are so many different terminologies now for parenthood.

These questions arise when there's a focus on technology, albeit with a very laudable aim of assisting infertile couples to have children. But the questions arise when that technology lacks the foresight to view the very personal consequences that sometimes occur decades later, that are not foreseen when the technology is there.

Our main argument is that the rights of donor-conceived persons to know their origins outweigh the rights of the anonymity of the donor so that's one of our specific arguments. We believe that these rights are not only about origins but about present and future possibilities involving other family members and also the unforeseen consequences of consanguinity.

We acknowledge the weight of anonymity arguments and agreements that are entered into by donors and we have great respect for the whole philosophy of anonymity and confidentiality in other areas. However, in this particular case of donor-conceived persons we believe that the rights of the third party must also be considered and our understanding of the anonymity and confidentiality agreements entered into by those who have donated gametes did not necessarily foresee the rights of the third party so involved.

The CHAIR — Rosalie, has the committee considered the impacts of the family unit on having a disruption of a donor-conceived child contacting that family unit?

A/Prof HUDSON — I'll defer to Nick for that.

A/PROF TONTI-FILIPPINI — Yes, we have. What we have suggested in the structure of this is that, firstly, anonymity shouldn't have been guaranteed and it was, so a wrong was done to donor-conceived people. We don't think that there is a moral obligation to honour that agreement because it was made without one person being represented in the agreement who is primarily affected by it. So what we're thinking is there should be a process whereby contact is made, when the donor-conceived person requests it, contact is made to the donor indicating that that's the case and giving them an opportunity to post an objection so we're not saying it should be an absolute right of the donor-conceived person to have the information but we think that the presumption should be in their favour so that the donor should have to raise a serious objection to the information being provided. So if there was a strong reason that that could cause enormous problems for that family, then that should be taken into account.

The CHAIR — So not a right of veto?

A/PROF TONTI-FILIPPINI — Not a complete right of veto, no. I would suggest that it be done by the Patient Review Panel that we already have, they should be given guidelines under legislation as to what grounds should be required to be met for the donor to be able to have a veto, and they should be very serious grounds of serious problems for them. We don't think the initial agreement that was entered into should be binding on anybody because it excluded somebody who was affected by it so it is necessary to handle it delicately but I think we should reverse the presumption of a veto.

A/Prof HUDSON — Did you mean by that question something like disruption of families where perhaps there might be siblings who were born before 1988 and since who would have different understandings and different access to knowledge about their origins?

The CHAIR — No, I was talking more in terms of if the donor now has his own family and partner and kids who may not know that he was a donor, just the impact on that family unit.

A/Prof HUDSON — Certainly, and I think we should be very sensitive to some of those very ——

The CHAIR — But you think the rights of the child outweigh the rights of the donor in that sense?

A/Prof HUDSON — Yes.

A/Prof TONTI-FILIPPINI — Yes.

A/Prof HUDSON — Unless there are extreme circumstances — that could be mental illness, there could be other vulnerabilities that they would not be aware of and therefore having a right to explore those issues would be very important.

A/PROF TONTI-FILIPPINI — There should be guidelines to that effect for the Patient Review Panel to apply in the legislation so that it should be an indication of the gravity of reasons that would be needed to allow veto.

A/Prof HUDSON — I've really appreciated the opportunity to read some of the other submissions, even since we made our submission, and I've very carefully read the submissions that go through the literature describing the consequences for many donor-conceived people in relation to their genetic origins. The question that I raise now having read some of those submissions is who knows what future research, and particularly longitudinal research, will reveal, particularly about the experience of being a donor, not only the experience of being donor-conceived but the experience of being a donor because it seems to me there's a dearth of literature from that very personal perspective.

