REPORT OF PROCEEDINGS BEFORE

COMMITTEE ON LAW AND SAFETY

INQUIRY INTO MANAGING INFORMATION RELATED TO DONOR CONCEPTION

At Sydney on Monday 6 May 2013

The Committee met at 9.30 a.m.

PRESENT

Mr G. D. Barilaro (Chair)

Mr G. K. Edwards
Mr N. Lalich
Mr G. Zangari

CHAIR: I declare this public hearing open. Good morning and thank you for attending the Committee on Law and Safety inquiry into managing donor information. This inquiry is examining the way information relating to people conceived by donor conception before 2010 is managed. A range of questions are being looked at, including whether retrospective access to information should be granted, what issues this may raise with individuals and donors, what support should be provided, and how donor information should be managed and by whom. I welcome our first witnesses today: Ms Fiona Hearne, Ms Sharon Hunt and Dr Cheryl Fletcher, representatives of Solo Mums by Choice Australia to this hearing.

SHARON HUNT, President, Solo Mums by Choice Australia, and

CHERYL FLETCHER, Senior member, Solo Mums by Choice, affirmed and examined:

FIONA HEARNE, Senior member, Solo Mums by Choice, sworn and examined:

CHAIR: Ladies, can you please confirm that you have been provided with the Committee's terms of reference and information about the standing orders which relate to the examination of witnesses.

Ms HEARNE: Yes.

Dr FLETCHER: Yes.

Ms HUNT: Yes.

CHAIR: Do you have any questions concerning these procedures?

Ms HEARNE: No.

Dr FLETCHER: No.

Ms HUNT: No.

CHAIR: Have you provided the Committee with a submission to form part of the formal evidence?

Ms HUNT: We have provided the Committee with a submission and I have a copy with me. We are happy for the submission to form part of the formal evidence.

Ms HEARNE: I would like to point out that I made part of the submission as a group member but I also made my own submission.

CHAIR: Would you like to make an opening statement or statements before we commence questions?

Ms HUNT: Yes. Thank you for the opportunity to speak to our submission today. I am President of Solo Mums by Choice Australia—a national support group for women who are solo parents by choice or who are considering this as an option for themselves. As time goes on we are also becoming a support and advocacy group for our donor conceived children. Fiona Hearne and Cheryl Fletcher who are present with me today are long-term members of the group. I should declare at this point that I am the mother of an eight-year-old boy conceived through a Sydney clinic using an anonymous donor. Following attempts to make some content with our donor, I now understand that he donated in a Queensland clinic. It is early days for us but I can already tell that my son will want more information about his background and that is information I simply do not have to give him.

Fiona is the mother of a 10-year-old girl conceived from an anonymous donor. With help from the clinic they have had limited contact with this donor for a number of years. There is no current contact but they hope in the not too distant future the donor will re-establish contact with them. If he does not, they hope that changes in New South Wales legislation will enable contact when her daughter is older. Cheryl is a mother of a 19-year-old girl who has wanted to know more about her donor for many years. Cheryl understands that the only information remaining about her donor is his name. We know a significant number of our members have used anonymous donors to achieve their pregnancies. This means a significant number of children in our group will be affected by any decisions made regarding retrospective access to or changes in the management of information related to donor conception. It is our hope and our aim that these effects on our children will be positive ones.

We believe that in the interests of the long-term psychosocial health of our children with anonymous donors retrospective information must be made available. We believe, firstly, that non-identifying information should be given to families as soon as possible, with identity released at a set age or earlier if agreed by both parties. Correct management of donor conception details will also allow information of siblings to be readily available. We propose that the age and gender of donor siblings be available to families immediately, with contact arranged following the consent of both families. We believe the establishment of a national body to manage donor information is preferable. However, given that a State body is more likely, we believe it should manage information, facilitate contact and arrange counselling and support groups. It would also need to run public awareness and information campaigns. Funding models for such a service may include both government and private contributions from clinics involved in donor conception. Cheryl has recently completed a thesis on the experience of Australian single mothers by choice and would like to table this thesis for the benefit of the inquiry. She has indicated the parts of thesis that pertain to the anonymity of donors. We thank you for the opportunity to be present today and put forward the views of our members.

CHAIR: Are there any other opening statements?

Dr FLETCHER: No.

Ms HEARNE: No.

Mr NICK LALICH: Some submissions have argued that donors' decisions to donate anonymously should be preserved. How do you feel about this?

Dr FLETCHER: I sympathise and I know that some donors are very anti being contacted. I do feel a staged process could occur whereby they could be approached confidentially and given some time to think about it. In adoption stories people frequently took one to two years of having a veto against contact before they were then able to consider, "Yes, I might meet this person." Other people might still refuse and not want to meet but at least be able to give a richer family history, some medical knowledge—just a bit of awareness of what that family is, even if they still feel unable to meet. Personally, I do not know that I am speaking on behalf of the entire group, but I think that a young adult, say my daughter at 19, if she knew that the donor was not keen on meeting her, she would not go ahead, but she would be happy to have a bit more information. I probably differ a bit, I do not think of forcing somebody into a room, but I think counselling, information or attending seminars on psycho-education would alter the majority of donors so that they would feel able to have their identity released.

CHAIR: Are you referring to non-identifying information or identifying information?

Dr FLETCHER: Identifying. My personal view is that to force it, so you might be confronted by somebody, like if somebody signed a veto saying they would not contact them, I think it could be given. I would be against a forced meeting where the donor might give an aggressive or unhelpful response to the young person, so a veto I think could work well.

CHAIR: We heard a story where there was an agreement prior to the whole conception process. Those who were interested in the donation in the first place were seeking a donor that was prepared to give that information, but three, four or five years later the donor changed his mind and said, "I rescind the permission to give out my information", and now that couple, along with the child, have no way of getting that information because the law protects the information. My concern is the right of people withdrawing consent during the process. Do you believe that, if consent was given, a donor should not be allowed at any stage to withdraw that consent? You are saying you do not want to force people into a room.

Ms HEARNE: I think that situation is different from anonymous donation. You appear to be talking about maybe a known donor or a directed donor. That is different from what we are talking about. We are talking about anonymous donations, people who have donated to clinics and do not know who their donation is going to, and the recipients do not know. That example is different from our situation.

CHAIR: And in that case you still feel very uncomfortable forcing people into a room to give up their information?

Dr FLETCHER: Yes, and I think giving out the identity does not actually force somebody to do very much at all really, it is just letting the person know what the identity is. Does that make sense? You can know the identity, but the person can still say, "I am not talking to you." You cannot force people to talk if they do not want to.

Mr NICK LALICH: But you cannot stop a person from stalking. If the child wants to stalk dad, then you have a problem in that instance as well.

Dr FLETCHER: Sure. I do not think that happens in adoption; I think it is highly unlikely.

Mr NICK LALICH: It would be a one-off.

Dr FLETCHER: It could be a one-off, and that can happen in the world on any day.

Ms HEARNE: A lot of the critics think that that is what they chose, to be anonymous, and no-one has checked back with a lot of the donors. Research anecdotally shows overseas and here that people who donated when they were 30 now, maybe 20 years later, think, "Yes, actually I wouldn't mind knowing how many children resulted from that. I don't particularly want to be in touch with them, but I am happy to give updated medical information and let them know a little bit more about me." Our kids have very limited or no information about their donors. It is very different now.

Mr GARRY EDWARDS: Did you give that any consideration at all at the time of donation?

Ms HEARNE: Absolutely.

Dr FLETCHER: Yes. My research shows that all the people using anonymous donors gave it great thought. If they were not happy about it, they sought out if they possibly could have donors who were willing to be identified, knowing that it would not be upheld in law but that it would give them some chance. One woman was very distressed. She was told that the legislation was going to change in a different State and then found out later it was not going to be retrospective, after she had already conceived, so she was dreadfully distressed. One woman—I think that was in New South Wales—was forced to sign a document saying she would never pursue information. People did give it a lot of thought, but you are weighing up somebody's desire to have a child versus what? They just do not have any other option. People would seek out known donors, and that is a bit of a thorny issue because nobody wants to have casual sex to have their child—what sort of story is that to tell your child? That is a bit of a different issue, but yes, it was very much considered and I have a lot of data here on women being very upset about their kids not having—

Ms HUNT: I think it shows in our membership base as well. People with children over the age of five, for example, or seven really, when the laws had started to move towards identity release donors, there is a very limited number of people with those older aged children, five and up. The number of children, now that identity release donors are available and people know that they can provide their child with more information as they get older or that, when they are adults, they can have information, it is very much a part of what people want for their children. We do not want our children walking around in this world thinking, "I wonder what the other half of my heritage is?" People now know that they can provide that for their children, and so our numbers and the number of babies born in the last five years in our group would be quadruple the children over the age of five because that is now available. I think that is one of the reasons.

Mr GARRY EDWARDS: Regarding the anonymous donors, can you cite many instances where those donors have since been tracked down and found? Will you give me an idea of the percentage of the number of donors who have agreed to make contact or for information to be given out?

Ms HEARNE: I think that is an issue for clinics. We could not tell you exactly how many donors have been tracked down. We would be telling personal stories. I went through a clinic that was open or willing enough to pass on an anonymous letter to our donor who had donated at a time when he was fully anonymous and then, you know, New South Wales was going to change. My daughter was conceived in 2002. You can see how long that took to change. So when I wrote a letter, the clinic willingly passed it on and we corresponded by anonymous email for quite some time. He is the exception to the rule. I know people who have gone through the same clinic who have been sent a letter and the donor has either not replied or is not willing, or has moved and is no longer at that address.

Mr GARRY EDWARDS: We came across the same problem.

Ms HEARNE: So how do they get into contact with them? The clinics are not proactive because it is not a revenue-making stream. If it is not a revenue-making stream, they are not interested.

Ms HUNT: Fiona was lucky that she was at a clinic that was willing to pass letters on. There are several clinics within New South Wales that refuse to pass letters on. They are open letters that the clinic can read. A lot of our members have sent them, obviously so we are not putting in the letters harassing donors. Whether they are willing to provide a little bit more information is primarily what we are looking for. I think it is fair to say that most clinics in New South Wales will not hand the letters on, even if they have knowledge of where the donors are.

Dr FLETCHER: Nor would they be interested in asking the donor whether they would like to go on a register. I can imagine donors, except maybe those who are in law or medicine themselves, would even have any idea that there is a register they can volunteer to go on. How would they know that? It is really hard to find.

Mr NICK LALICH: Over the 12 months that we have been doing this inquiry, my feelings are that, at the minimum, the genetic information should be given to the child or to the mother. How do you feel about that?

Ms HEARNE: What do you mean by genetic information?

Mr NICK LALICH: When considering the health side of things.

Ms HEARNE: Medical information.

Mr NICK LALICH: Medical health.

CHAIR: Are you going so far as non-identifying?

Mr NICK LALICH: Yes, non-identifying, just giving the medical history.

Ms HEARNE: Like, "When I donated everyone was fine", and I wrote that. But "Since then I have now aged and so have my family, so there has been breast cancer", all of that?

Mr NICK LALICH: Yes, do they know what has happened in their families: mum had breast cancer or dad had prostate cancer?

Dr FLETCHER: I think that is absolutely imperative.

Mr NICK LALICH: I will not speak for my colleagues but, at the minimum, my feeling is that that should be mandatory.

Dr FLETCHER: I know an adopted woman who thought she was at risk of bowel cancer and was very anxious about it for many years. She did not know she was adopted. She was really angry when she found out.

Mr GUY ZANGARI: Thank you for coming today and for your submission. Throughout our inquiries it has been suggested that information should be stored on a central register, whether that be a State register or, as many people have suggested, a national register. How do you feel about that?

Ms HEARNE: Nationally would be great, but we had a Senate hearing on that and what happened?

CHAIR: Nothing.

Ms HEARNE: The way Federation is set up here, everyone likes their little bit and wants to keep it tight. While Victoria does not do everything fantastically, it is pretty much a gold standard for—

Dr FLETCHER: This area.

Ms HEARNE: —this area and I doubt that they would give it up for a Federal—

Mr NICK LALICH: They held up their legislation and are waiting for us now.

Ms HEARNE: Yes, I know. I think our best hope is to let us go forward with the States, and let us hope that maybe they could all talk to each other.

Mr GUY ZANGARI: However, the storage of such information would be available in one central register.

Dr FLETCHER: It would be, yes—

Mr GUY ZANGARI: And it has been agreed by all.

Dr FLETCHER: —because people are frequently getting donor sperm from other States. They are importing from all over the place.

Mr GUY ZANGARI: It has been pointed out, and you would know from your experiences, that clinics close down, records are not being passed on, records are then somehow being stored in garages, and records are missing. There really is a jigsaw puzzle of information that is then, by the determination of individuals, being put out.

Ms HUNT: That is our biggest danger. The longer we go on, the further we get away from 19-year-olds, 30-year-olds who have used anonymous donors. That information is just not going to be there or it is going to be so old that nothing is chaseable.

Ms HEARNE: Because the doctor never thought about it.

Ms HUNT: Also, when there are these different schemes—for want of a better word—available for people to go onto the voluntary registers here and so on, people do not understand enough. If there is one central register with some good public awareness campaigns and some good information that is passed on to donors when we still do have contact, people can participate in them if they want to. They can get their name onto them. We can start to move forward.

CHAIR: In this inquiry and a prior one, we heard the importance of a child having that information as early as possible, to make it part of their life story as the child grows up and therefore there would be less of an impact on that child with that information. You represent a group of mums. Have you got mums or families who do not support that information and would never tell their child?

Ms HEARNE: No, we are sole parents; there is no father there.

Ms HUNT: There is no father. It is not like someone is hiding out the back and you can say, "Yes, sure."

Ms HEARNE: Our kids all know right from the get-go. If you ask any of them, "When did you find out?" None of them will say, "We went for a special dinner when I was five." They will all say, "I have just always known."

CHAIR: It is part of the story.

Ms HEARNE: It is part of their story. Their families are their mums and themselves and their siblings, if they have got them.

Dr FLETCHER: Grandparents, and sometimes donor siblings, half-siblings, who they know have used the same donor.

Ms HUNT: What happens is occasionally we will have someone who comes to the group in what we call the thinking stage. So they are gathering information about whether it is the right path for them to move to having a donor-conceived child. They come to the group with a bit of a, "I do not know if I want to tell them and I do not want to tell other people." What would you tell them then? Kids realise from two or three, "Most people have someone called dad and I do not." What are you going to tell them? You cannot lie to them. You do not want to tell them, "I had a one-night stand somewhere." You have no choice but to tell them the truth. From the experience of senior members, we know that to do that early and repeatedly is better for them.

Mr GUY ZANGARI: If retrospective legislation were to be considered, how do you think its impact on the sperm donors and their families might be mitigated?

Dr FLETCHER: By an intense public information campaign initially, with confidential letters to all the donors, telling them about forums or linking them to articles. I think a gradual approach would not scare them. But if they were told, "Someone will be knocking on your door in the next year", I think they would be running. That is my feeling. They need time to think about it, realise there is no financial pressure on them; they do not have to be dads. We just would like the kids to know that is what you look like.

Ms HUNT: We do not want them to be dads.

Dr FLETCHER: And a bit about your family. No, they do not want dads. My daughter is not absolutely sure she would like to meet. She would just like the possibility, the option. Perhaps when she has children it might be more important.

Ms HEARNE: Sure, it may impact on their families as well, but that is part of the education process. I know our donor has his own family and his children know that he donated as well. We also know a family with one sibling. My clinic is now part of IVF Australia, and they have set up a thing called Siblinks. They do the occasional media story. They have not sent out anything to past patients and have not sent anything out to donors. I know how many families we are connected to and I think many of them are probably conventional mum and dad families. A whole lot of them do not tell their kids despite the intention to start off with because it changes when the baby comes. I suggested many ways that the clinic might be able to assist with that, even confidential ways, but they are not interested.

Mr GARRY EDWARDS: And your clinic sounds pretty good.

Ms HEARNE: In the scheme of things, absolutely, it is good.

CHAIR: The Committee is struggling to get information from clinics—

Ms HEARNE: Surprise, surprise.

CHAIR: —without forcing them.

Ms HEARNE: I imagine Mark Bowman was not terribly interested and Joel Bernstein is going to be fun this afternoon.

CHAIR: You said earlier that you were forced to sign away your right to pursue further information at a later stage. Is that the normal practice?

Dr FLETCHER: No.

CHAIR: Again, the Committee has not seen any agreements, although they have been requested.

Dr FLETCHER: That was unusual. I think it was a Sydney clinic. I am not sure, but it might have been one at Bondi Junction, and I do not know whether it still exists.

Ms HEARNE: I know I have seen something, but I cannot remember off the top of my head if it was about contact with the donor. I am happy to look.

Mr GARRY EDWARDS: Do you have any ideas about how the voluntary register might be better advertised?

Ms HEARNE: A budget.

Dr FLETCHER: A lot of old donors were medical students. The donor of my child was a medical student. I managed to wheedle the first name out of someone, but I will not mention it now. I went through old records of doctors trying to find out who it might have been—not that I would do anything with that information; I would just like to know. I thought of advertising in medical journals. It might be a short piece saying, "If you were a donor before such and such a year would you be willing to go on a register and provide information with the possibility of contact?" I am not sure where else, but there were certainly many medical students and other students invited to donate for $30.

Mr GARRY EDWARDS: You would do that in Law Society and engineering association journals and the like?

Dr FLETCHER: Perhaps university alumni groups and in *Good Weekend* articles and so on. There could be general public awareness articles in Sunday papers and those sorts of things and some targeted mail-outs. Clinics must keep some kind of record. There could be targeted mail-outs, general public awareness and targeted public awareness.

Dr FLETCHER: In my situation the clinic would not send a letter and said that the phone number did not make any sense. I asked whether they would do a search because it is not that hard to search for people on electoral rolls, but they were not interested. It would be possible to search for old donors on electoral rolls and send them a very gentle initial letter about what is happening with legislation. I cannot see any harm coming from that.

Mr NICK LALICH: The media would be quite interested in this after the article in yesterday's newspaper. I am sure all the radio and television stations would be interested in doing articles about this, which would be a form of advertising. You could use that exposure as an advertisement and say that we need people to put their names on a register and at least provide their DNA and health records.

Dr FLETCHER: Yesterday's article was good. It was not sensational. A lot of that still happens.

Mr NICK LALICH: I liked the statement that we look after dogs and cats better than we do human beings.

Dr FLETCHER: Yes. This document is very large, but if members are interested in seeing some of the members' comments I can table it.

Mr GARRY EDWARDS: It is available on line?

Dr FLETCHER: Yes. There is a link to the thesis on this piece of paper.

CHAIR: Would you like to table that today?

Dr FLETCHER: Yes.

Document tabled.

Dr FLETCHER: Much of it is irrelevant, so I have highlighted the parts that are relevant.

Mr NICK LALICH: There might be a situation where a donor-conceived child never asks and mum never tells. What do you feel about a flag being put alongside his name and when he turns 18 and he applies for a birth certificate or a drivers licence he is informed that there is more information available? I lean more towards the English system: If a person never asks you never tell him; if he finds out and comes and asks you, you tell him everything. That is how it operates in England. How do you feel about that? You could devastate a person who thinks that this is his mum and dad and all of a sudden he finds out that is not true.

Dr FLETCHER: That is a vexed issue, but it does not apply to us. It could happen at 18 because if they find out too late they may not be able to talk to their parents because they are deceased. I think 18 is a reasonable age. If parents know that their kids will be told at 18 it will push them to do something. They can be given counselling. That happened in Victoria because many parents had kept it a secret. When the kids were turning 18 they had a lot of seminars to help parents to deal with the issue that their kids were turning 18.

Mr NICK LALICH: You do not see any problem with the child being told something he never knew and probably could not care less about? He would probably go his entire life not knowing and live a—

Ms HEARNE: Many of those kids end up saying, "I always thought there was something strange but I could never put my finger on it." It is hard for us to answer because our kids are not in that situation.

Dr FLETCHER: I would never do it to a child—keep a secret.

CHAIR: Are you aware of the Nuffield Council on Bioethics report?

Ms HEARNE: This is the executive summary.

CHAIR: Have you examined it?

Ms HEARNE: A little.

CHAIR: Instead of mandating retrospective access to donor-conception information it recommends that the government provide an environment where patients are equipped with information and support and encouraged to make the choice to tell their children about their conception. What is your response to that report?

Ms HEARNE: I support that. The United Kingdom has been at the forefront of changing laws and it has a very active donor-conception network. I think it had some government funding and support, but I do not know whether it still does.

Mr NICK LALICH: It is a separate organisation. It is not put on the births, deaths and marriages register. It is a different organisation but it is funded by the Government.

Ms HEARNE: It is a support group not a registry. They are really active and we support that.

CHAIR: Is that one of the recommendations you would like this Committee to make? Are you still looking for retrospective legislation forcing people to give information? Or would you prefer an environment where we promote the register and counselling? Do you want us to create the right environment to encourage people to come forward voluntarily with that information or do we need the heavy arm of government?

Dr FLETCHER: The heavy arm.

Ms HEARNE: The heavy arm of government. It is too easy to avoid it.

Dr FLETCHER: It should be mandated but with common sense with regard to forcing meetings.

Ms HEARNE: Yes.

Ms HUNT: We should mandate the kinds of things you were talking about—medical information, heritage and so on. You cannot mandate that people meet and we do not want to do that.

CHAIR: We feel limited, but we also understand that many arrangements are done privately and we will never be able to govern, mandate or anything else in that field. We are caught in the sense that we would be legislating for only part of the sector and there might be divisions later on as a result.

Ms HEARNE: If people decide that they want private arrangements—

Ms HUNT: It is their responsibility to maintain the information if they have entered into a private arrangement from the beginning. You then need to continue to ensure the security of your own information.

CHAIR: They would still have the opportunity to have that voluntarily put on a register.

Dr FLETCHER: Yes, as they do now, I think.

CHAIR: Yes, I cannot see government mandating or legislating in a way that we can force these people to give us that information. They could just say it was a one-night stand, or something else.

Dr FLETCHER: Or we entered into a private agreement and the donor donated, and that is where it is, and we have this person's information and we hope to keep in contact but we are putting this information here just in case the wheels fall off.

Mr NICK LALICH: The Committee heard from a witness last week who wanted a donor who would consent to their information being available. When she started she had something like 20 donors from whom to choose but when she asked for that information to be available it dropped down to only two potential donors who would then sign up to being a donor. That is what happens when they want all the information—you lose the donors.

Ms HEARNE: These people are not going through clinics though. They have not had to step through hoops, be vetted, be tested, and come back six months later. I think it is a different sort of donor.

Mr NICK LALICH: She did go through a clinic.

CHAIR: If we mandate it and they do donate that information at some time during the child's life, do you think we will lose donors?

Dr FLETCHER: The clinics will tell you that.

CHAIR: That is right, clinics are telling us that.

Dr FLETCHER: There has been some research overseas—I cannot reference it at the moment, I apologise—that has shown that a different kind of donor comes forward, a slightly more mature donor, often having had children, who understands the importance of children knowing. So you attract a different sort of donor. I think the clinics just need to advertise for that different kind of donor who often knows somebody who has used donor conception, knows somebody in their network. They know the issues a bit more, so times are moving on.

Mr GARRY EDWARDS: In your own situations with anonymity of your donors, at the time did you sign something to say that you would not pursue—

Dr FLETCHER: No, that is what we were going to check. No, that was a one-off. I mentioned earlier a woman in Sydney who had been forced to sign it or she would not get a donor.

Mr GARRY EDWARDS: In your cases, that did not happen?

Dr FLETCHER: No, my doctor did say though that he would destroy the records if the law looked like it was being changed, and that is why I think there is only a name remaining.

Mr NICK LALICH: If you are a donor you have to watch that in 20 years' time one of your kids does not knock on your door and say, "Dad, where is my inheritance?"

Ms HEARNE: That is what the media are telling you. That is not what the kids are interested in doing.

Ms HUNT: And they would not be entitled.

Mr NICK LALICH: That is one of our problems, that is, the legality at the end and what the lawyers tell us.

Ms HUNT: But they would not have any right if it is a donor.

Mr NICK LALICH: They are genetically his.

Mr GARRY EDWARDS: It comes down to a whole lot of legal argument.

Dr FLETCHER: I do not think children would have a right in a court of law to get an inheritance. I cannot see that happening legally.

CHAIR: The Committee may send a series of other questions. Are you happy to answer them? The answers to those questions will form part of your evidence and be part of your submission.

Dr FLETCHER: Yes.

(The witnesses withdrew)

SONIA ALLAN, Senior Lecturer in Law, Deakin University, sworn and examined:

CHAIR: Have you been provided with the Committee's terms of reference and information about the standing orders that relate to the examination of witnesses? Do you have any questions around them?

Ms ALLAN: I can confirm that and I do not have any questions.

CHAIR: In what capacity do you appear before the Committee?

Ms ALLAN: I am a senior lecturer in law at Deakin University and my primary area of research is information release for donor-conceived people.

CHAIR: Have you provided the Committee with a submission? Do you want that submission to form part of the formal evidence?

Ms ALLAN: I have, and I do.

CHAIR: Do you want to make an opening statement before we ask questions?

Ms ALLAN: I am happy to start with questions. I think the Committee knows generally what my position is.

Mr NICK LALICH: Your submission notes that the release of medical information raises issues about health, privacy and confidentiality which are general practice in Australia. What are your views about the impact of retrospective release of information?

Ms ALLAN: My views are that the retrospective release of information would have a very positive impact on those people who are seeking information. There are a number of psycho-social, medical and legal reasons, I think, that would support information release and that would include retrospective information release. I think though we also have to be aware of the possible impact, as was mentioned earlier, on donors and their families. I think any form of retrospective release would have to be very sensitive to that.

Mr GUY ZANGARI: The Committee has heard evidence of the value of DNA testing in establishing genetic relationships. Do you have a view on that?

Ms ALLAN: As part of my research I have visited every country that releases information to donor-conceived people, including countries that implement DNA testing and that includes the Netherlands and the United Kingdom. They do that in relation to their voluntary registers, the retrospective, the people who do not have access to information on registers by law. In both those countries I saw a very effective system. You can never link people by a DNA testing 100 per cent but you can give them probabilities and that can increase the likelihood that they are actually being matched correctly.

It is a little bit easier when it is donors to children rather than sibling to sibling where there have been some errors. So any form of DNA testing has to be done very carefully and it also has to be done voluntarily. You can set up a DNA testing system but you have to, of course, have everybody willing to be tested in the first place. So it can be effective. It is an added tool that can be used but it is not the only way that you can match people. In that sense that is why I think we need something more in legislative form because you cannot hope that people get on the voluntary register and then go through that process. But it is certainly something that could be added in.

Mr NICK LALICH: You said that you have been all around the world. Which country do you believe has the best system?

Ms ALLAN: It is very hard to pick one country that shines in every aspect. I think Victoria—sometimes we can start by looking in our own backyard—has in some ways set up a system that is a benchmark but it has flaws and problems and that is the reason why there have been extensive inquiries, and there is unequal access to information. Also the approach to information release has not been ideal. The Netherlands had a wonderful system which, again, I think really reflected the Government's and the community's commitment to providing information to donor-conceived people but also supporting the donors in that information release. I think the Netherlands really shone for me. This was mentioned when I was listening to the questions earlier. In relation to donors who donated before 2004, when the mandatory register was implemented, the clinics were required to contact the donors. Rather than searching for the donors and writing them a letter the clinics were required to contact them but the clinics were also mandated to hand over all records to the register. There was no choice. It was not a question of, "Have you contacted the donor and has he said it's okay?" All records went to the register, and that is a way to protect the records and avoid their being lost or destroyed. Then the issue with retrospectivity was addressed. They took a slightly different approach by asking the donors whether they would consent.

Mr NICK LALICH: Does the Netherlands have a central register or do the provinces or states keep it?

Ms ALLAN: They have a central register and they contract out to a service to do the social support and the intermediary work if it is needed. The voluntary register is run by that organisation. It is still a two-tier program but the central register is held at the health department and it is implemented by them.

Mr NICK LALICH: How is the register paid for?

Ms ALLAN: It is part of the health department so the budget comes from the Government. The Government also funds the support service. As happens, when the economy declines funding for support services generally declines as well so there was some issue about whether the funding would continue for the support service but for now that seems to be going ahead. The Government register is definitely there and it will be funded into the future.

Mr GARRY EDWARDS: You make a distinction between the provision of information about donors and the issue of contact between donors and donor-conceived people. What is your view about the possible retrospective release only of non-identifying information?

Ms ALLAN: I have looked at this for over a decade now and I have thought about these questions and worked with all people—recipient parents, donor-conceived people and donors. For some time I thought non-identifying information would at least be a compromise but I think it does not go far enough. My position is it does not go far enough. I make the distinction between information release and contact. Providing somebody with information is not the same as saying they are going to have a relationship with these people. Often these two things get conflated. I think the issue of whether somebody can proceed with contact needs to be treated separately from whether you are giving information about a name. Sometimes you will find that donor-conceived people do not want to meet the donor but they do not want to call their donor "donor". They do not want to call their genetic—I do not want to say "parent"; the person who has contributed half of their genetic material, by a number. It is very depersonalising, so a name is important.

As to identifying information and non-identifying information. I think I provided the Committee with more extensive information, but if you look at the lists of what constitutes non-identifying information in various jurisdictions you will see it becomes a really grey area in regard to what you get.

In this country in some States or in some clinics they will only go so far as to give you eye colour, hair colour, height and blood type. That really is not enough information for a donor-conceived person. In some clinics in America, non-identifying information includes silhouettes, childhood photographs up until the age of donation, voice recordings, extensive information about family history, medical history, the donor's hobbies, and a little written statement from the donor. This is all considered non-identifying. All they do not get is a name. If you want only non-identifying information I would go with the United States model because eye colour, hair colour and blood type simply just are not enough. Once you do that and a person has all this other information except for the name, in this day and age with technology it is not too hard to find the donor if you want to. That is why regulation would be good because it releases that information in an environment that is somewhat controlled rather than having people searching on the internet. It is very easy to find somebody with that significant amount of information.

CHAIR: In your submission you spoke about contact vetoes and alternatives. Can you elaborate?

Ms ALLAN: This was the conundrum that I was faced with when I was thinking about what we should do here. It appeared to me that the history of donor conception has focused on recipient parents, donors and the clinics. I do not think anonymity was ever ill-intended but that was the starting point. To me, what was missing was the child at the centre of all this and the child's need for information. However, you have to recognise that there is a group of people involved and in order to release information, particularly retrospectively, there is a need to balance the rights and interests of the other parties. I looked at the requirements in law if you want to pass retrospective legislation and it always talks about balancing of interests and weighing of the competing rights. I was thinking about how best to do that and I think having a contact veto can protect those donors who do not want to be contacted, but releasing information gives the information that some donor-conceived people want. It is also the case that not everybody wants it. It would open it up so that they have a choice while still balancing the interests of people who are saying, "I thought I was going to be anonymous and now you're telling me I'm not." It protects their private sphere in a different way so they cannot be contacted. You can extend that to not contacting their family. It is not an original idea. It was implemented with adoption and has worked very effectively. I think it is about baby steps if we are going to release information retrospectively. We have to have something that makes everybody comfortable that it is going to be done in a controlled environment and in a supported way.

I have a study that looked at the implementation of contact vetoes over a period of something like 15 years and I think in Australia or New South Wales—this is off the top of my head so I may have to correct it—there was one breach and it was not by the child but by the birth mother. She just wanted to see her son; she wanted to see what he looked like. Generally when people are told, "This person does not want you to contact you", they will not move forward to impinge on that. It is a way of balancing everybody's interests.

Mr NICK LALICH: There was a case last week where the child wanted to know its donor parent but the donor had vetoed it and taken back the right. The clinic then told them more or less to go away and it would never write to the donor again. Our argument was: What if in 10 years time the donor changes his mind? You do not have to write constantly and upset them but what if the clinic wrote every five or 10 years and asked, "Have you changed your mind? Can we give the information?" This clinic just said no, that is it, never write again. How do you feel about that?

Ms ALLAN: I feel very disappointed.

Mr NICK LALICH: This was only one clinic.

Ms ALLAN: Yes. That is the problem with not having a clear standard that everybody has to operate against. Some clinics do the right thing; other clinics, for whatever reason, are not doing the right thing. Even though we do not have laws we have National Health and Medical Research Council guidelines that require clinics to take an active role in contacting donors and negotiating that information release. Some clinics are just not doing that; it is really not good enough. That is how I feel about it. But then, having said that, it is also a reflection that people are just not treated uniformly depending on where they were actually conceived or where the donation took place, and that leads to injustice and inequality. So that needs to be addressed.

Mr NICK LALICH: What do you consider are the advantages and disadvantages of all donor records initially being placed on a register with a contact veto in place and donors then being able to remove the contact veto?

Ms ALLAN: That is an interesting one. An automatic contact veto?

Mr NICK LALICH: Yes.

Ms ALLAN: That would work, and then if a donor did not want the contact veto they could remove it?

Mr NICK LALICH: Yes.

Ms ALLAN: Is it your suggestion that that would be subject to information release?

Mr NICK LALICH: Yes, it follows my last question.

Ms ALLAN: As long as it was separated. This conceptually is really important too—the existence of a contact veto does not negate information release. So it is not an information veto. In that sense donor-conceived people would get the information if they made the inquiry but they would not be able to contact the donor unless the donor gave approval. I think though in doing that there would or, I would suggest, should be some way of contacting the donor when an inquiry is made so that the donor is actually informed: Somebody has made an inquiry, would you be willing to move forward rather than just having your information released? And negotiating that with the donor and supporting them through that if they said yes or no.

Mr NICK LALICH: As a lawyer would you see any advantage or disadvantage in having legislation in place that states a child cannot have a lien on a donor's property, inheritance?

Ms ALLAN: Yes. That is one thing that I think—sometimes in a misinformed way there is a real fear by some. It is raised sometimes at some of the forums that I have spoken at that people are worried: What if the donor-conceived is after his—it is usually "him" because if we are talking retrospective it is sperm donors—is after his money? In reality that is not the case. It could easily be addressed by a simple one liner in a piece of legislation saying: In this environment with retrospective release the donor-conceived person has no claim on the donor's estate. That would resolve that fear. Perhaps too reflective of the fact that we know that many donors were young university students and so now, 20 or 30 years later, they may be in quite an affluent position. That would easily be addressed by clearly stating in legislation that that is not the case.

Mr GUY ZANGARI: The Committee has heard evidence about the importance of collecting and collating all donor-conception information in one place. We have spoken at length about that. Regardless of any future decisions made about how information may be accessed, in your view what would this involve?

Ms ALLAN: The collection and collation of all donor-conception information?

Mr GUY ZANGARI: Yes.

Ms ALLAN: I think whether or not retrospective release occurs all that information should be collected and collated. What would it involve? As I said, the approach the Netherlands took was to make it a legal requirement that clinics have to hand all records over. Of course it would involve somebody sitting there and inputting those records. Although having said that, I think the way that the Netherlands did it was that each clinic was given a code to a central database and they were responsible for actually inputting the data. So that saved a lot of cost. You did not have a person sitting at the register having to input the 20,000 donor-conceived people; the clinic had to transfer the—

Mr GUY ZANGARI: So they are responsible for uploading that data?

Ms ALLAN: Exactly.

Mr GUY ZANGARI: It is mandated by law that they must do that?

Ms ALLAN: Yes, onto a central register. Each clinic is given a code to get into the database. They cannot see anybody else's records; they can only see their own. They enter it onto the database and then the database has all the information. So it keeps the costs down.

Mr NICK LALICH: I know the reference to 20,000 was a throwaway line but—

Ms ALLAN: No, it was not.

Mr NICK LALICH: —in those countries what are the donor numbers? They are not massive, are they?

Ms ALLAN: Okay, the Netherlands is not massive. The 20,000 is the number that I came up with when I tracked across Australia the number of reported donor-conception births through clinics. So in Australia we are looking at 20,000. I do not know what the number would be for New South Wales. Donor-conception support groups in Australia put it closer to 60,000 because you have to think about the GPs and the private arrangements—20,000 through clinics. New South Wales and Victoria would share a large proportion of those numbers. So we are talking pretty significant numbers; the Netherlands not so many. I do have figures—I cannot tell you off the top of my head but I can give them to you—numbers from other jurisdictions as well such as Finland. The ones that have central registers, the numbers are actually easier to track. Again if you just rely on clinic information it becomes much harder but I mean its thousands, tens of thousands; it depends on where you are.

Mr NICK LALICH: What security measures do they take to ensure that a donor does not change his name? For example, he could say, "I am Joe Bloggs. I live at Manly" or give a different address?