We take the right to know one's parents argument from the United Nations Convention on the Rights of the Child. This goes to the terms of reference in relation to the *Charter of Human Rights and Responsibility Act 2006*. In relation to that, we concentrated on section 17, the protection of families and children, noting that every child has the right, without discrimination, to such protection as is in his or her best interests and is needed by him or her by reason of being a child. We understand that this can be interpreted to mean providing the child with relevant information about their genetic origins at a time determined by their parents, or at least by the time they are 18.

We are concerned about the outcomes of ART more generally but in the context of the donor-conceived persons under this particular inquiry we believe the best way to address the current situation is to give greater weight to the rights of donor-conceived persons and to ensure they have equitable access to information in a way that is personal and empowering. This goes to the heart of some of the comments I have read in some of the submissions about just general information provision compared with adequate, relevant, appropriate counselling that takes account of the unique personal issues involved in every situation. Otherwise these people remain, in the words of one or two of the submissions, in an otherwise disenfranchised context. I was interested to note the word disenfranchised appearing in a couple of the submissions.

In just drawing these points to a conclusion, we believe that the law has struggled to keep pace with long-term implications, particularly of the technology in this area. We are persuaded as a committee by the words of Margaret Somerville who says, "It is one matter for children not to know their genetic identity as a result of unintended circumstances. It is quite another matter to deliberately destroy children's links to their biological parents, and especially for society to be complicit in this destruction."

That's my summary of our submission and I have some notes on the various terms of reference.

The CHAIR — Just in relation to the rights to know your genetic background, do you draw a distinction between the right to know essentially who your father is, genetic father is, in terms of medical background, information about themselves, do you draw a distinction between that and the actual social knowledge of who the person actually is?

A/PROF TONTI-FILIPPINI — No, we're arguing for identity.

A/Prof HUDSON — Yes, I think it goes beyond medical information.

A/PROF TONTI-FILIPPINI — Not only that, they need to know if they've got siblings, they need to know if they've got half siblings, they need to know what family there is that's related to them.

The CHAIR — Do the siblings have rights, in your submission, to be able to contact each other and identify information about each other?

A/Prof HUDSON — We didn't go into that point specifically but I would argue that that right is inherent in the right of a child to know who their genetic parents are.

A/PROF TONTI-FILIPPINI — We didn't discuss it obviously but there's the right to know who the father is or the mother is because it's also donor eggs. There's the right to the information, when they've got that they'll then be able to find out information about have they got siblings and so on with that family. The information about who else may be donor-conceived in that sense, so a half sibling in that direction, is something we didn't discuss.

As has happened, if a man has 160 kids through an insemination program, do they all have a right to know all the others? I would have thought that there is some right to privacy in the others that if they don't want to make access themselves then they should be allowed to retain that, I would have thought.

The CHAIR — Why would you give the siblings privacy when you don't give the parents?

A/PROF TONTI-FILIPPINI — They should be able to find out about those siblings only through the father, I would have thought. The first instance is to know the father and in knowing the father then the half siblings that exist in his family. If someone is conceived by donor conception I think they have a right to protect that privacy. I know that 40 per cent of kids conceived through IVF are not told they are conceived through IVF and if that privacy has been protected in that direction, that is they don't tell others about it, then that person should be able to protect that, I would have thought. It's difficult but I think that's a different thing from the relationship to the father; the father had some responsibility for all of this and he entered into an agreement that I don't think he had any right to enter into. It's difficult.

There are lots of things that are complicated in this area. For instance, we know that around about 10 per cent of firstborn children are not the son or daughter of the man that the mother lives with, that's just a biological fact, so there's a lot of people who are related to others who aren't particularly aware of it. But what I'm concerned about is that the state might be involved in causing this sort of thing, so where the state had some responsibility, which they do have, in relation to the technology that they not actually foster that. We've changed the law, we've changed the ideas on this, we've recognised that people have these rights to that information and we need to extend that to the pre 1988 group. The discrimination that exists between the pre 1988 and the post 1988 and between the donor-conceived and adoption kids, they ought to be treated the same.