Ms ALLAN: That is where the DNA testing comes in as well. The first step is to try and get all this information before it is lost and have it stored somewhere. The next step is to say we are going to release information, and then if there is going to be contact or really trying to match people then it goes beyond that. There are issues that maybe DNA testing can resolve in some circumstances. It will not be perfect because people change their names, they move away. It depends on who is implementing the system and what sort of action they take.

CHAIR: If we were to make this process mandatory, I mentioned earlier that the clinics are not forthcoming with information. We have also heard stories of misinformation and that some clinics have even deliberately destroyed information.

Ms ALLAN: Yes.

CHAIR: When the witnesses from Births, Deaths and Marriages were giving evidence before the Committee about a central register they spoke about the integrity or the truthfulness of the information. I am concerned that the clinics will not give us all the information and I am concerned also about the integrity of that information. Is there a way around that?

Ms ALLAN: You can make it an offence—I think it is an offence to tamper with medical records.

CHAIR: But it is happening.

Ms ALLAN: Yes, you can prosecute. You can have penalties and actually follow through. I really do hope that it is only a small number of clinics that are doing that and that overall the medical profession is one of integrity, that they would not do that and that they do respect the rights of children and their interests. To have information. There are other countries—I actually found a clause in the Swiss legislation that is retrospective, but because the retrospective legislation still is clinic-based when you try to trace information through the clinics they will say that the records have been destroyed. That has happened in other countries but they have been legally destroyed.

CHAIR: But you have not heard of examples where a donor-conceived individual who was seeking that information believed there was information at a clinic but by the time it was transferred to a central register it was lost?

Ms ALLAN: I certainly know firsthand of donor-conceived people who have approached clinics who are given all sorts of inconsistent information and varying records at different points in time, which means somewhere between the request and the provision of information, and even the provision of information over time, things are changing. I think the best we can do is to try and get these records. A lot of the records are not in the hands of the clinics anymore; they are in archive boxes in the bowels of libraries.

Mr NICK LALICH: Garages.

Ms ALLAN: Yes, garages. I have an example too. Narelle, a young girl in Victoria who for 15 years was searching for information, everybody knew where it was and who the donor was—that was the clinics and even the authority that looked after the register for some time—but nobody could tell her or took action to tell her the information. Finally one of the politicians stepped in and she was given information. She met with her donor and died two weeks later of a hereditary form of cancer. I think this is the big—it is an awful scenario. She was saying it 15 years ago. I met her 10 years ago as a young teenager and she was asking for information. It is that journey, and what the clinics did in terms of the doctors denying her information. I think the best thing we can do is do what we can to get the information on the register so that that does not happen again.

Mr GUY ZANGARI: In your submission you discuss the United Kingdom, the Netherlands, Finland, Austria and Sweden.

Ms ALLAN: Yes.

Mr GUY ZANGARI: In relation to what you are discussing at the moment, the way they collect and manage information, is best practice occurring in the Netherlands or across those countries that I have mentioned? I am really interested in what is happening in the Netherlands.

Ms ALLAN: The really interesting thing when you look across nations is that you get a better picture of how the best practice is to have a register. In Austria it is all clinic-based. There is mandatory release of information, but I could not even get in to talk to most of the clinicians, they are so tight-lipped. When I did talk to a clinician, he said his clinic was willing to release information, but in Austria you also have to take into account that donor conception is limited to heterosexual couples and a lot of heterosexual couples will not tell their children, so the number of inquiries is limited and the clinics are very tight-lipped. The countries that run central registers—Finland has set one up, but the children are not of age yet to get information, so it is hard to assess how it is working. I think the Netherlands has best practice but I would still maybe take a different approach. Australia is a different place, so in terms of the support system or the intermediary services, I do not necessarily think that we need to set up exactly the same system—we could do it in a different way—but certainly countries that have central registers work best.

Mr NICK LALICH: We have a bit of a road to hoe to get a central register, judging from the young ladies who were here earlier. It is not going to be easy.

Ms ALLAN: A central register can be State based. You already have a register in New South Wales.

Mr NICK LALICH: Yes, but what we are talking about is Federal.

Ms ALLAN: No, I meant central State based. Australia would have to take a different approach. The Federal Government said that it would not set up a national register, but I think what you can do in the long run, if you get agreement between the States, is link the registers, and that would be a way of exchanging information. You need quite good technical assistance to make this happen and the right kind of database and register to work because it can be very complex, because you are dealing with lots of different families and information, but you can do it across States if it was not one Federal register.

CHAIR: We asked that very question last week of the Registry of Births Deaths and Marriages, and they believe that in their current system they have the information technology, the knowledge and the database to maintain and control the release of information, so I think that is there already

Ms ALLAN: Yes, and when I was working for the Law Reform Commission in Victoria, we were the body that suggested moving the information to Births Deaths and Marriages, and it seemed like a good idea because that is where everybody's birth information is held and you have all those links and systems which enable that sort of communication across States.

Mr GARRY EDWARDS: Going back to something that Mr Lalich asked earlier about perceived fear of donor individuals later making claims on estates, you mentioned that we could probably provide for that in legislation.

Ms ALLAN: Yes.

Mr GARRY EDWARDS: To your knowledge, has that been put in place in any other jurisdiction and, if so, has it been tested?

Ms ALLAN: No, it has not been put in place in any other jurisdiction. Secondly, there have not been any claims on anybody's estate by donor conceived people.

Mr GARRY EDWARDS: That is in Australia to date?

Ms ALLAN: Yes, or anywhere. If you look at the United States, State to State there have been some funny kind of child support issues, but that is because they do not have legislation like we do. We have Status of Children Acts in all States that basically state that a donor has no rights or responsibilities over a donor conceived child, so that statement already exists in Australia. The countries where it has been an issue, and it is not a claim on a person's estate but more a claim for child support, are those countries that do not clearly delineate what the donor's parentage is, and we do that. A donor is not considered a legal parent in Australia, and has no rights or responsibilities, and that legislation exists in each jurisdiction of Australia.

Mr GARRY EDWARDS: The Law Society of New South Wales submitted that consent is an important consideration in determining whether donors should be identified. Could you comment on whether or not a donor's consent should be received before identifying information is released?

Ms ALLAN: Again I think that that negates the balancing of interests, so whilst it would ideally be, you know, you go and ask the donor and he can say yes or no—that is what that is saying—it ultimately then becomes the donor's say whether or not the child gets the information, so there is a problem because it is in the lap of the donor basically, and I think that fails to balance the interests of the child properly. I do, however, think that one of the better approaches is, if you are going to release information, to contact the donor first and let them know that that information is going to be released, so you do not just hand over somebody's information without them knowing, but you contact them and say, "There has been an inquiry made and this information is going to be released within X time frame." If there were already a contact veto in place, you would explain what that is and whether or not they want to remove it, and if there were no contact veto in place you would explain to the donor, "Your information is going to be released, but you have the option of placing a contact veto and this is how that works."

The other thing they did with adoption in this State, and I cannot think what it is called now, but they gave an added time frame for some people. They could place a different type of stop, which meant that the information would be released over a longer period of time, which might give the donor the opportunity to explain or to share information with his family, if he has not already told them, because I think that can be an issue too. Some donors have not told their wives or their children, and that is quite a big talk to have with your own family. So I do not think necessarily that the consent first approach is the best. I think that the information release should occur, but I certainly think that should occur in a way that is sensitive to donors.

CHAIR: We have heard that what we are trying to work through is the way we first collect information and how we release that information, and that it is similar to what is happening already around adoptions in this State. Can you elaborate on similarities and differences between the two?

Ms ALLAN: Sure. I think there are similarities between donor conception and adoption in the sense that you have a group of people who feel that they are being denied a certain really significant part of information about their own personal genetic heritage. There are many similarities in that sense. There are also many differences. For one, a donor can donate to many different families, so either the real or perceived risk of forming relationships with people you are related to and do not know that you are related to can be a bit more present with donor conceived people. On the other hand, unlike adoption, you do not have issues of abandonment or "My parents didn't want me." Donor conceived people are very much wanted and loved, and in some adoption situations so too were the children, but there are significant differences in the way that the relinquishing of children occurred in adoption situations in our history.

Nevertheless, I think the central core that ties the two together is the need for information. Their personal family situations are quite different, but they share the commonality of wanting information. In that sense, though, if you are looking at counselling or support services, you have to be very careful that you are not implementing an adoption model on donor conception, because there are significant differences in the way that donor-conceived people feel, and the way their families function; recognising that not all of them are harmed and that many donor-conceived people are really happy in the families that they have and that they are just seeking information.

Mr NICK LALICH: Doctor, what do you think of the model used in managing adoption information where there are several different agencies, both government and non-government, involved in the process of releasing information and providing counselling to adopted people and their families?

Ms ALLAN: I am all for the simplest approach possible when you are dealing with complex matters. It complicates things when you start to have numerous bodies involved. The simplest approach possible for me is to streamline it and then possibly in respect of counselling or support services, depending on funding, outsource but to particularly skilled infertility counsellors or people who have experience in the donor conception realm. When you start to have a number of bodies responsible for various bits of the information or pieces of the puzzle, it can get even more complex to navigate for people who are trying to access the system. So you can create problems that do not need to exist when they are already seeking information in maybe a stressful environment or things that are very personal to them, so it would be better to be able to go to one place and have that all dealt with, rather than having to navigate lots of different bodies. The Committee made the point, too, that if you are looking at cost, it can make things far more costly when you start to share the responsibility amongst many different agencies.

CHAIR: We hear constantly that the Victorian model is far more superior to any other State model, and we probably agree. One of the problems is that there are too many agencies involved to get information.

Ms ALLAN: It did not work.

CHAIR: We have heard back from some who have said that that process did not eventuate.

Ms ALLAN: The process did not eventuate?

CHAIR: No, people went through the system feeling like everyone kept passing the buck, so who was responsible to give that information.

Ms ALLAN: Yes, from one place to another and nobody is really taking responsibility.

CHAIR: Correct.

Ms ALLAN: Anecdotally, if we again look at Narelle Grech's situation, even the Registry of Births, Deaths and Marriages in Victoria sent her a letter saying that they had conducted an extensive Australia-wide search and could not find her donor, and then two weeks later the politician who stepped in was able to open her records because we knew where the records were. But it is all about who is responsible for what. We fragmented the system when we moved the register over to the Registry of Births, Deaths and Marriages. We also handed the support services over to an adoption support service agency and that has not operated as effectively as initially we thought would occur. Having said that, there are also issues with having support services provided by people who are primarily supporting infertility—depending on how you look at it—but, if they are supporting recipient parents or their focus is infertility, then they do not necessarily understand the issues faced by children. So it is difficult to get the balance right, but certainly fragmenting the system does not seem to have worked in the best or most ideal way.

CHAIR: Is there anything else you would like to finish with?

Ms ALLAN: I do not think so.

CHAIR: That is fine. I thank you for appearing today and for your submission. We may write to you seeking answers to other questions. If you are comfortable with that, that will form part of your evidence of today's hearing.

Ms ALLAN: Thank you. '

(**The witness withdrew**)

(Short adjournment)

GERALDINE HEWITT, Member, Donor Conception Support Group of Australia, affirmed and examined, and

CAROLINE LORBACH, National Consumer Advocate, Donor Conception Support Group of Australia, sworn and examined:

CHAIR: Welcome to this morning's hearing of the Legislative Assembly Committee on Law and Safety. Thank you for appearing today to give evidence. Please confirm that you have been provided with the Committee's terms of reference and information about the standing orders that relate to the examination of witnesses.

Ms HEWITT: Yes.

Ms LORBACH: Yes.

CHAIR: Do you have any questions about them?

Ms HEWITT: No.

Ms LORBACH: No.

CHAIR: Have you provided the Committee with a submission and do you want it to form part of your formal evidence?

Ms LORBACH: Yes.

Ms HEWITT: No, I have not made a submission. It is lovely to be here and thank you for the nice smiles you have given me. I was born in 1983 and I am 30 years old. I have been doing media and meeting politicians since I was 12 years old—that is, I have been advocating for openness in donor conception for 18 years. We have a terrific template in terms of what should be done with the adoption model. It is all laid out in black and white—having registers, contact vetoes and birth certificates with extracts. I think the importance of having open and honest conversations with people about their origins is well established within the adoption community. I do not understand why we are meeting here today. This should have been rectified many years ago. I am very interested to see what will happen today. To be honest, I do not have many expectations; I have had my hopes dashed year after year. I am doing this on behalf the children conceived today who will be in exactly the same position as me.

This should be a federal matter not a State matter because gametes are being imported into Australia from a number of different countries. It is not best practice that Australian citizens should have to apply to a foreign country to find out information about themselves or that we have medical professionals suggesting to their clients that they go to countries such as Greece to get anonymous egg donors. I find it very interesting that there is a resounding silence from the Australian Medical Association. The fact that there is no official statement from the association speaks volumes. Of all the parties involved in this arrangement, the medical profession should understand implicitly the importance of having an updated and comprehensive medical history. I inherited a condition—endometriosis. It is not related to my mother and my sister does not have it. I have had three operations and I am about to have a fourth. I am at risk of being infertile. What more can I say? That is my opening statement. Thank you very much.

Mr NICK LALICH: Some submissions have argued that a donor's decision to donate anonymously should be preserved. What are your views?

Ms HEWITT: My views are reflected in the evidence I have heard from past donors. Inviting them to review their decision is always the first point of call. Of the hundreds of donors that the Donor Conception Support Group has contacted only five have said that they wanted their anonymity preserved. Those decisions were made 20, 30, 40 or 50 years ago and they were made without really understanding the long-term implications for them and their families and for the person created. I know that many of them were not given counselling at the time that they donated.

Some donors were forced to donate under duress. Medical students at the University of New South Wales were told that all male students were expected to provide a semen sample by the end of the year. If they did not donate they would not pass the course. They might have been failing and they would be told to donate and the fail would be turned into a pass. Inviting people to review their decision based on current information is the way to go forward, which is what we have done with adoption. Having contact details in place can protect both parties. Some donor-conceived people do not want contact with their donor; it is a two-way street. That is a good measure to put in place if need be, but people should be invited to review their decision and at a minimum medical information should be exchanged.

Mr NICK LALICH: You say the decision should be reviewed over a number of years. We have had situations where a donor has decided veto and the clinic has said that it will never write to him again so do not ask again. You are suggesting that the donor should be approached every five years or so to see whether he has changed his mind.

Ms HEWITT: Certainly if there was new information from the donor-conceived person. They might have a child and that child might have been born with a condition, they might have a condition or there might be another reason to want contact. They should not be harassed, but asking them once is a very good starting point. Perhaps they could be contacted every 10 years and definitely if there is more information that is relevant, such as medical history information.

Mr NICK LALICH: Given your condition do you believe it should be mandatory for the donor to provide at least health or genetic information?

Ms HEWITT: I believe that most reasonable people would think that would be the bare minimum from a human decency perspective.

Ms LORBACH: As Geraldine said before, we have a very good model in adoption. In adoption it was considered necessary a long time ago to have complete anonymity and relinquishing parents were promised anonymity and some of them at the time wanted that. But New South Wales, along with all other States, decided in the best interests of adoptees that they would retrospectively change it. The current legislation in New South Wales for ART states that its prime objective is to protect the interests of three groups of people: women undergoing treatment, donors and at the top of that list is people born from ART. How can it possibly be in their best interests to deny them information about their identity, their medical health histories, their relationships when all those things are crucial to them. It is crucial to their psychological wellbeing. It does not make sense.

If you are going to say, "Okay, all those donors who were promised anonymity years ago, we are going to keep it that way", in whose best interests is that? It definitely is not in the best interests of people born from ART. A lot of those donors were not given a choice. I would say in the early days, the vast majority of those donors were not given a choice about anonymity. It was, "This is the system we have in place, you will abide by it". I have spoken to donors who said that when they hinted at thinking about leaving a photo for the children being born they were told "no".

Ms HEWITT: And they were kicked off the program.

Ms LORBACH: Some were, yes. We know of a lot of donors who, at the beginning, went along with that. Some never cashed cheques from clinics that they were paid for their donations because they did not think it was the right thing to do because they said, "We are creating a human being who is going to have thoughts about all this; we cannot be paid for doing that." Two of my children are in their twenties and one is in her last year of high school. My middle child, when we tried to contact his donor a number of years ago said he did not want any contact at all. He has since changed his mind. He now is willing to have contact when my son decides that he is ready for that. It is possible for people to change their minds.

Ms HEWITT: I can give examples in my own family. I have a younger brother and a younger sister who were born from different donors to my donor. Both of their donors donated anonymously. When they were contacted by the hospital—the Royal Hospital for Women—both of them changed their mind. They have sent letters, emails, photographs and letters from their wives and birthday cards have arrived for my brother and sister. My sister gets travel advice for every new country she visits. I think that this is human interest. This is a sense of curiosity to want to understand your origins to have a well-rounded and complete jigsaw puzzle. I do not think that we are seeking to impose ourselves on somebody's life unnecessarily but I think there is a responsibility and a duty of care to consider the long-term implications, not just for myself.

Last night I spoke to a donor-conceived person who lives on the northern New South Wales coast. She is incredibly concerned. She has three young boys and she considers it a ticking time bomb to not know what she can pass on to her children. It does not stop with us. I think that the information on donors needs to be preserved by an independent body. I do not trust the hospitals. I have worked for 4½ years implementing a project for the faculty of medicine at Sydney University. I have worked in most of the major teaching hospitals across New South Wales. I know the state of the documentation that they keep. I know their interesting methods for document retention. I think that it needs to be an independent body.

CHAIR: When you say "independent" do you mean non-government?

Ms HEWITT: I mean government.

CHAIR: Something like Births, Deaths and Marriages?

Ms HEWITT: Absolutely, definitely.

Ms LORBACH: Or an independent authority as in Victoria.

Ms HEWITT: Like in ITA?

Ms LORBACH: Yes.

CHAIR: There are three steps going forward. We have record keeping—and we have done a bad job up to this stage, and there will be question marks about the integrity of that information that will be forthcoming. I would assume there will be some huge gaps in the information that we will at the minimum get from clinics and those involved. From there, how do we issue that information and what legislation will be required and will it be retrospective? The third step is about contact. I think they are three different steps going forward. I am concerned about the lack of information. At the moment, the clinics are not forthcoming to this inquiry.

Ms HEWITT: And really they have been allowed to get away with this because all they have had to work within are guidelines. Guidelines are a toothless tiger. I think that clinics need to be more accountable. They are earning a lot of money out of this. I would also like to piggyback on Caroline's point regarding donors and payment. We do not allow organs to be bought and sold. We do not allow babies to be bought and sold, so why on earth are we allowing monetary value to be attached to donor gamete? I am very uncomfortable with money being attached to a human life. I think it attracts people that are very desperate.

Mr GARRY EDWARDS: Ongoing contact was referred to earlier, possibly every five or 10 years, with the donor asking, "Have you changed your mind?", "May we give out this information?" Who do you see should administer that? How will it be paid for?

Ms HEWITT: How is it going to be paid for? Being a taxpayer I would say it would come out of the tax. Truth be told, I am not an administrative person responsible for answering that question so I am not going to touch the question on that point. I would say that the responsibility for contact would be the government body or the independent authority. I think the way that donors were contacted by the Royal Hospital for Women where I was born is a good model. They sent letters by registered mail and used a blank template so it had no letterhead that would in any way imply that this was from the infertility clinic.

All they said was, "Dear so-and-so, We have information to say that you were in contact with our hospital during these years, 1982 to 1984. Please contact this person." They would get a note from the post office saying they had a parcel to collect. They would have to go there and present identification to receive that letter. As I explained, the letter would have no information if they left it lying around their house and their wife picked it up. If I am honest, the number one concern of most donors is that when they donated they were single guys and they are feeling really guilty and scared of what their wives are going to say. Those men need a lot of support in terms of counselling and how to approach that subject with their wife.

If you were looking to donate in present-day New South Wales and certainly in Victoria you would have to go in for counselling with your partner or your wife. I think services need to be available for counselling for donors and for donor-conceived people, and for recipient parents in relation to how to go about disclosing to their children. Free DNA testing could be paid for by the State, maybe even by the clinics. That needs to be implemented given that the record keeping is such a mess. The detective work by the clinics is admirable to an extent but as a 12-year-old I went in and met with medical professionals at the Royal Hospital for Women and they said, "There is no information on your file." I said, "Did you cross-reference that with the other recipients of my donor?" and they said, "We haven't thought of that."

It is very interesting that every five years there is a new trickle of information. I have a letter that says, "There is no information pertaining to Geraldine's donor". One sentence; not worth the stamp. Five years later I wrote a letter. It got chewed around the system and the reply went back to my parents. They did not even have the decency to answer me. It said, "Geraldine is one of four live births, one male, three female, 1983." All of us are the same age. I have asked them to tell me the months that my brother and sisters were born in and they will not even tell me that, based on the fact that they do not have a policy on giving out information about donor-conceived people. This is not good enough.

Mr NICK LALICH: How do you envisage that we keep track of the donors—not so much their name, because we know it, but they could move around and move overseas? It would be very draconian to have a law that said they have to inform us every time they move.

Ms HEWITT: The hospitals have gone about trying to locate donors through the electoral roll. That has been a key source of information. I do not want to undermine the authority of this Committee or the New South Wales Parliament but I really believe there should be a Federal register. That is based purely on anecdotal evidence within my own family and Caroline can give you evidence too. My brother's donor, Grant, donated to three different clinics, one in New South Wales and two in South Australia My brother is one of 29 children born to Grant. Caroline knows of children with 40 half-siblings. I know of one donor that donated something like 358 times across nine different clinics in Sydney over an 11-year period. The money that man made put his daughters through private school.

CHAIR: What period was that?

Ms HEWITT: That was around the time I was conceived.

Ms LORBACH: Starting in the 1970s and going through to the late 1980s.

Ms HEWITT: The reason we know this is that this man kept a date of every donation and every clinic, and I have seen the two A4 sheets and it is sickening. It makes you want to be ill. Most of those clinics do not have records for this man so I think in terms of keeping track of these donors it is an incredibly difficult undertaking to expect that people will update their contact information. Perhaps the electoral roll would be the best fallback.

Ms LORBACH: I think education plays a huge part in this. We have to educate people and past donors about the importance of updating contact information. A lot of them donated when they were very young, which is not the case these days. The profile of donors has changed since our legislation. They tend to be older and most of them have completed their own families, so they are a different type of person. But most of those who donated years ago have gone on to have their own children now and tend to understand more about what is needed. That is why I think we get people coming to us who donated under the anonymous system and are quite happy to provide information. So education going out to donors is very important because I think a lot of them would voluntarily come forward providing they know what it all means, what their responsibilities are and what their protections are. We got it right in adoption. I think the last major changes to the New South Wales adoption laws were in 1990. Twenty-three years later we are still basically arguing what was argued about adoption. Why have we not learnt from that?

Ms HEWITT: Retrospectivity is seen as this terrible evil and for donor-conceived people like me it is a case of "Whoops, you missed the cut-off date", whereas for adoptees there was no question. Is it that we exist within the health model and a lot of the past donors were the doctors themselves?

Ms LORBACH: I think one of the major problems is that our legislation is within the health model. Children who were relinquished for adoption were born in hospitals. That comes under the health model, but their legislation is not under the health system. People decided that their records and information should be within Community Services. It was not all about health and health was not really the right place to be looking after that sort of information. Our group has never been happy with our legislation being firmly entrenched in the health model because it makes it just about the medical side and more about the conception than about what comes afterwards. It is about the infertility treatment. Our children may have medical problems now but so do adoptees. They also have other problems in line with adoptees: the lack of true identity, the lack of knowing who you are related to so you can look out for perhaps meeting a half sibling. Our children go through life as they grow up wondering at what point they tell someone they are donor conceived. At what point do I ask them whether they are donor conceived as well or whether they are the child of a donor? At what point do you tell someone that? I am sure adoptees go through that as well. This is why we need legislation for this area to be moved sideways, into Community Services if possible.

Ms HEWITT: I want to take up a point Caroline has mentioned about finding out that you are donor conceived. There is a study by Golenbock that shows one in 10 donor-conceived children are told the truth, so the vast majority of people affected by this, the many thousands, are in the dark. It may already have been tabled but I would like to see our birth certificates reflect our true identity. I would like to see a birth extract in line with those of adoptees so that when you apply for your birth certificate as an adult, similar to adoptees, you will be told by the clerk, "There is extra information. Would you like to request that?" Most people, out of human curiosity, will say yes. When you get your birth certificate you are taken into a room and the official says, "Here is your birth extract." I am not saying on any level that I want somebody to find out about how they were conceived from a Births, Deaths and Marriages clerk, but information is more valuable.

Mr GUY ZANGARI: That point regarding the addendum and further information being available has been raised through our inquiry last year and this year. The key point also in disseminating such information is that the support network is in place.

Ms HEWITT: Definitely.

Mr GUY ZANGARI: The Department of Births, Deaths and Marriages made it quite clear that it is not within their expertise or their jurisdiction to provide such services, but you are saying that once the trigger is put in place and information is given the support network must be in place and counselling must occur?

Ms HEWITT: Absolutely. Like Jigsaw for adoptees.

Ms LORBACH: This system is in place in Victoria already, where they have addendums to birth certificates now. VATA was told in advance that this was going to happen and they started an education program for parents, holding seminars to encourage parents who had not already told their children to tell them and giving them the support and wherewithal on how to do that. So parents would know there was a chance that their child was going to find out and they could then tell them in their own way, which is the best model, if parents can be given that support. That is probably why a lot of parents are still not telling their children the truth. I have always been convinced from the numbers of people that I have spoken to in the last 20-something years of doing this work that most parents do want to tell the truth; they do not want to lie to their children. It is a huge burden to carry to keep that a secret because there are so many times in your life where people will say: "Doesn't your child look like so and so?" The concern that must bring to those parents who are not telling their children the truth must put a tremendous weight on them. I think most parents want to be honest with their children. Parents want to bring their children up to believe that honesty is very important because that is what our whole society is based on.

Mr GUY ZANGARI: You are saying that once again it is about a support network being available for those parents as well as the donor-conceived child.

Ms HEWITT: And the donors too.

Mr GUY ZANGARI: So we are really tapping into a big issue about support networks—

Ms LORBACH: Yes.

Ms HEWITT: Absolutely.

Mr GUY ZANGARI: —and what is available for the three major parties involved: the donor, the parent and the donor-conceived child.

Ms LORBACH: Yes.

Mr GUY ZANGARI: Parent have the anguish of when is the right time to tell the child and how that information will place the donor-conceived child.

Ms HEWITT: Most people have found it is from birth.

Ms LORBACH: Yes, very early.

Ms HEWITT: If you start getting comfortable with the language.

Mr GUY ZANGARI: The Committee has heard evidence where, unfortunately, some donor-conceived children have found out in their mid-20s and mid-30s and beyond.

Ms LORBACH: And beyond, 55; not always in great circumstances.

Mr GUY ZANGARI: No.

Ms LORBACH: But if you speak to those people and ask them, "Would you rather have not found out?" They will say, "No because it answered lots of questions I had in my mind that I have never voiced."

Ms HEWITT: Children have a sense of what's going on; they are sponges for information. I did a study in 2001 when I was a high school student where I interviewed 46 donor-conceived people from around the world. It is still the largest study of its kind to date—it is disgusting to be honest that an 18-year-old can claim that and it is 12 years later. What I found was that when most people found out later it was usually from their mother and it was often after their dad had passed away. That brought an extra sense of grief because they could never go to their dad and say, "I still love you; you could have been open with me." I think this destroys families. I have been at a conference where there were 19 donor-conceived people and 17 marriages had broken down—that is above and beyond the usual statistics for divorce in the Western population.

I think that having education, a very well-articulated education campaign out in the community warning people that these changes are happening and that these services are available—this is who to contact if you are one of the three major groups—and giving parents of donor-conceived people a template for how to broach this conversation: If your child is under five this is how you tell them and these are the books to read to them, and if they are five to 10: This is the language we have found is very useful. I think that tailoring the information will give people a sense of comfort that this will be okay.

Mr GUY ZANGARI: There is nothing in the model about the timing for parents to undertake that most daunting task of telling a child they love that story and then the repercussions from telling that story when the information is not available, period.

Ms HEWITT: No, and I think the repercussions of not telling are far more disastrous than being open.

CHAIR: As a member of this Committee one of the concerns I have going forward is that as legislators we can mandate laws and put in place processes for record keeping, how we disperse that information and the right to have that information. We have also heard that some of the conception happens in private arrangements and as legislators that is an area in which we will never be able to force people to do anything.

Ms LORBACH: No.

CHAIR: Do you have a comment about that?

Ms LORBACH: Education about the importance of why this information is vitally necessary to donor-conceived individuals.

Ms HEWITT: I can say that on Facebook last week I had a friend put a status saying, "My friend is looking for a sperm donor." I was like, oh my goodness. So I gave them a lot of information and I kept giving them information. I was saying, "If they are in Victoria they need to go through ITA. This is far too important. The child's right to information needs to be preserved. It is all well and good that you want to circumvent the system because your biological clock is ticking but the implication for your child to know who this person is far outweighs your desire to conceive."

CHAIR: The key is education. But if we legislate and force people so there is no more anonymity, will we then force more people into private arrangements?

Ms HEWITT: To go underground?

Ms LORBACH: No, I don't think so.

Ms HEWITT: I don't think so either. For the countries that have already removed anonymity and the States within Australia like Victoria, I guess it is very difficult to glean numbers in terms of how many private conceptions are happening—we simply do not know. But in terms of reflecting the number of people accessing the services of donors who are contributing—Caroline already touched on this—you see a difference in the their profiles. You do not get the 18 or 20 year-old-students who are doing it because they are financially poor and they have not started their families. You get guys who are in their late 20s or early 30s that have already started their families or completed them. I think that is a very interesting point for the donors themselves, both men and women. There are donors who donated when they were young and when they went to start their families in their 20s and 30s they found that they had infertility themselves. This is a very sensitive topic.

For instance, when they contacted the man they believe is my donor he said, "I can't really talk about this right now. I and my wife are experiencing infertility. I think it would be too sensitive a time for contact." Then the clinic turned round and said, "Oh, we actually don't think it's him." I think in terms of answering your question I have probably done a terrible job but I think that the information in terms of what we have seen in other areas is that people still turn up to the clinics and receive treatment, donors still present themselves. If anonymity is removed all that we can do is plan for the best case scenario—that is, that people work within the framework. There are always going to be people who are off the grid—don't pay taxes, aren't on the electoral role—but all that we can do is the best possible practice.

Ms LORBACH: Logically if we make our New South Wales legislation retrospective it is not going to affect those people accessing treatment now because anonymity has been banned since 2010 here anyway and there is going to be no change to that. From the people I have talked to over the years, the majority of people accessing private donors are single women and lesbian couples. Most of them have done this because age is getting the better of them. They do not want to go through the process of going to a clinic and having to have counselling meetings. Most clinics have what is called a cooling-off period—you go in for your initial meeting, then you have to wait six months and then go back and have another meeting so you are given time to consider all the issues. A lot of them are too impatient to go through all that. That is part of the reason why there are I think so many people accessing private donors and there are donors offering it.

Ms HEWITT: Sorry to interrupt you but can I expand on Caroline's point? In terms of the perceived donor shortages I have never heard of a clinic saying, "We have got too many" and I think it needs to be quite clearly explained to the community that there are many more people accessing these services. As Caroline touched on, there are now three different types of recipient parents: your heterosexual couple, your lesbian couple and your single woman. Donors nowadays are invited to decide who they want the recipients to be. Most men decide on the heterosexual couple. So you have now got most of your gametes going to that group and you have these other two parties that are not receiving the same level of, I guess, services.

In addition, I have heard from clinics that it is sometimes very difficult to attract donors from specific religious backgrounds or ethnicities. Within Islam it is illegal to adopt so therefore it is illegal to donate sperm. So for Islamic families it is very difficult to attract Middle Eastern looking donors and the same can be said also for people of Asian backgrounds. It is very interesting when you hear a clinic saying, "We do not have enough sperm" to ask "Who are you actually seeking the sperm for? What kind of donor? What background or what ethnicity are you looking to match the father and the donor with?' It is good to drill down in that line of questioning.

Ms LORBACH: Also if you go back to news articles where clinics have gone to the media and put forward the fact that they are trying to find donors, those clinics will get donors. They always get people coming forward.

Ms HEWITT: Also the level of sperm count that is required for a sperm donor is incredibly high.

Ms LORBACH: Yes, very high.

Ms HEWITT: Because it has to be able to survive the freezing and rehydration process. A man that would be able to conceive naturally may be considered not a suitable candidate as a sperm donor because his sperm count or motility does not match the requirements. It is actually incredibly difficult to get a person that will match all of the requirements of the clinics.

Mr NICK LALICH: You mentioned devastating families when you cannot find information.

Ms HEWITT: Yes.

Mr NICK LALICH: What about devastating a family where a donor-conceived child does not know any better and is quite happy to go through their whole life not knowing? They do not know, so they do not ask, and they think, "This is my natural mum and dad", and at 18 we give them something on the back of their driver licence or birth certificate saying, "There is more information for you." Would we not also devastate them and wreck the whole family by giving out that information?

Ms HEWITT: I think, as Caroline mentioned before, it is devastating, but the people that I have spoken to have said, "I would rather know than not know." Information is the key. I think that we are not recognising the true resilience of humanity. I think that people have the ability to overcome a lot of things. If you are going to live to 80 and that upsets you at 18, I think you have a lot of years in between to get over it.

Mr GARRY EDWARDS: Surely you could include an option that said something like, "If there is additional information attached to your birth certificate, would you like to receive it", and they could tick yes or no.

Ms HEWITT: Exactly.

Ms LORBACH: Yes. I have spoken to people who have found out in their twenties that they were donor conceived and they said there was an initial anger almost that "Why didn't you tell me earlier; why didn't you trust me with this information", but once they got over that—and some had to seek professional help to get over it—they said things changed within the family. The relationship was then built on a more solid foundation and their parents, for some reason, changed in the way they treated them. They put it down to the fact that suddenly their parents could be totally honest with them; it was two adults speaking together instead of an adult who knew something about the other adult but was refusing to tell them.

That is an awful situation to be in because I think we talk about the parents' right to tell or not to tell. Okay, they are a child and we allow parents a certain degree of autonomy in this State—not in everything. In adoption you do not really have autonomy on whether you are going to tell your child they are adopted. You will not get a child to adopt if you even hint that you are not going to tell them the truth. But in this area you are allowed to, so they are allowed a certain amount of autonomy. But whose information is it when that child becomes an adult? This is information not about the parents' identity, not about the parents' medical history, it is information about that adult and other people are keeping that information from that adult. I cannot see how, in this day and age, we can honestly justify that.

CHAIR: You have touched again on the adoption process, and I think one of the opening statements was that we already have a template in place through what happens in adoption.

Ms LORBACH: Yes.

CHAIR: Is there anything around the adoption process that would be different, if we were to adopt a similar model, or how do we enhance it to suit? There will be differences between adopted children and donor-conceived individuals.

Ms LORBACH: Yes. In adoption, not all adoptees want to have information about their birth parents. Not all want to have contact. I would say that the percentage of donor-conceived people who do not want to have that information or are not interested in it is probably higher than in adoption. The number of conceptions is probably higher in our area and I think the number of people who do not want to access that information is probably higher, but in 23 years of working in this area I have only ever met one donor-conceived person who does not want the right to have that information.

Ms HEWITT: I can second that as well. In the study that I did of 46 people three said that they did not want to have information about their donor, and that is because two of them already knew their donor, so that leaves one person out of 46. I would say if they do not want to know that information now, great, but when they start to have children I bet there are going to be triggers going off for themselves, and that information should be kept forever because it is relevant to their grandchildren as well. The line continues. I am sure that Narelle has been brought up before.

Ms LORBACH: Yes, our friend Narelle passed away recently in Victoria. She was diagnosed two years ago with stage four bowel cancer. She was told by her specialist that it was most likely hereditary. She went back home and asked her mother about her medical history. Her mother said she knew of no-one in her family who could have possibly had this condition. Her first thought then was that she had to let the other children of that donor know, and she was barred from doing that. She was told that she could not get access to her records. She fought and fought and fought with the Victorian Government until we were told that there was some sort of legal impediment in place to say that those records, which belong to the old Prince Henry Hospital in Melbourne, could not be accessed. It took the now ex-Premier of Victoria to somehow—and we still do not know how he managed to do it—access those records. She finally met her donor only about a month before she died.

Ms HEWITT: And at her deathbed were her mum and dad, her brother, her donor, his wife and her donor's son.

Ms LORBACH: Yes, and he said that if he had known earlier that she was looking for him he would have come forward a lot earlier.

Ms HEWITT: He was living in Tasmania when they found him, to touch on your earlier point about donors moving around, so that was the electoral roll finding him.