A/Prof HUDSON — If you'll forgive a personal example here, I asked the opinion of my son and daughter-in-law and with their permission they said it's okay for me to discuss their particular case. My son and daughter-in-law have 12 year old twin sons born through IVF and donor sperm so I asked my daughter-in-law about this issue of siblings and her response was: the biggest issue for me is to know the number of siblings and I would want to know all the details. My son said: all I would need to know is the number of children, their sexes and their ages.

One of the twins said: I would want to know about the siblings because I wouldn't want to marry one, but so far I haven't seen anyone who looks like me. The other twin, his opinion about details of the donor, he said: I think we should know limited details like what's his name, what's his employment, how many children were born from his donated sperm. So there was a difference of opinion between my son, my daughter-in-law and the two twins on a range of issues.

A/Prof TONTI-FILIPPINI — They're 12, did you say?

A/Prof HUDSON — They're 12 this Saturday. I would also suggest that their opinions have changed over time. I think they were eight years old when they were first told and I believe — and the literature would support this — that there's a window of opportunity around puberty when children born of donor gametes are perhaps exploring their identity at a greater pace and at a great rate than they were when they were eight or nine or 10, and I suspect that my grandchildren's views will change as they grow older.

The CHAIR — So at the moment as it stands there is no contact or knowledge of the donor?

A/Prof HUDSON — They understand that, and they believe that they are at an advantage because they were born since 1988 and they see some discrepancy in the law.

A/Prof TONTI-FILIPPINI — They can find that information if they want to.

A/Prof HUDSON — That's right, yes. When I asked them: how should you get the information — and they're pretty techno savvy — one of them said: there should be a website and you can get the information on-line. But, of course, there's that personal privacy of access. And the other one suggested that a website like ancestry.com would be a good way. When I asked them did they want to meet their biological father, one of the twins said: it's not that important now but it might be in the future, but I reckon people should have the option. The other twin said: the donor should approve. If I was a donor I would like to have that option. The other twin said: I reckon the donor should be able to get information because we're his biological sons. He may not love us in the way dad does, but he might like to know how successful we are.

So I thought that their comments revealed a lot about the nature and nurture argument and they were even at their great grand age of 11, approaching 12, when their information needs might change in the future. One of them said: it would be a good opportunity to meet him but I'm not really enthusiastic; my whole life doesn't depend on it. The other one said: I wouldn't mind meeting him one day just to shake his hand and say 'thanks'. So they had various opinions. One of them said: I would like to be able to have the information, be able to print it off on the website, and have access to it, to refer to it when I need to. Implying that my needs when I'm 18 or approaching marriage might be different than they are now.

When I said: should everyone be given the information? One of them said: it depends on what sort of person you are but it shouldn't make any difference when you were born. I said: do you need to know who your biological father is and do you need to know who your biological father is to know who you are? One of them said: I know who I am but I only know half of who I am, but I don't know what I might become because of my genetic inheritance. And then he paused for a minute and said: I know who I am but I'd be interested to get more information if I want it, but I don't feel as though there is anything missing. The other one was quite clear: there's no gaps for me as to who I am.

When asked the question: how many fathers do you have? One twin said: dad's my only father and the other one is a guy who helped make me. The other one said: I feel gratitude towards him, he must be a good person because he's helped to make us live and other people live. The other one commented: I'm thankful for him but I won't love him in the same way I love dad.

These kind of conversations lead me to enquire about this whole process from the personal perspective of a grandmother, and I think that this enlarges my view to want to know not only about the genetic origins in terms of health, sex and how many siblings there might be but the whole ancestry questions like: where is my identity shaped if I go back further? One of the twins said: it would be interesting to know if I had a grandfather or great grandfather who had been in the war, for example. So that kind of raises how much is carried on through the inheritance of my daughter-in-law, how much is carried on through the nurturing of my son and how much will continue down the line to my grandchildren's descendents in terms of their inheritance. So they're the reasons, I think, that go beyond just the technology and go beyond just the moment of the donated gametes but have a larger societal perspective.