Ms LORBACH: Yes. How many half-siblings of Narelle—and we think there are about eight—are going to die from bowel cancer? She was 30 when she died. It is very young for getting bowel cancer.

Ms HEWITT: It sent ripples through all of the donor-conceived people because this is stuff that we have thought of. We have all thought of the long-term medical implications for ourselves and our children. The fact that Narelle was the same age as me terrifies me. When I got diagnosed with endometriosis, again the first thought was that I need to let my half-sisters know. I just think that we have the best model with adoption and with the State of Victoria; I do not see why we cannot just get the ball moving.

Ms LORBACH: Can I ask a question of the Committee?

CHAIR: Yes.

Ms LORBACH: If the New South Wales Government enacted retrospective legislation in the area of donor conception to allow all donor conceived people to know the identity of their donors, if those records still exist, what are you afraid will happen?

CHAIR: That is a good question. I do not think we are afraid. We have obviously come to this from our previous inquiry, which was about how we keep records and how we record information on birth certificates. We were confronted with many stories about record keeping and who had a right to that information. That is why we self-referred to go into a further inquiry and broadened our terms of reference. We genuinely have come into this particular inquiry completely open to retrospectivity across all grounds.

Ms LORBACH: My question was not really aimed at you wonderful people sitting here, it is more aimed at the Government as a whole.

Mr GARRY EDWARDS: From a personal point of view, I would think that if there is a fear it is the fear of the effect that it could have on the donor and possibly the donor's family. However, before we get to that point, we should be balancing who has the greater right—the donor or the donor conceived individual.

Ms HEWITT: I think that adoption is the best model and they have said at the very top the rights of the child are paramount.

Ms LORBACH: Yes.

Ms HEWITT: I never signed an agreement that said I agreed to have no information given to me, and my parents went to Justice Michael Kirby and he said that when parents sign away the rights of the child to seek information—you cannot do that. You cannot sign on behalf of somebody else and you definitely cannot sign on behalf of somebody that has not even been created yet.

CHAIR: Yes, we have heard comment about that, that in law you cannot sign away the rights of someone who does not exist.

Ms HEWITT: Adoptive parents, as Caroline mentioned before—it is so obvious. They gave up their children with anonymity in place. That has been removed retrospectively. Donors have given away their gametes anonymously; adoption has the contact vetoes in place if you do not want to be contacted. What we are looking at is that if there is any contact in place, it goes through the governing body. When my brother and sister get letters the donor sends the letter to the hospital; the hospital is the intermediary, and then the letter is sent on so they do not have each other's postal addresses. If they want to exchange phone numbers or email addresses that is up to the discretion of the individuals. If it is very well laid out, most reasonable compassionate human beings will see that this is a human interest, it is a curiosity. We are not looking for anything that even hints at a child-parent relationship. We have got dads. We have got amazing fathers that in no way—if I could change anything, Warren would be my biological father, but he is not. This other guy helped out: Kudos to you, I will shout you a beer.

CHAIR: Going back to the original problem, all members of this Committee sat through Parliament last year. We apologised for the forced adoption practices of past years and that drives us. Whatever we do, at the end of this inquiry we want to enact legislation that does not have consequences on others. I do not want to see a Parliament in 40 or 50 years also having to apologise to a group of people. We are trying to work through the complexities of legislation that will protect but at the same time give rights to donor-conceived individuals.

Mr GUY ZANGARI: I ask a question of Geraldine before we wrap up. One of your earlier comments was regarding the Federal legislation in government and State jurisdictions. You said that you did not want to undermine what is happening in New South Wales because obviously when we are looking at keeping information that should be a Federal matter. However, if I could add to your comment there, if we could get the ball rolling in New South Wales, put a foot forward to say that we do have a central register and it is mandated that clinics provide the information to the central register and that they keep updating the register, I think that is a step in the right direction. I know you did not mean to deride what happens in New South Wales.

Ms HEWITT: Absolutely not.

Mr GUY ZANGARI: However, we have an opportunity to do that.

Ms HEWITT: Terrific.

Mr GUY ZANGARI: It is vitally important for that to then carry throughout the country and see how it goes.

Ms HEWITT: Thank you.

Mr GUY ZANGARI: I wanted to add to what you were saying. You did say you did not want to undermine what we are doing. It has been noted and I concur with your sentiments in that regard.

Ms HEWITT: Thank you. Putting pressure on other States adds impetus. Touching on Garry's earlier point regarding funding, if we make it a condition of every clinic's funding that they contribute to the ongoing costs of the register, of counselling, I think that needs to be—they are making a lot of money out of this.

Ms LORBACH: I think you will find there are a lot of parents who would be willing to pay money for counselling, to contribute because we, along with the clinics, conceive these children. We have to have responsibility as well. It has always been our group's point of view that donor-conceived people should not have to pay to get their own information. Going back to what Garry was saying before about the worry that donors might have about being contacted, et cetera, all those questions were answered in adoption. If we put in place a system similar to adoption, we will be putting in as much protection as humanly possible for all parties concerned, and we will be treating all parties concerned with as much dignity and respect as we possibly can. I would love for my home State to be the first jurisdiction in the world to have retrospective legislation. I think we could hold our heads up really high. We could beat Victoria. They have the recommendations in place at the moment. Maybe we could beat Victoria, and would that not be wonderful?

CHAIR: We would love to beat those Mexicans.

Ms HEWITT: Yes, State of Origin.

CHAIR: Are there any concluding remarks?

Ms HEWITT: I would to thank you for having open ears and asking such mindful questions. It has been a lovely experience to meet you all.

Mr NICK LALICH: Thank you.

Ms LORBACH: Thank you very much. Again, it is most appreciated.

CHAIR: Thank you both for attending today's committee hearing. We may have a series of other questions that we may need to ask you. If you are comfortable, we will write to you and your responses to those questions will form part of your evidence in today's hearing. Are you okay with that?

Ms HEWITT: Yes. Thank you.

Ms LORBACH: Yes.

(**The witnesses withdrew**)

LEANNE O'SHANNESSY, Director, Legal and Regulatory Services, Ministry of Health, affirmed and examined:

GREG McALLAN, Associate Director, Private Health Care, Ministry of Health, affirmed and examined:

CHAIR: I welcome Ms Leanne O'Shannessy and Mr Greg McAllan, who represent NSW Ministry of Health. I am John Barilaro, member for Monaro, and the Chair of the Law and Safety Committee that is conducting this hearing, along with my colleagues. I thank you for appearing today. Can you please confirm that you have been provided with the Committee's terms of reference and information about the standing orders that relate to the examination of witnesses and do you have any questions concerning these?

Ms O'SHANNESSY: Yes we have been provided with them. We do not have any questions.

CHAIR: Have you provided the Committee with a submission and do you want that submission to form part of your formal evidence?

Mr McALLAN: Yes, we have.

CHAIR: Would you like to start with an opening statement before we commence questions?

Mr McALLAN: No, I think the questions should run through our process.

Mr NICK LALICH: Were retrospectivity introduced. Can you outline how the donor conception information might be obtained and entered onto the central register? What issues do you see arising from this process?

Mr McALLAN: I would see retrospectivity being driven by questions from the offspring of donor’s of gametes. I would imagine we would not be collecting all the possible information we could collate about every donation and every resulting child. It would be driven by the question from the donor-conceived offspring. Issues arising for us administratively would primarily be the integrity of the data. The further you go back the more fragmented is the record. Some records from the 1970s and 1980s are simply a code and a blood type, and you could not work with that at all. If retrospectivity were introduced with existing assisted reproductive technology providers they would have varying opinions on privacy. The legislation would have to be amended to enforce our ability to deal with that information. That would be particularly true where the donor offspring knows which service provided the gametes.

Ms O'SHANNESSY: From a legal perspective as a minimum you would have to a look at a provision that would enable the providers to breach a privacy clause and their own confidentiality obligation as medical professionals. Second, you may need to consider a power of compulsion. Health privacy laws work by saying that these are restrictions but we enable you to release; privacy law never compels release. That might be a factor that needs to be thought through. As you would know, compulsion is more confronting to clinicians than enabling powers. That would need to be thought through as well. If the Committee is heading in that direction members might want to ask some clinicians what they think. Sometimes they prefer compulsion because it is easier and they have to do it. There could be arguments either way.

Mr McALLAN: The other issue is that different clinics may have retained records for different periods. They have been obliged by legislation to keep them only for seven years. They are obliged to keep them for 25 years from birth for the child, but the assisted reproductive technology providers do not have records for the child; they only have records on the mother.

CHAIR: And that is limited to seven years.

Mr McALLAN: Seven years for the mother. Most assisted reproductive technology providers keep all their records. That is my understanding, but I would have to confirm it. However, others may have stuck to their obligations under the legislation.

CHAIR: They could be limited to that seven years?

Mr McALLAN: They might have destroyed the records.

Ms O'SHANNESSY: It is a matter of availability.

Mr McALLAN: There is the integrity of the record and availability.

Mr GUY ZANGARI: Different levels of retrospectivity have been suggested from complete identifying information being made available to only information that the donor consents to being provided. What level of retrospectivity that exists impacts on the way information was collected or the type of information collected?

Mr McALLAN: The type of retrospectivity will impact on the way information is collected in the sense that if we have to seek consent there will be an administrative burden. There is no specific preference.

Ms O'SHANNESSY: I suspect we would still have to get the identifying information to link it.

Mr McALLAN: To provide the non-identifying information.

Ms O'SHANNESSY: There are research processes within health where we can combine identifiable databases when researchers ask for the information, but we de-identify it. A unit does that; it crunches it all together and gives it a new identifying number and sends it to researchers and no-one's privacy is compromised. Obviously that process, which is very secure, needs to have the identifiers to link it. I suspect we would have to collect that. The same issues of trying to figure what relates to what—which is part of what Greg said about the veracity of the data and knowing to whom it related—would come into play.

Mr GARRY EDWARDS: The New South Wales Government submission offers four possible options to consider regarding retrospective access. Are any easier to implement than the others; if so, why? Do you consider that any have particular merit; if so, why?

Mr McALLAN: I do not think that the ministry has a view on issues such as the merit of each of the options. We would leave that up to advisers such as the Privacy Commissioner in terms of retrospectively without consent. In terms of what is easier to implement and why, it would clearly be easier to implement if it were mandatory because we would not have to see consent—we would simply get the information and provide it to the inquirer. That would be the easier option. On the other hand, that does not obviate any other concerns; it is purely an administrative concern.

CHAIR: If the central register were expanded to include retrospective information as some submissions recommended there are likely to be issues relating to the health of individuals as well as the continued need to regulate assisted reproductive technology clinics as has been identified in the New South Wales Government submission. What are the main issues that would arise if the central register were expanded in that way?

Mr McALLAN: We already collect information about health and it is on the mandatory register. I do not see any major issue.

CHAIR: The information you have on your register at the moment was mandatory since 2010 and I am talking about if it was made retrospective?

Mr McALLAN: We could collect that information.

Ms O'SHANNESSY: I think there would necessarily be some practical administrative issues. We would have to have some legal capacity to do so whether it is by enabling legislation or mandatory legislation. Then I think there would be some practical issues of identifying who we need to get the retrospective information from because what we have going forward, some providers are registered, the system has been built properly going forward. There is not that comfort going backwards and I think it goes back to what Greg was saying in the first question about the integrity of the information. I think Greg said to me that in some of the very older cases a lot of the times it was general practitioners who might have been involved in the process. How do you identify them? I think they are the practical issues. I am cognisant of the fact no-one has done this yet so there are probably practical issues that need to be discovered. I think the best we can say is the further back you go the harder it will be and that is probably self-evident from what you have heard already.

Mr McALLAN: It works identical to the voluntary register. We would use the same matching process, then we would get the same variable levels of information.

CHAIR: We have no processes in place using DNA?

Mr McALLAN: No, not through NSW Health.

Mr NICK LALICH: The Government's submission also mentions the use of letterboxing services and contact preference forms. Both those options require an entity to administer them. Do you have any thoughts on the capacity of the Ministry of Health to manage this? What would be required in order for you to do it?

Mr McALLAN: The letterboxing service is similar to the Victorian system. It is a service where correspondence comes into an agency. They send it out under their address so that there is no contact unless requested. At the moment on our voluntary registration forms we already have contact preferences, like the levels of contact and the information. Should a match be made they can restrict the amount of information and contact so that already exists for us. I do not see an enormous amount of effort for going into it. It would depend on the volume of inquiries that we got to volunteer this information.

At the moment we have 11 offspring on the voluntary register and 14 donors. At the same period in Victoria from the commencement of its voluntary register in 2001 it had 48 donors and nine offspring and I attribute that to the fact that although the voluntary register only started in 2001, they had been operating since 1988 so there was much greater public awareness, particularly among donors, of the existence of the infertility authority. For us we have just kicked off so we have a lower profile of donors. In terms of offspring we have more than for the same period in Victoria.

Mr GUY ZANGARI: The recent government response to our previous inquiry into the inclusion of donor details on the register of births refers to a statutory review of the Assisted Reproductive Technology Act 2007 that is currently underway. Will you outline what the review involves? When will it be completed? Do you have any preliminary findings that you can share with the Committee?

Ms O'SHANNESSY: It is a five-year statutory review, the standard review of legislation. To date we are only at the stage where we have sought preliminary comments from people who are involved in those areas. There will be a discussion paper which we anticipate will be released shortly. It is designed to recognise the work of this Committee and to pick up on it and, hopefully, depending where we are in the process, we will be current with wherever you have got to. That paper will have to be signed off by the Minister so I cannot confine the Minister's discretion but we would hope to have it out by the end of this month or early June. The final report to Parliament, under the five-year review clause, has to be in by December.

At the moment this is only one of a number of issues the paper is dealing with. There are some interesting operational and ethical issues about the number of families or women who can access one donor. There are some issues about the use of people's sperm and ova after they have died. We have stayed away from this issue because we think this Committee is basically doing the work, so we are just parking it and saying, "Yes, this is an issue that is on" but it is not saying, "This is the Government's preliminary view", it is basically saying, "These are interesting and complex issues. This is an area that is changing so rapidly since the legislation was introduced, what do you think?" As I said, there should be a report in Parliament by the end of December. We would be happy to provide a copy of the discussion paper to the Committee.

CHAIR: That would be fantastic, thank you.

Mr GARRY EDWARDS: One submission expressed frustration at the passive nature of the current voluntary register, that is, donors or donor-recipients seeking to make contact with the other party are unable to have communication place on file but the communication would only be offered to the other party if that person themselves were to contact the register. What impact would there be on NSW Health if the voluntary register moved from a passive service to an active register conducting, for example, letterbox type services? I understand you have partially answered that part.

Mr McALLAN: Obviously it depends on volume. At the moment voluntary is low. If the offspring or donor wanted to collect information on the file awaiting the other party to consent then we would be able to maintain that information.

Mr GARRY EDWARDS: If it were to increase 100-fold, how would things work then?

Mr McALLAN: I would need more staff. It would still work perfectly well. We would be scanning the information and attaching it to files and awaiting the other person's contact.

Ms O'SHANNESSY: It is also about making it more electronic. At the moment the basic current register, they provide us information, it is entered to the register. We are looking at developing a database that will actually provide users to enter all the compulsory material directly in. That is a way of easing that administrative burden and clearly if we are headed in the direction of increased usage, you would not look just at old-fashioned administrative staffing issues you would look at other resources and mechanisms to deal with it.

Mr McALLAN: This database, going down the RFQ stage of it, we are looking online where each provider can log on, enter their own information or amend it if they discover an error. I am not promising obviously but there may be a possibility of having a module where identified and authorised users can get a log in once they have register on the voluntary. That may be a possibility in which case they could put whatever they liked onto it.

CHAIR: Do you think that Births Deaths and Marriages has a better system of database to control a register of this type rather than the Ministry of Health?

Mr McALLAN: I am not aware of its register, so I could not tell you.

Ms O'SHANNESSY: I do not think we would be able to comment.

CHAIR: The Committee understands that the Ministry of Health recommends that people who are seeking donor conception undergo some counselling. Who offers that counselling at present? How is it funded? Does the Ministry have any suggestions for how it might be funded in the future.

Mr McALLAN: At the moment it is provided by counsellors. I am not sure where they obtain them from, probably from the assisted reproductive technology [ART] provider. On our website we refer them to the Australian and New Zealand Infertility Counsellors Association [ANZICA]. With their consent we put them on our website and they would refer them to appropriately qualified people. At the moment that would be user-pays. We do not really have any view on the funding as such.

Mr NICK LALICH: The Committee has heard evidence about the value of DNA testing in establishing genetic relationship. Does the Ministry of Health have a view on the value this may provide or how it may work in practice?

Mr McALLAN: We do not have a scientific view, obviously, but in terms of identification it would run into the same problems as obtaining any information, I presume. You have to find the person to obtain their DNA in the first place so it might not necessarily assist in the sense that the further back you go the poorer the records are, so your ability even to find the person is reduced. As you come forward the records are better, in which case you might not necessarily need the DNA. We obviously cannot guarantee with evidence such as this that our match will be 100 per cent accurate because we are relying on records that are not our own.

Ms O'SHANNESSY: Part of that issue is, as we said earlier, there would need to be legislative enabling or compulsion to keep records. If you are talking about a DNA test that clearly raises issues about the donor consenting to the test. We have not looked into this area but just anecdotally you can look at the whole issue of genetics testing and counselling and getting access to information. They have very strong and complex processes around that because of all those issues. That to me, just on a personal level, would raise that issue. Similarly, the use of DNA in relation to databases that are used in criminal justice cases involves quite a complex legislative regime or guidelines regime. That would need to be considered if you chose to proceed without consent.

Mr NICK LALICH: The DNA would be another form of identification?

Ms O'SHANNESSY: It would be.

Mr NICK LALICH: Over time records could be incorrect or something could go wrong. At least if you have the same genetic information, as long as that is not mucked up as well somewhere along the line, at present that is the best way of identifying—

Ms O'SHANNESSY: Yes, but it is not like a paper record or a record held by a provider. It would involve, particularly for the older ones, identifying a sample to test, which brings in the whole issue much more closely about the testing of someone's blood and the implications that may have for relationships that they may or may not be aware of.

Mr GUY ZANGARI: What resources or experience do you have in undertaking public awareness education campaigns with sensitive issues such as donor conception?

Mr McALLAN: As you may be aware we have had a low-level campaign producing pamphlets and distributing information through GPs across New South Wales. The Ministry itself obviously has vast experience in running high-level more intense campaigns in areas such an immunisation, sexually transmitted diseases and HIV. I think the Ministry is well placed to produce more campaigns in this kind of area.

CHAIR: But you are limited in a way. They are only public campaigns, they are not targeted. For instance, if we opened up the opportunity to access the information about donors you could target directly to donors—let us say retrospective legislation in the future.

Mr McALLAN: I see no-one can target donors. They are hard to find.

CHAIR: Yes, we are struggling.

Mr McALLAN: That is why it would have to be a broader public campaign.

Ms O'SHANNESSY: I think you would turn to the expertise in the Ministry, which is largely in the population public health area. I would be turning to them to find out the best way to do that.

Mr McALLAN: Obviously they target groups for vaccination.

Ms O'SHANNESSY: Do you start with a broad public awareness campaign and then move in? That is expertise in a different type of area.

Mr GUY ZANGARI: However, with the campaigns you mentioned the department is well placed to go ahead with such a campaign given the experience you have, whether with sexually transmitted diseases—

Ms O'SHANNESSY: Yes, but of course it is a matter of prioritising what the Ministry—

Mr GUY ZANGARI: Of course.

Mr GARRY EDWARDS: I am not too sure about this question. If donor-conceived people were granted access to their donor conception information do you see any significant health-related or other repercussions arising from this?

Ms O'SHANNESSY: I would have thought that is what you are looking at.

Mr GARRY EDWARDS: That is why I said I was not sure about the question.

Mr McALLAN: Yes, I think it is basically your terms of reference. It raises issues that your other interviewees are better placed to answer.

Ms O'SHANNESSY: We caught the end of the previous evidence, which was very persuasive and very knowledgeable and much closer to the front line than we could possibly be. The problem in this area probably is mainly unqualified statement about donor families and donors because they are, I gather from the comment just made, very difficult to engage with. It is very difficult to move beyond the theoretical. That would be the main issue—how you would go about getting that information.

CHAIR: I think you were lucky you only caught the end of their comments because earlier they were not kind to the Ministry of Health in relation to data.

Ms O'SHANNESSY: I am sure.

Mr McALLAN: I have read the submissions.

CHAIR: Would you like to make any closing remarks? If not, thank you for attending. We may have other questions that we will send to you in writing and your responses to those questions will form part of the evidence from this hearing. Are you happy to do that?

Ms O'SHANNESSY: Yes.

Mr McALLAN: Yes.

(The witnesses withdrew)

(Luncheon adjournment)

JENNI MILLBANK, Professor, Faculty of Law, University of Technology, sworn and examined:

CHAIR: I welcome Professor Jenni Millbank to this hearing. Can you please confirm that you have been provided with the Committee's terms of reference and information about the standing orders that relate to the examination of witnesses?

Professor MILBANK: I have seen them, thank you.

CHAIR: Do you have any questions concerning these?

Professor MILBANK: No.

CHAIR: In what capacity are you appearing before the Committee today?

Professor MILBANK: In my personal capacity as a researcher with expertise in this area.

CHAIR: Have you provided the Committee with a submission and do you want that submission to form part of the formal evidence?

Professor MILBANK: I have and I do.

CHAIR: Would you like to start with an opening statement before we commence questions?

Professor MILBANK: I would. In the written submission that I have provided I have given some information drawn from our recent report, which I have also submitted to the Committee, and I have also responded directly to some of the questions in the Committee's terms of reference. In my opening statement I want to say a few things more directed to the level of principle of things that I think should guide an inquiry such as this. In particular I have been influenced by the recent Nuffield council's report on donor conception information, which I think is a tremendous resource and a very thorough and thoughtful, balanced inquiry into these issues. There are three main things that I want to touch on. Firstly, I guess framing the question as one of interests rather than competing rights between parties. Secondly, the idea we talked about in our report of facilitative regulation in which the Nuffield council frames as a question of stewardship—the rightful question of the Government's role in these issues. Thirdly, the issue of whether adoption provides the correct model for thinking about issues of information sharing in donor conception. If the Committee will indulge me I would like to say a few brief things about those questions.

CHAIR: Thank you.

Professor MILBANK: On the first issue of interests and rights the Nuffield council has a lovely quote in its executive summary where it states, "Talking about these issues of right is to present a conclusion rather than to have a process of inquiry and consideration and balancing of needs." It maybe strange to have a lawyer appear before the Committee and say rights talk is not very useful but I think a lot of the talk in donor conception has been about the rights of children and whether the rights of children trump the rights of donors. My position is that all parties of donor conceptions have interests and needs. The role of the State and the role of regulators, clinicians and everyone else is to think carefully about those interests and needs and to try at all times to balance them and to meet those needs. So I urge avoiding the language of rights on the basis that it overlooks that question. I think it also places the interests and needs of all parties as if they are oppositional; as if one trumps another, competes with another, has to be held to be more or less important. It overlooks the fact that in donor conception the interests and needs of all of the parties are deeply interrelated.

One of the things I draw attention to in my written submission is that parents are the guardians and interpreters of their children's needs when their children are very young and that speaking of the rights of parents and children as if they are in competition is quite misleading. In our research we found that all of the parents in our study were deeply concerned about their children's interest in or possible need for information at later points in their lives. We spoke to 20 parents of donor-conceived children—two of whom were actually pregnant at the time of interview. I also omitted to mention that we spoke to 10 embryo donors and four recipients of donor embryos. Although I think we conclude that embryo donors and gamete donors have slightly different interests and needs, we did talk to donors as well and those donors were also very concerned about providing information and what they framed as "leaving a door open" for offspring to make a decision at a later point. They thought about information in terms of doors that should not be closed, things that should not be concealed.

There was no point at which we saw parents ignoring or riding roughshod over the interests of the children. They were very keenly aware of these issues. I also think it is interesting if we look at the data from the previous Infertility Treatment Authority in Victoria, many more parents than children have gone through the voluntary registers and I think that is a trend that we are continuing to see in other jurisdictions as well. I am not speaking for parents or for donors; I am speaking for open disclosure and flexibility and support for donor-conceived individuals and their families. But I oppose retrospective disclosure and I oppose marked birth records on the basis that I do not think those things meet the needs and interests of either donor-conceived individuals or any other party in the donor-conception triangle. That was my first point.

When we talk about interests and needs it is easier to acknowledge that those interests and needs are really diverse and varied. Some children will want access to identifying information, some will not. Some children will want contact, some will not. Talking about things as rights makes it seem as if it is an absolute universal that all children will and must find their generic progenitors and be reunited with them. I do not think that the research, although it is very recent research from the United States, shows that that is the case. It shows that donor-conceived people have a very strong interest in knowing that if they want that information they can have it. That does not mean that they are all going to want the same information.

The other point I wanted to make about interests and needs is that the HFEA inquiry in 2011-12 published annexes on the results of their focus groups with members of the general public, parents and donor-conceived adults and young people. One of the things that I think was very interesting about the findings from those focus groups was a very stark difference in the perspective of donor-conceived people who had always known—they call them the "always-known group"—and donor-conceived people who had found out that they were donor conceived as young adults. They said that the always-known group had a much more laissez-faire attitude to information sharing, to identity questions. They described them as not bothered basically whereas donor-conceived people who had been deceived and lied to by their families about the circumstances of their conception had a much more passionate hardline interest in access to information which they saw as much more profoundly important to their identity.

When we are talking about the interest in information for some people it will be a crucial piece of information in their identity formation; for other people it will be a mere curiosity, it will not be fundamental. I think it is a mistake to take the experience of a group of people who have suffered under previous regimes as being emblematic or giving us a universal truth about donor conception. Again thinking in terms of interests, experiences and needs helps to identify that diversity with that group. The second point I wanted to make—and I will make it a bit more briefly—is the question of facilitative regulation or stewardship. In our report and in the Nuffield report we make very strong arguments for the role of the State as one that supports and facilitates families to make the right decisions for them, that presents them with the fullest range of options, the best range of current research and information but that fundamentally respects that it is parents who raise children and it is parents who make the decisions about how they raise those children.

A lot of very broadbrush analogies have been made with adoption in arguing for retrospective disclosure but the one I would like to draw attention to is State intrusion in family formation and the role of the State in past bad practices such as duress adoptions or closed-door donor conception regimes where States were not overlooking the needs of children, they were not unmindful of the needs of children; they absolutely thought they were doing what was best for children and they mandated it. When we are having policy debates about the role of the Government encouraging openness in providing information, we should be doing exactly that—thinking about encouraging and providing rather than mandating or prohibiting.

It is very important that we be mindful of the extent to which research in this area is very new and practice in this area is very new. Open disclosure in New South Wales has been practised for seven or eight years at a clinic level, the registry has been in place for three years and as far as I know no matches have been made as yet under the voluntary register. Victoria is held up worldwide as a great leader in this area. They have changed their register three or four times—it has gone through four different government departments and it is very likely to be bumped to a fifth one. We are learning as we go. I urge us to think very carefully about making change in this area in a way that is careful and incremental. That openly acknowledges that it is new terrain; we have to learn as we go. There have been mistakes made in the past and I dare say they will be made again.

My final point is about the issue of the adoption analogy. I have looked through a number of submissions that have been made to this Committee and I know that a lot of the openness movement draws from adoption literature. I think there are very important lessons to be learnt from the adoption context in terms of deception as well as coercion, but the issue of genetic links in donor conception is fundamentally different to that of the adoption experience. I urge the Committee to be very cautious about uncritically mapping across that experience. Adopted children have been born to a mother who relinquished them. They were taken, whether by consent or by duress, from one family into another family. Donor-conceived individuals were intended to be born into their family and were conceived with the assistance of a donor—a third party outside of their family.

Some donor-conceived people will want contact; some will want information. Some will see that genetic relationship as something of importance. Some will see it as a form of kinship or relationship; others will see it as a family friendship or as nothing even that significant. I am very cautious about adoption service providers positioning themselves in this field as the right agencies to provide information or intermediary services, support or counselling services. Adoption service providers provide what they call "tracing and reunion" for relinquishing parents in adoptions; there is no reunion with a donor because they were never united with them in the first place; they were never part of their family. I think it would be problematic to be using that experience or using those service providers in what I see as a fundamentally different context.

I think there are additional issues with the fact of a number of adoption service providers and post-adoption service providers being religious organisations. Those organisations have either opposed donor conception entirely in the past or they have opposed same sex family formation or single parent family formation. We know from the emerging research coming out of Canada and the United States that a lot of the families seeking contact with donor siblings, or seeking early contact, are same sex families and single parent families. They are more likely to think of donor-conceived siblings as part of their extended family and want to form bonds with those people. Having religious service providers providing that intermediary service I think could be an issue.

I also think that fertility counsellors who have worked in this field in Australia have worked really hard on this issue. They have thought a lot about it and they have done a lot of practice in it—actually a lot more practice in it than State agencies have. The Australian and New Zealand Infertility Counsellors Association [ANZICA] has done guidelines. A lot of clinics have put in place voluntary protocols for early contact or for donor sibling voluntary contact. They have thought about it a lot, and they have actually learned from trial and error with some of their practices as well. I think fertility counsellors are much better placed to do this kind of work if you are thinking about service provision because they have actually seen everyone in the triangle—they have seen donors, they have seen parents and they have seen donor conceived young people. They are more able to understand the context of donor conception and the range of needs and interests that take place in that field. Those are the three big things I wanted to say up front.

CHAIR: That was an extensive opening statement—which is great.

Professor MILBANK: It was rather long, sorry.

CHAIR: It has probably touched on a number of the questions that we have already formed, but we will work through those questions. There might be some areas where you can elaborate, or we may skip some if we think that you have already responded.

Mr NICK LALICH: Your submission notes that:

> Not all parents will want to make contact with other recipient families, nor with donors … we support consideration of the ways in which such contact can be made, while still respecting the privacy of all participants.

Could you elaborate on the range of options for contact?

Professor MILBANK: Yes. What I propose as I guess a middle path is a combination of approaches. One is the approach that the Human Fertilisation and Embryology Authority [HFEA] took in Britain where they approached all of their pre-disclosure donors, all of their anonymous donors, and asked them if they would re-register as identifiable donors. To me, before you mandate retrospective disclosure, it seems a logical step to ask donors. Instead of just telling them "We are now going to throw it open", say to them "We have learned from what donor conceived people have to say and this is why we want to do it." Re-registering donors in the way that the HFEA did I think is a very important step.

I think that the previous Infertility Treatment Authority in Victoria developed very good practice in one-on-one approaches when they had donor conceived people who wanted to make contact. Again, they were donors who did not expect that their identity would be revealed, and they made contact with them, explained the situation and provided counselling to actually make it clear what people were looking for. To mediate people's expectation, it was not, "Dear sir, you now have six children and they are all looking forward to you putting them through university", it was actually saying, "This person wants to know about this for this reason, and this is where they are in their life", so they could actually be clear about what people were looking for.

I think that that practice was a very good practice, and that could be developed into an active register so that when someone is seeking that information steps are taken to approach the individual and explain to them the importance of why that information is being sought, explain to them the limits of what is being sought and seek their consent, and then I think we are much more likely to see good results than if we throw in place retrospective disclosure. There are two harms that I see. One is that a lot of people who noticed would put contact vetos in place, and for those who did not, the likelihood of positive contact I think is greatly reduced because they are not prepared for it. So an active register, a process of re-engaging with donors who may have donated 20 or 25 years ago, some of whom are out there wondering what happened, would be much more constructive and much more likely to meet the needs of donor conceived people.

Mr NICK LALICH: You mentioned in the United Kingdom going to retrospective donors and asking would they like to re-register. What was the outcome of that? What percentage re-registered?

Professor MILBANK: It was quite a significant number. I do not have the number to hand, but I think it might be in the submission from the HFEA that you have received already. I do not think they made contact with all of them because they had lost details of some, but it was a goodly proportion who did re-register.

Mr NICK LALICH: And was it positive or negative? Was it "Yes, we want to", or "Thank you very much for your letter, but we do not want to be registered"?

Professor MILBANK: Most of the people who responded did re-register and, interestingly, the experience of the Infertility Treatment Authority in Victoria, where they approached I think 48 or 50 donors over time, all bar one of them accepted ultimately that their identity be revealed and most of them were prepared to make contact, so I think you can say that that process was successful.

Mr GUY ZANGARI: A number of submissions have made a distinction between the provision of information about donors and the issue of contact between donors and donor conceived individuals. What is your view on the retrospective provision of information, and I know you have touched on that as opposed to contact, so it is the provision of information compared to contact.

Professor MILBANK: Again it is worth unpacking the information. Identifying information is one piece of information. Actually non-identifying information can be incredibly valuable as well. Some people just want to know how many other kids are there, are there girls or boys, how old are they, or information about the donor's life. In the 1980s and early 1990s we know people got hair colour, eye colour, height, maybe religion, and that is it. A lot of donor conceived people say, "Even if I knew my donor's first name or what they did for a living". I think the HFEA has the pen portrait approach, and a lot of clinics are taking that approach, particularly for young people who are coming to terms with being donor conceived, like little kids, that information is really valuable.

We heard from one embryo donor who said that when she was counselled about her donation the clinic said, "Look, you might not hear from us for 10 years, but we might just ring you one day and ask you what your husband's favourite superhero is. We will do that because the child has asked us for that." So they had an open flow of mediated communication, which was non-identifying between the parties, but was basically structured around what did children need to know—and children want to know things like what is your favourite song and who is your favourite super hero. That information is very meaningful to them when they are 10 and they are coming to grips with the idea that this is not their dad.

CHAIR: But do you believe that at some stage that information is not sufficient; all it does is feed into that child wanting to know more as they get older?

Professor MILBANK: That information may be sufficient or it may not. There may be a 10-year-old who actually says, "I want to meet him now", and we say if you have the consent of both sides that should absolutely be possible. For some people—not for everybody—that kind of early contact is really important and meaningful, but thinking through ways in which a system like this can adapt for the whole range of needs, it is a really complex question and I do think to some extent clinics have been muddling through in terms of working out, as each new request comes in, how to deal with it.

CHAIR: We have heard from those that have attended this hearing and others that clinics are not very forthcoming, that they are not interested in getting in contact with donors from the past and almost want to shut that down straight away.

Professor MILBANK: Some clinics have taken the approach with newer donors that they have a box on their form when they are recruited, "Are you prepared to have early contact? Are you prepared to receive communications from the clinic? Tick yes or no." With older donors who did not indicate their readiness, some clinics say, "We can put a letter on the file, but we will not approach them", so their approach is passive contact in the same way that the government register in Victoria has been a passive register, and we heard exactly that from a number of parents, and donors actually—and recipients—who were very frustrated that they could not make contact. They just had the letter put on the file and it was like, well, unless the other person contacts the clinic, there will never be a match made. I think it is important to take a step forward from there to an active approach where, no matter what you have signed, you are given the option of some form of information exchange.

Mr GARRY EDWARDS: Could you give your views on the use of contact vetos?

Professor MILBANK: I have a view on it. I think if there were to be retrospective disclosure it is a logical safeguard, because if this is primarily in the service of donor conceived people presenting them with a really negative experience with someone who did not ever want to make contact with them, who has maybe changed their mind about their donation or has a new partner who never knew, or has had a religious conversion, or any one of those situations, where they are just not prepared for an approach and indeed might be quite hostile, a contact veto is important as well as respecting the donor in saying what they want their position to be. My preference would be that it actually did not come to that, but again, because there has been no retrospective disclosure, we do not know if they work.

Victoria has recommended them, but frankly, with Mr Google and Facebook, if someone has an uncommon name you can find them very easily, but if someone has a very common name you will never find them. I think registers that have not been in place for that long have not thought through questions like, "If we can follow through on the promise of registers." We had a number of people in our study who wanted to make early contact, not because they wanted to meet the donor but they wanted to know that they actually had that information if their child ever wanted it. They did not trust the government register in 20 years' time to still be able to find them and they were concerned to have a direct line of contact so that they could control that information. And I think more and more people are sidestepping those kinds of controls if they choose to, so I guess I query whether they can be effective.

CHAIR: Your submission recommends the establishment of an independent organisation to manage the voluntary register to facilitate donor recipient offspring contact, including counselling. I assume you are referring to something like the Victorian Assisted Reproductive Treatment Authority [VARTA]?

Professor MILBANK: I do think VARTA is a very good model.

CHAIR: I was just going to ask if you could expand on that.