Mr NORTHE — Rosalie, in the submission you speak about the donor register and how that might work. If you could maybe just extrapolate that out a little bit more, how you see that working. Obviously the committee has already heard on this from an ad hoc approach, that is the register and so forth and where donor-conceived persons' details are kept as well as the donors.

A/Prof HUDSON — I think that there are many and varied issues, as you're well aware, but I think that I would opt for a national register because I think there's so many discrepancies across state and territory borders and that would create an inequity if people in one state or territory were able to access information and those in another were not, and particularly with regard to finding half siblings across the border and when various clinics and hospitals have different methods of data collection so it would seem to me that it's after the horse has bolted in many respects but in another respect if something could be done from now to ensure that there was a consistency of the data collected.

Which registry or which agency is better able to hold that register, I'm not convinced of which is the right one but I am convinced by some of the arguments that suggest that the bureaucratic agencies whose only role is to give out information in an impersonal way does leave the person disenfranchised whereas another agency like VARTA, for example, who has an extensive role in counselling and how to give the information it would seem to me that that would be a big issue so it's not just a bureaucratic keeping of a register but it's how people would be given the information that they're seeking and in what way because I've read, as you have, the many and various ways in which counselling has been given and has not been given so counselling, I think, is a very important part of keeping the register.

A/PROF TONTI-FILIPPINI — Can I pick up on that. Before I do, I should say that I'm on a Commonwealth government committee and I was on the NHMRC that drafted the national guidelines for this area and I'm still on it, and I don't speak for that committee and I don't speak for the national NHMRC but I thought I should mention that I have an interest having been on that committee that drafted the national guidelines.

On this question, the constitutional responsibility versus the states, I think it's going to be a state register rather than a Commonwealth register for this sort of thing, it will be state by state, because that's the way Births, Deaths and Marriages worked. The obligation, I think, should rest with Births, Deaths and Marriages but they should be resourced to provide the kind of support that's actually provided to people who seek their information in relation to adoption. So if you're adopted and you seek information, then you go through a process of counselling and support in order to attain it. I think that should be the same thing and it should go through the same body, it should go through Births, Deaths and Marriages as the body that retains the birth certificate information.

My view is that all the parenting roles that go into a person should be recorded on their birth certificate and available to them when they apply for it and there should be counselling available. The way we falsify birth certificates at the moment is totally inappropriate so we ought to have on the birth certificate the genetic parents, the birth mother because that's another issue — you do need in this inquiry, I think, to address surrogacy and you will need to address this issue and not create further problems in relation to surrogacy. If we're talking about surrogacy arrangements then you've got a birth mother who may or may not be the genetic mother and then you've got people who have entered the relationship with a child as a substitute parent. So you've got all those roles of parents and I think all of them should finish up on the birth certificate when these decisions are made so that the child can access them when they seek to access them and you would do that on the basis that's done within the law now, when the parents hold that they're mature enough or when they reach 18, but the understanding would be from the outset that this information would be available by the time they have reached 18 but the parents would sensibly address that before the child reached 18. But the information should be there. If somebody was the birth mother of the child she shouldn't be taken out of the picture altogether whether she was the genetic parent or not.

Under the new law there are people who can move in and out as parents — the natural parents, genetic parents, a birth mother or a substitute parent — so parenting needs to become a more fluid concept but we shouldn't, in making it more fluid, lose the record and lose the child's right to know who contributed to that child's parenting.

Mr CARBINES — You talked earlier about the Patient Review Panel and perhaps how there may be serious problems that a donor might raise that they would want considered before information was made available. Could you shed any light on what you think some of those serious problems or examples might be, flesh some of that out?