Professor MILBANK: I think VARTA has a wealth of experience. Formerly they were the Infertility Treatment Authority [ITA] and I guess previously they straddled a more awkward divide in the sense that they were both a regulator and an agency providing consumer information to individuals. Now that VARTA's primary function is community education and support, I think they are a unique agency in Australia and the counsellors that they have working there have 15 or 20 years of experience each. They have thought very hard. They have run things like the Time To Tell campaign, trying to get people to voluntarily come on to the registers, and they have the experience of having counselled people through what they used to have in the ITA—they had a DNA matching service for people whose records had been lost or were inaccessible—as well as their counselling and facilitation of contact and communication with formerly anonymous donors. The range of their experience is really valuable and I think that having an agency that is just there for families, it is not about regulating clinics, it is not about being part of government as such, it is an independent agency to give information and counselling, would be very helpful.

CHAIR: You say that VARTA is the model that we look to. How can we improve it? I think there were gaps in counselling and how genuine that counselling was.

Professor MILBANK: Yes.

CHAIR: To me—and it is my own personal view—it felt like it was just a process that had to be ticked off for someone seeking information. Was it genuine counselling? The alternate was that I felt that the counsellors were going into these meetings quite blind because of the Privacy Act and what information they had prior to meeting with those donor conceived individuals seeking information. They are some of the negatives that I got from a very short period with them. How would you improve VARTA, or is there an opportunity to improve VARTA and, if so, where would it be?

Professor MILBANK: I think that is right, and I think again infertility counsellors have been grappling with the question, for instance, the difference between counselling and information giving, and the difference in roles being a contact intermediary, which is again different from counselling when as infertility counsellors you counsel people coming into the process, and working as an intermediary between different individuals in the triangle is a different role again. I think some specialisation around the different functions and thinking through those different functions is important. Obviously proper resourcing is important. The Victorian Assisted Reproductive Treatment Authority does an enormous amount with quite a small staff.

CHAIR: There is the release of information through the Victorian model. If one goes to the Registry of Births, Deaths and Marriages; there is a notation or something that tells you there is further information. To get the extra information I have to go through a counselling process.

Professor MILBANK: Yes.

CHAIR: That information comes back to me from the Registry of Births, Deaths and Marriages. We have heard there are blockages along the way and everyone is passing the buck.

Professor MILBANK: Yes.

CHAIR: Do you believe that the Victorian Assisted Reproductive Treatment Authority should be responsible to also give you the information?

Professor MILBANK: To manage the register, absolutely I do. I have struggled to find someone who has a good word to say about the transfer of those functions to the Registry of Births, Deaths and Marriages. I do not think it has been a success. Having a specialist agency to manage the information, to manage the register is important. I do not think it is a function for the Registry of Births, Deaths and Marriages. It is not a register of births, it is a register of legal parentage. They are a government records office. They do not do counselling or have special expertise in this area. It is instructive that if you go to the NSW Ministry of Health website and look for information on the New South Wales register, it says in quite strong terms if you are thinking of putting yourself on the voluntary register or accessing information under the register, you really ought to have counselling. There are two links, neither of which will take you through to any counselling. You cannot find the phone number of a counsellor on that website. I think that is not adequate service provision.

CHAIR: We agree that occurs in New South Wales, which is why we are having such an inquiry.

Mr NICK LALICH: The Victorian Assisted Reproductive Treatment Authority has a separate register. If we do that here, we know the funding is not there. The problem is getting the funding. If we can get the funding, it will be no trouble at all but we will find it hard to get funding. That is why it is tied to the Registry of Births, Deaths and Marriages. A lot of that information is already kept there.

Professor MILBANK: I would see that information as part of the bigger picture, including the provision of non-identifying information and proper facilitation and support for assisted reproduction more broadly, rather than just donor conception.

CHAIR: We are talking about registers and the collection of data. This Government and those in this area need to collect all the data that is available today, including identifying information. How we manage that is another question, and whether we ever release that information is another question. Our responsibility right now is that we collect and protect the data as best as we can.

Professor MILBANK: yes.

CHAIR: Currently that is not happening. A lot of that data is held with clinics, especially prior to 2010. There is an emphasis to have an agency of some sort that collects the data.

Professor MILBANK: I do think that is the issue. I am aware that the Fertility Society has a different view on the retrospective collection of that data by State agencies. I think it is noteworthy that the Human Fertilisation and Embryology Authority in Britain and the Reproductive Technology Council in Western Australia were able to put mandatory registers in place because they had a central collection point of that data for 10 or 15 years before then. It is a very different situation to put in place a mandatory central register when you do not have mandatory central collection of the information preceding it. I do think that is a much harder question.

CHAIR: Would you struggle to accept retrospectivity concerning data collection—

Professor MILBANK: Data collection.

CHAIR: —not dispersing the information?

Professor MILBANK: I would see that as much less problematic, but I would have to think about it more carefully before I gave you a concluded view.

CHAIR: That is fine. Thank you.

Mr NICK LALICH: Professor, your submission identifies confusion in the community about the current register and what information may be accessed. What measures do you suggest to alleviate community confusion?

Professor MILBANK: I do think that clear information services that let people know what the voluntary register does, where the information is, what kind of information is there is really important. In our study we found a deep level of confusion amongst people about information that the National Health and Medical Research Council guidelines say should be available to donor-conceived adults and to parents who have undertaken donor conception. It says you should be able to access the number of children, their sex and age. We had a number of people in our study who did not know that they were entitled to that information, or had asked for it and had not been given it. We had donors who did not know whether there had been offspring born of their donation. No-one ever told them; they were still wondering. That level of lack of information is really profound.

For that reason, I think when reforms go through, careful thought needs to be given about public education around those reforms, and that those reforms are done in a way that does not add to uncertainty or confusion or alienation for people who are frightened about what it means for them. The Victorian Assisted Reproductive Treatment Authority did ads, it has done podcasts, it has stuff on its website. It is a very useful way of doing something other than issuing a brochure, so having a specialist agency with a community education focus: people appearing on radio, podcasts of people who have been through it and to project them on its website or YouTube. There are a multitude of ways to communicate the information, but you cannot communicate that information until you have a clear regime that you are communicating. If it keeps changing, you keep adding to that uncertainty and the confusion.

Mr GUY ZANGARI: The Committee has heard evidence of the importance of collecting and collating all donor conception information in one place. I know you have touched on that. Regardless of any further decisions made about how the information may be assessed, in your view, what would this involve?

Professor MILBANK: A central repository of all that information?

Mr GUY ZANGARI: Yes.

Professor MILBANK: Getting the clinics on board, I guess, would be your first step in terms of the information that they have gathered over time and their own concerns about the privacy of their patients and the consents that their patients signed under earlier regimes. Interestingly, in Victoria they found that the hardest place to access retrospective records was the State office of records, because they had the most inflexible protocols for who was allowed to access the information. When clinics have closed down and handed them to the State office of records, they were the ones they could not get to. The clinics were prepared to go back.

CHAIR: We heard that from witnesses from the Ministry of Health today. It wants legislation that will enable it to not be concerned about the Privacy Act.

Professor MILBANK: Thinking that through in respect of putting all the safeguards in place about protecting those records and access to those records.

Mr GARRY EDWARDS: Your submission notes that the DNA-matching services should be made available to donor offspring born pre-disclosure. Will you elaborate on this?

Professor MILBANK: Yes. There are two models that I am aware of. The Infertility Treatment Authority used to provide donor-matching services, which was, in fact, largely donor non-matching services. Almost everyone they tested turned out not to be matched with the person they hoped or thought they were a match with. UK DonorLink was a voluntary organisation that has recently been de-funded in Britain. If those services are run properly they do provide a last port of call for people who if you are a donor-conceived adult and you do not know who your donor was, or if you have fears that you are related to someone who you are in a relationship with or even in a friendship with, so that basically you can rule that out. You get to do the test and find out. It is a needle-in-a-haystack process if you were hoping to track someone down, but as a rule-out measure, I know that the experience of the Infertility Treatment Authority was that it gave people some peace of mind. Although it ended up with disappointed young donor-conceived adults who were hoping they were brothers and sisters and were not; most of them were not related. I think it is an additional support among a range of supports that would be very useful.

CHAIR: I had a question in relation to the differences and similarities between the model concerning adoptions versus the donor-conceived individuals. You touched on all of that information in your opening statement. Is there something else you want to talk about?

Professor MILBANK: No, that is fine.

Mr NICK LALICH: What do you think of the model used in managing adoption information where there are several different agencies, both government and non-government, involved in the process of releasing information providing counselling to adopted people and their families?

Professor MILBANK: Again, I reiterate my concern about non-government agencies, particularly religious agencies, taking that role and my concern about adoption agencies taking that role, as well as the issue about movements of information, and who is allowed to know that, and who has a statutory right to access whatever and who does not. I know from talking to people who have worked in post-adoption tracing they have said, for instance, with genetic fathers, even if they are listed all through the file, if they are not on the birth record they are not allowed to reveal that information, because they are only committed to reveal what is on the birth certificate. There are all kinds of issues that come up when you have several parties working together in a field like this. My preference would be for a single specialist agency to do it and to have the statutory power to do things like access the electoral roll to get the information that they need.

Mr NICK LALICH: Regarding the identifying information, this morning we heard that in America they have silhouettes, pictures of the person before they reached maturity and things like that. Also, voice messages are left. In the non-identifying information, would you go so far as to tell the child asking that there is another six siblings from the same donor, thereby letting them know they have brothers or sisters? How far would you go with the non-identifying information? That is the least information I thought we should give to the person.

Professor MILBANK: My preference with any central register would be to keep it to a minimum or baseline level of information, whereas clinics themselves can develop a practice of gathering more information or a different quality of non-identifying information. Again, because of privacy concerns, if you have a central register with voice recordings and photos and so on, it is only a matter of time before somebody's facial recognition software can turn that into who they turn into. One of the concerns that is raised with non-identifying information is the extent to which the things that we think are non-identifying actually can be identifying. There are parties in our study who had taken non-identifying information, run it through Google and found identifying information. It is not impossible. I would keep a register to a fairly limited amount of information—that is, the basics—while supporting practice within clinics of sharing other kinds of information on request with the parties. I think things like the pen portraits are really valuable, as can be things like photos.

Mr NICK LALICH: Regarding the information that is given, we are looking at giving all the information to a person when they reach 18 by an addendum or a flag on their birth certificate or their driver licence that tells them there is more information. My understanding is that the Human Fertilisation and Embryology Authority in the United Kingdom gives you no information unless the person asks for it. If the person asks for it, they will give them everything they have. Which approach do you believe is the better one?

Professor MILBANK: I am deeply opposed to the addendum on birth certificates. It coerces disclosure and indeed might lead to inadvertent disclosure. We know from the experiences of donor-conceived people that inadvertent disclosure and late disclosure has been experienced as very harmful by some people. The Nuffield report makes the interesting point that Miranda Montrone makes in her submission as well, which is that for people who never know that they are donor-conceived, that is not necessarily a harmful thing. I am not advocating lying. I want to be clear about that: I am not advocating lying.

CHAIR: You might find that more common in a heterosexual couple having used a donor rather than a solo—

Professor MILBANK: In the history of humanity, it is a wise child who knows their own father. There are many of us generally who may have been mistaken about our genetic parentage who, nonetheless, grow up with the parents we know, happily loved with a completely functioning family. The research points to the fact that there is damage in relationships when there is deception and secrets and when secrets come out. Using a marked birth register as a way of either coercing parents into telling or enforcing late disclosure on children, I think, could be very damaging. The recent research, both from our research and other countries, does show that parents who are given information from the most recent research, the importance of telling and who are supported to tell, and tell early and tell often, do that. They internalise those messages and they are doing it. I think it would be a much more constructive path to take than the State enforcing that disclosure at a late point in an adolescent's life and in a potentially harmful way.

CHAIR: Would you like to conclude by making a statement?

Professor MILBANK: I stress my key themes: building a range of information and services and a supportive environment which respects the needs and interests of all the parties in the donor-conception triangle and which allows parents to care for and raise their children in the way they are best able.

CHAIR: We may write with further questions. If you are happy to reply to them your responses will form part of your evidence and be made public. Are you comfortable with that?

Professor MILBANK: Yes. Thank for hearing my evidence today.

(The witness withdrew)

DAVID HANDELSMAN, Director, Andrology Department, Concord Hospital, affirmed and examined:

CHAIR: Welcome and thank of you for appearing today before the Legislative Assembly Committee on Law and Safety. Have you been provided with the Committee's terms of reference and information about the standing orders that relate to the examination of witnesses? If so, do you have any concerns or questions?

Professor HANDELSMAN: I have been provided with a copy and I have no concerns.

CHAIR: In what capacity are you appearing before the Committee?

Professor HANDELSMAN: I am the head of the Andrology Department at Concord Hospital. I am providing evidence as a spokesman for the department because we have a unique perspective. For 35 years Ann Conway and I have been continuously and directly involved in sperm donor recruitment. As I stated in the submission, we have a distinction in that virtually every clinic has the same doctors and clinic staff recruiting donors when their primary responsibilities are to the recipients. If it were a legal matter—and it has become a legal matter—it would be completely unacceptable to have the same representation for the recipients as for the donors. We recognised that long ago for other reasons and we have been completely independent of any clinic or treatment service. We almost uniquely represent the interests of the donor, and that certainly was not true in Victoria and many other places. That is why the title of the submission is "In defence of the sperm donor". The donor is a shadowy figure who is not understood. A lot is said about the donors, but we have direct experience in this area. We have recruited and screened 600 to 700 men of whom 200-odd have become sperm donors with at least one child. More than 90 per cent were before 1997 when we changed and anticipated the State Government's legislation.

CHAIR: Sorry to interrupt, but I simply wanted to know the capacity in which you are appearing. You will be invited to make an opening statement.

Professor HANDELSMAN: I am sorry, I just launched in.

CHAIR: I am happy for you to make an opening statement.

Professor HANDELSMAN: I have said most of what I wanted to say. The main thing I want to say in addition to establishing the grounds for being here is that we know directly from the donors with whom we have had direct contact and from other related experiences that many of them would not have been donors if disclosure had been forced on them. They are innocent, altruistic parties and I gave them advice—as did Ann Conway—when they were providing sperm that it was a one-off, obligation-free donation like a blood donation. In fact, the State-decreed forms were very similar for many years. They had the expectation that they would not be contacted or approached. That was the understanding. We may look back and disapprove of it now with hindsight, but they are innocent parties and they are not represented by anyone else. They do not have a lobby group and they have no-one to speak for them apart from us. To a certain extent the clinics also speak for them, but with a divided responsibility. Even then, they agree with us that they should be invited and not legally oppressed into retrospective disclosure.

Before the last election when NSW Health set up the voluntary register it outlined an advertising campaign to let donors know that they could take part and change their original agreement at their own discretion. We took part in briefings about that campaign but it never eventuated. That is the proper way to do it—to ask people to change their mind rather than to take the lazy, legal and oppressive route of compelling them to do it. They are innocent parties in this and many of them will agree, but not all. I do not think it is fair to those who do not wish to have their life troubled now. Our lives change over 20 or 30 years and some of them may be in second marriages or they may be ministers of religion for whom this would not be an acceptable thing to do. We cannot say that on average there should be disclosure and force it on everybody. We do not do that to the families, half of whom have not told their children that they are donor conceived, so why would we force disclosure on donors?

CHAIR: Have you provided the Committee with a submission and do you want it to form part of your formal evidence?

Professor HANDELSMAN: Yes.

Mr NICK LALICH: My question follows on from your statement. A number of stakeholders have argued that the promise of anonymity given to the donors in the past is invalid because the people born as a result of donations were not represented when such agreements were entered into—they were not even born. Can you comment?

Professor HANDELSMAN: If the offspring have a gripe it should be with their mother, who chose to go down this route. Given the information provided, the donor made an altruistic gift or a gesture that had no strings attached. It is not reasonable; we would not do it in any other setting in the community. We would not simply take a contract and void it because of someone else's wish. We could not run businesses or any other human affairs if every contract was subject to people saying subsequently that they regretted it or that they were not there to comment. It happens and it is not the greatest tragedy. I can certainly understand and appreciate that the offspring would like to know. However, reasonable ends do not justify any means, and in this case the means are forcible retrospective disclosure. That is not the way to do it. Many donors will agree to change their consent agreements, but they have to be asked, not bludgeoned into it.

Mr NICK LALICH: How far would you go in providing non-identifying information?

Professor HANDELSMAN: It has always been available. Since we started we have made it known to donors that they could get non-identifying information on the number and sex of children born. We have also always provided non-identifying information to the offspring.

Mr NICK LALICH: You have no problem with that?

Professor HANDELSMAN: No, and never have had. It has always been available.

Mr GUY ZANGARI: Thank you for your submission and your time today. The Committee has heard evidence of the importance of confidentiality and faith in the doctor-patient relationship. In relation to the issue of gamete donation, is the donor considered a patient in the same way as the person receiving the fertility treatment?

Professor HANDELSMAN: That is a very interesting philosophical question. I cannot answer that in any definitive way except to say that our department is part of a hospital and everybody who walks in the door gets a medical record number and becomes a patient by virtue of that because they have to have certain tests and procedures. In that sense they are a patient, but they are not a patient with an illness. We also do medical research with human volunteers who are not patients, but they also become "patients" of the hospital because they are participating in activities that the hospital conducts.

Mr GARRY EDWARDS: Can you clarify the status of the agreements made with the donors? For example, were they made with the doctor or the clinic? Do you have an example of such an agreement that you can show the Committee?

Professor HANDELSMAN: We have consent forms that go back to the beginning of the program. Consent is obtained in two parts. Part of it is verbal discussion: we explain the situation and what will happen. That is important. The consent form is usually a few specific points that they sign and agree to.

Mr GARRY EDWARDS: Would you classify that discussion as a form of counselling?

Professor HANDELSMAN: No, it is information towards consent; it is not counselling. You could loosely call it counselling, but essentially it is implications information. That is probably how I would describe it. We have consents and I can provide copies, but I would need a written request because they are hospital documents and the legal people would have to agree. I cannot see any problem, but they are not mine to give out without the health service's agreement. The consent form they signed always had a statement that the hospital would not voluntarily disclose their identity, full stop. There was no mention of coming back to them or them coming back to us. We used to tell them that if they wanted non-identifying information about outcomes—the number of children and the gender—they could contact us at their discretion. However, as we pointed out, they are not patients so we did not have a routine follow-up as we would with a person suffering an illness. We made no arrangement to follow them up.

As it happens, we do a great deal of sperm cryopreservation for cancer patients who are undergoing treatment. We must follow them up every year to make sure they continue to need storage. If they do not, we can discard the sperm and make room for more. We have a lot of information on tracing people in the same age group and it is a complicated task. They are a very mobile population and they are not easy to contact. Even if you decreed that everybody had to be contacted you would not find everybody. Some would be overseas, some would have changed their name, some have very common names and so on—they might even be in jail. We would confront all manner of difficulties.