A/PROF TONTI-FILIPPINI — Let's suppose a donor has developed a mental illness and just isn't up to facing, you know, that would be good reason. There's an issue that's talked about anecdotally about the doctors in the clinics and medical students both being frequent donors, and that raises questions about how many siblings there might be in terms of one man donating many times. It's less likely on the other side because for women it's much harder for women to donate eggs but it could be quite a problem that needs to be considered in terms of a child realising that, say, he's got or she's got 200 or 300 siblings. There would need to be an understanding of how that was going to be dealt with, how the counselling was to be approached.

Let's suppose you've got a doctor in a clinic who is now retired and has fathered several hundred children. How is that going to impact on him when this information is revealed? Is he going to be able to cope with the sheer demand of that, if there are 200 or 300 kids who are going to be contacting him? What's that going to mean for him and will he be able to cope with it?

The CHAIR — Are you aware of how many people would be in that situation of having that many?

A/PROF TONTI-FILIPPINI — I don't know; it's anecdotal. I've been involved in these debates since 1982 with the beginning of the original legislation, but there was a meeting that I attended at

Monash on donor-conceived conceptions when Louis Waller was chairing the first inquiry and they had a meeting on the donor conception issue. There was a gynecologist, who is dead now — Ian Johnston — who was on the stage at the Alexander Theatre at Monash and he was on the stage speaking on this topic, and somebody said: what would you do if the law changed to give access retrospectively? And he said: we'd destroy the records. And I remember Louis Waller saying from the back of the hall: and we'd put you in gaol. It was a kind of memorable kind of conflict.

In that discussion that was going on it was mentioned in passing that it wasn't uncommon for the doctors in the clinics to be donors when they couldn't attain sperm otherwise. I don't know how wide that practice was, or how many doctors were involved in that, but it was said at that meeting so that would be a factor. Medical students were encouraged to donate and it was common for classes of medical students of the men to donate. How often, I don't know. They were paid a fee for their sample so I don't know how often they donated. They would have been paid for each so it would have been in their interests to donate often. I attended a meeting in Sydney where a donor who was a doctor said that he knew, to his knowledge, he had 180-odd children but, you know, whether he was typical or not I don't know.

Mr CARBINES — That gets back to then how you might address, or give consideration to addressing, how providing the information would potentially throw light on practices that haven't continued beyond that.

A/PROF TONTI-FILIPPINI — I think that it's a good idea to throw light on the practices in the interests of the children, that those sorts of things should be known, but I am sensitive to what that could mean for somebody who is now retired or mentally ill or they're not in a position to deal with it well, and I think that there needs to be a step so that there could be a veto if there was a need to veto.

The CHAIR — All right. We've got a few minutes left for any final questions anyone has or final comments?

A/PROF TONTI-FILIPPINI — I'd just like to raise that question of whether your inquiry is including surrogacy and birth mothers or whether you're just looking at genetic?

The CHAIR — We've been given the Terms of Reference from Parliament and surrogacy isn't included.

A/PROF TONTI-FILIPPINI — It depends on what you mean by donor-conceived. Donor-conceived would include surrogacy, I would have thought. I would ask you to consider it that way anyway because otherwise you're going to have another set of problems. If they aren't dealt with then we are going to create another set of problems. If we don't do something to record the birth numbers now they will be the 1988 group.

The CHAIR — So the issue on that point is not so much that there's a different set of issues to consider, it's simply the recording of the birth mother.

A/PROF TONTI-FILIPPINI — Yes. I think a woman who has a pregnancy and gives birth to the child has a huge investment in that child and if she's done it as a donor she still has that investment in the child and from the child's perspective that's the child's mother in any ordinary sense of the woman who gave birth so that child would want to know who that woman was. If that record has been destroyed or not kept, the child won't have that opportunity.

The CHAIR — All right. We'll make a note of that. Thank you very much for coming in today.

A/Prof HUDSON — Thank you.

A/Prof TONTI-FILIPPINI — Thank you.

Witnesses withdrew.