CHAIR: You said earlier that donors do not have a lobby group or a voice and they are an innocent party to this yet the Committee has had two inquiries around this issue and donors who want to speak on their own behalf or on behalf of other donors do not come to the inquiry. This Committee hears only one side of the story.

Professor HANDELSMAN: I could not agree more.

CHAIR: It has been very hard for the Committee to engage them. Is there an opportunity for this Committee to ask you to facilitate targeting and getting in contact with some donors to come and voice their concerns?

Professor HANDELSMAN: The short answer is I agree with you completely. I think what you have said is absolutely right. You do get some lobby groups like the Donor Conception Support Group that have two or three donors who are very vocal and exceptional. We do have a list of donors but they basically just want to go about their lives in their own way. They do not have a common view. Some of them would agree to be in contact but some would be very indignant. When it came up some time ago in the Senate inquiry we got phone calls from them very angry and indignant saying, "Don't you ever disclose my name" and that sort of thing. Now that is one end and the other end is the people who want to come and talk about it. The problem is that they do not form an identifiable group. I say exactly what you said that they do not form an identifiable group so you can only get by inference what they think.

We do have the unique ability that we have seen the same people, particularly Anne Conway and myself, for 35 years. We know them. We have seen them all personally. I can tell you that most of them typically were affected by infertility through their friends. They knew some couple who could not have kids so their wives often would tell them, "Why don't you be a sperm donor?" They have had their own family. They were not students; these were often men who just wanted to help, to give a donation like a blood donation and that is it.

We may look back on that say that is not a good idea. In fact, when the disclosure came in, whereas previously we could get many men to do that, just like you did with a blood donor drive, it was almost impossible to get donors. Eventually we had to shut down the program because we could not get anyone. That is using the same people, the same clinic, the same procedures to get it. The fact is that many of them just simply gave a gift, like you give a blood donation to somebody. They do not want to be engaged with it any more—some, not everybody. But we must not assume that they all want to do it or will be willing to do it. Some will be very annoyed and very angry at it.

CHAIR: Maybe 30 years ago those donations went to heterosexual couples, therefore, it was easier to hide that a child was donor-conceived whereas these days single mothers and lesbian couples choose to go down this path. The kids grow up knowing that there is not a father figure so therefore the demand for further information is growing.

Professor HANDELSMAN: I agree with you. I am sure you are right. What I can say from our clinic is that before 1997 we did not treat single women or lesbians. All of those ones where there is an anonymous permanent anonymity only affected heterosexual couples of whom about half do not tell their kids, at our best estimate. The later years, when the treatment of single women and lesbians was introduced, although the law had not changed we and most clinics had anticipated that and made it clear that they have to be prepared to do it. That was not the basis of law; it was the basis of their agreement to be a donor. At least for our clinic that is not an issue and I do not think it is much of an issue in New South Wales actually because of two things that went hand in hand: the end of truly anonymous donations coincided with or even preceded roughly when single women and lesbians became acceptable patients.

CHAIR: If the Committee were to exclude a group, be it the heterosexual couples getting a donation from a group of people, then there would be less—

Professor HANDELSMAN: That would be the compromise that I think we could live with. Personally I prefer to stick to the idea of no forcible disclosure.

CHAIR: I am just suggesting it as an option.

Professor HANDELSMAN: It is an interesting idea and I have got to say we have not talked about it in our department. But because of the way in which it shakes out, if you excluded heterosexual couples from forcible disclosure, because in half the cases they do not even know, we would have almost no problem with that. I think it is understandable that where there is no obvious father—

CHAIR: The Committee has heard that in those cases they are telling the donor-conceived individual the story.

Professor HANDELSMAN: They have no choice. Kids go to school and are asked, "Where's your father? What happened to your father?" I think that that is understandable and I do not have objection to that. Even then I think it is still better to ask donors. We may have had donors that we stored in 1995, they were there for a long time and then we used them in 2005 when there were single women and lesbians. I am answering off the top of my head with that and there could be complications with pre 1997 donors —in fact, if sperm is stored for a long time it may not be quite certain.

CHAIR: The Committee has heard evidence about making it voluntary rather than mandating it by government that the take-up from heterosexual couples would be a lot lower than the other two groups.

Professor HANDELSMAN: Correct.

CHAIR: You could possibly get even close to 100 per cent from the other two groups.

Professor HANDELSMAN: By anecdote rather than first-hand experience, I think that some single women and lesbians simply do not want to get involved with a donor. They have that view that they do not need a donor in their life. It would not be 100 per cent but I agree with you it would be much higher there than in the heterosexual.

Mr GARRY EDWARDS: Professor, you mentioned you had a discussion with the donors before they signed an agreement. In terms of non-identifying information and retrospectivity, are you able to provide through that discussion a fairly substantial and thorough medical history of the donor? For example, I am about to become a donor, you interview me, and in that interview do you extract from me a thorough check of my medical history?

Professor HANDELSMAN: Yes, and that information was not typically given to the recipients because they were not particularly interested in it but it was always non-identifying. Therefore, recently in a request through the health district we have made it clear that that information can be provided as part of non-identifying information. We have always given other non-identifying information; it is just that the recipient, the potential mother, was not really interested in whether they had hemochromatosis. We would have that screening information but we can add more non-identifying information that has been available before, but it should be non-identifying.

CHAIR: The Committee heard this morning the definition of "non-identifying" information. We heard that in the United States of America it is quite broad what they offer as non-identifying information compared to some States here.

Professor HANDELSMAN: I agree very much with the previous person being interviewed who said that the term "non-identifying" is very loose. If you consult Dr Google you can find a great deal. Out of curiosity I went to a private investigator who is not bound, as you probably realise, by what is and is not legal. I said, "I will give you a date of birth and a name" and he said, "Within 24 hours I will tell you where they are". What is "identifying" and what is "non-identifying" is all a matter of degree.

CHAIR: So that broadening the definition of "non-identifying" might be of concern?

Professor HANDELSMAN: It depends. We broaden it with medical history information and it is pretty neutral. By definition if they had a medical disease they would not be a donor. I would like to take it on notice.

Mr GARRY EDWARDS: Maybe they were not aware of one at the time as their parents had not told them, "By the way, there is a family history of testicular cancer".

Professor HANDELSMAN: If they did not know it then we could not know it. But we have had two instances in 30 years: one an offspring was born with a genetic disease that was not present in the mother. We went back to check the donor and his family and it was not present there either. It was just a new mutation that occurred in pregnancy. We had another instance of a donor coming to us and saying he had a disease which had only been picked up 20 years after he had been a donor. We then passed that back to the clinic to take it up.

Mr GARRY EDWARDS: Can that be incorporated as a more active program?

CHAIR: To get updates around medical issues specifically?

Professor HANDELSMAN: It is hard to do. It is not that easy if you take, by definition, carefully screened, perfectly healthy people as donors to incorporate them into an ongoing screening program. Maybe with new donors now under the full disclosure regime, yes, it is possible. But, in retrospect, I do not think so. Mostly the donors have goodwill and if they have a disease that is what happens. One guy came to us and told us that he had something new happen. It was not a terrible disease but it was something.

Mr NICK LALICH: In your submission you stated that a voluntary register has not been effective so far in obtaining donor information. Do you have any suggestions of how details of this register could be publicised to encourage more people to register?

Professor HANDELSMAN: Clearly it needs a publicity campaign. The Health department recognised that when before the last election it called all the ART providers in and said, "How are we going to do this?" They had an advertising person there who they were briefing as to running a campaign to go past donors: Please consider registering. We went through all the scenarios. Can we get a past donor to do it? They were going to get an actor to do it and so on. It would not be hard if the will was there. It would need a publicity campaign. A health district has contemplated trying to do it but we really are only a small part of the picture. It should be done on a State basis. I think it can be done that way.

I should say though that not only is the voluntary register almost invisible to the community but also the parts of it that are actually operating are not terribly well run. I had a donor ask me, "Should I register with it?" He said, "I am very concerned if I give my information to anonymous clerks in the government if they will handle it properly." I said, "Do your best". Frankly, my experience with them is they were anonymous clerks, mishandling it, repeatedly making mistakes, misaddressing, all sorts of mistakes happening all the time. It is not a very well run operation.

CHAIR: We know that the public awareness campaigns are not working and are not hitting the target they are trying to reach, like most public campaigns. Is there an opportunity to work through people like yourself and the clinics to go direct to those donors?

Professor HANDELSMAN: One of the issues I have put in my submission that I think is important to bring out, and this is a good opportunity, is that it is not a neutral matter to go to donors. You know yourself if someone rings you up and leaves a phone message, or writes you a letter, it is quite likely that your friends, family or if it is at work your workmates may wonder, "What on earth is this?"

CHAIR: One witness told the Committee a letter is written along the lines of "Dear Mr Smith, you had contact with Concord Hospital between 1983 and 1997. Could you please contact the hospital?"

Professor HANDELSMAN: We would not do that. Frankly, if someone were to write a letter like that to me my wife would say, "What contact did you have?" "What is that all about? What illness have you got? What's going on?" In many cases, the partners may open the letter for them. You immediately void the privacy by making such a contact. You cannot write a letter. I do not believe you can leave phone messages. As I said, we have a lot of experience with tracing men of the same age group where we have to follow them up each year.

You cannot do it without involving their family, friends and people at their work. All of those things immediately violate their privacy and the privacy is lost.

CHAIR: There is no real opportunity right now to make any contact anymore with donors?

Professor HANDELSMAN: Not without breaching their privacy. It is not that there is no way to do it but the way to do it is with a publicity campaign. You also have a realistic expectation. We found we offered all of them a chance to find out if there were any outcomes. Very few of them ever did. The likelihood is that many do not want to do it, so you will have a publicity campaign and maybe 30 per cent, if you are lucky, will contact.

CHAIR: That is a good number, I think.

Professor HANDELSMAN: As I say, a lot of them just simply will not. You cannot expect too much from it but you will find people who will do it. I think that is the way to do it where you are doing it at their volition, at their discretion and not oppressing them into doing it.

Mr GUY ZANGARI: The Committee has heard evidence of the importance of collecting and collating all donor-conception information in one place. Regardless of any future decisions made about how the information may be accessed, in your view what would this involve?

Professor HANDELSMAN: If we can judge by how the voluntary register has operated, which has been hardly a shining example of tact, discretion and efficiency, the idea that it or its successor would collect all the information and handle it from thereon fills me with a bit of dread, frankly. I do not think I would have a great deal of confidence in that.

If there was a more specialised agency maybe with people who had been involved in reproductive medicine and understood some of the issues—at present the register is run by well-meaning people in the Health Department in a section that has nothing to do with reproductive medicine. They learn on the job but I do not think they have the same appreciation that, say, nurses who had worked in an IVF clinic would have. I am not an enthusiast for that. I think the doctors established the rapport in the first place and the donors have that degree of confidence that that is an inviolate contract. To hand that over to a public agency you would have to have a lot of confidence in that public agency. I am not totally against it but I am sceptical that it would work in the way people expect.

CHAIR: Further to that question, we were talking about retrospectivity. If we were going back to past donors to collect information, not disperse information, do you think we would have a higher rate of—

Professor HANDELSMAN: You do not have to go to the donors. It depends what information you want. We have some of it. I am not sure which information you are thinking of.

CHAIR: You have some of it and so do a lot of the clinics, but does the central register have that information? We have it since 2010.

Professor HANDELSMAN: No, it does not.

CHAIR: We as a government should protect information for the future.

Professor HANDELSMAN: Yes. A government has already legislated that the information must be kept for 50 years. That is already the law since 2010.

CHAIR: That is since 2010. I am talking about retrospective changes going back to try to protect information that we know we are losing each and every day. We hear examples of it being lost, of clinics closing down and in some clinics it has been deliberately destroyed.

Professor HANDELSMAN: I appreciate the dilemma. We would never destroy information, but I know that where that is done it is done for precisely the reason that the doctor at that clinic had no confidence that his records would not be seized and disclosed compulsorily in the way in which we are discussing it now. That is the reason they do it; it is the only reason they do it. You should bear in mind that it is a vicious circle if you make it clear that you want to seize the records. We would certainly never destroy our records but I would not want to say there would not be a single doctor who would not do that out of a sense of obligation to the privacy that they entered into in all good faith.

CHAIR: Fair comment.

Mr GARRY EDWARDS: Do you have any figure on the numbers of donors or donor-conceived people born before and since 2010 when the laws on anonymous donation were changed?

Professor HANDELSMAN: No, I am afraid I do not. The best information I have is informal. A number of the clinics met to consider how to make a submission to this inquiry and, just [from discussion] around the table, I think there were probably 600 or 700 men who had been donors who produced at least one child.

Mr GARRY EDWARDS: Before?

Professor HANDELSMAN: No, I think that is in total. I would not call that very reliable information. It is just rough. Our information is that we screened 600 or 700 and a bit over 200 produced at least one pregnancy and about 90 per cent of those were before 1997, not 2010. They were the ones who had complete anonymity. I would say we are probably talking about 600 or 700 donors. On average they probably produced two or three children. You can roughly estimate it like that.

CHAIR: You commented earlier that since we changed the rules about donors remaining anonymous you had seen a drop-off in the number of donors.

Professor HANDELSMAN: Oh yes.

CHAIR: A significant number? Did you say your program, closed because of it?

Professor HANDELSMAN: Yes. We used to have a small advertising campaign, often just local newspaper advertisements saying we needed donors and we would get dozens—30, 40, 50, a hundred even. As I said, we eventually got 600 or 700. When the disclosure requirement came in it went down to a trickle. From 1997 onwards till we closed it eventually because it was futile to try to recruit we would not have had 10 donors. We probably had five or six in eight years where we had had 600 or 700 before that. There was a 95 per cent drop-off probably. That tells us that the disclosure requirement had a very big influence on that and that many of those men who had given before would not necessarily have done it if they had been expected to disclose. They just would not do it.

Mr GARRY EDWARDS: Are you aware that a lot of people may now have gone offshore to anonymously receive donor sperm?

Professor HANDELSMAN: Yes. There are websites in Australia where people can make contact with sperm donors. They buy sperm from Denmark. There are at least two programs in Denmark and several United States clinics that sell sperm. People do go offshore. My understanding is that that has not been legal since 2010 but nevertheless it is done and often in a way that bypasses clinics or hospitals. It may be done fairly informally it is just insemination not involving IVF procedures.

CHAIR: We touched on this earlier on today but I will go through it again. Many of our submissions and a lot of witnesses have talked about the current model with adoptions and we saw retrospective legislation introduced to deal with adoptions and the way that agency gets in touch with biological parents, the counselling services and so on. Do you have any comment on that if we were to go down the path of retrospectivity and adopt a template such as the adoption template?

Professor HANDELSMAN: One of my pet irritations is using an adoption analogy. It is not an appropriate analogy to donor insemination. In every adoption there is a relinquishing mother. It was always a tragedy of some sort and many of them very bitter and many of them affected the mother's life. Reuniting an adopted child with a relinquishing mother, maybe a father as well, is a great good, which just does not occur in donor insemination. There is no central tragedy in donor insemination, there is just an altruistic gift—a gift like a blood donation intended as a one-off, obligation-free gift. That is all. The drive to do it and maybe even the drive to force retrospectivity—I was never involved in adoption but I would probably have similar reservations about it. It is a little bit more understandable where you are reuniting a tragic relinquishing mother with her child. It is just not the case in donor insemination.

Mr NICK LALICH: I think the witness has answered the last question I intended to ask, but I will ask it. The Committee has received evidence which compares the situation of donor-conceived people wanting to access genetic information with that of adopted people. Would you outline your understanding of the main difference or similarities?

Professor HANDELSMAN: I think it is fundamentally different. It is a very superficial analogy and it is misleading and emotively tendentious.

CHAIR: They use it for their argument for retrospectivity more than anything else.

Professor HANDELSMAN: It enriches some arguments but I do not think it is really that material. In any case, we are talking about individuals.

CHAIR: Would you like to make any closing remarks?

Professor HANDELSMAN: No, I think you have given me a good hearing. I have passed on what I can. If you want a copy of the consent forms, if you write to me I will provide you with the exact wording.

CHAIR: Thank you for appearing today. If we have other questions we will write to you and your replies will form part of your evidence today and will be made public. If you agree to that it will be great.

Professor HANDELSMAN: Thank you.

(The witness withdrew)

DAMON MARTIN, Manager, International Social Service Australia, and Secretary, New South Wales Committee on Adoption and Permanent Care Inc. affirmed and examined:

CHAIR: Welcome. I acknowledge that you have been here for some time listening to some of the witnesses and I thank you for taking an interest. Can you confirm that you have been provided with the Committee's terms of reference and information about the standing orders that relate to the examination of witnesses and do you have any questions concerning these procedures?

Mr MARTIN: I have received them and I have no questions.

CHAIR: In what capacity are you appearing before the Committee?

Mr MARTIN: I am the manager of the New South Wales office of International Social Service Australia. We are one of the four government-funded post-adoption services in New South Wales. When I wrote the submission I was the Chair of the New South Wales Committee on Adoption and Permanent Care but I am now the Secretary.

CHAIR: Have you provided the Committee with a submission and do you want that submission to form part of the formal evidence?

Mr MARTIN: Yes. There is a submission from both International Social Service Australia and the New South Wales Committee on Adoption and Permanent Care.

CHAIR: Would you like to make an opening statement?

Mr MARTIN: Something fairly brief, just to put to the Committee that I do not think you can underestimate how important it is for donor-conceived people to know their family and medical history. This is information that the majority of us just have and we have the luxury of taking it for granted. I want to stress that point. There are a lot of similarities between donor-conceived people and adoptees. I also acknowledge there are a lot of unique differences as well. The most obvious similarity is the issue of identity. There is also grief and loss and family relationships and contact.

We know that donor-conceived practice and adoption have both been shrouded in secrecy but the world of adoption has changed significantly over the past 30 or 40 years and we have embraced a real spirit of openness. We know from working with adoptees now that without information about their family and medical history they can have longstanding identity issues that continue to manifest themselves. I believe the world of donor conception has a lot to learn from the mistakes that we made in adoption and now should really embrace the spirit of openness. When I say that I mean all donor-conceived people should know they are donor-conceived and all of them should have the right to access family and medical history. This is a basic human right.

CHAIR: Would you go further than that? Are you speaking about non-identifying information?

Mr MARTIN: Exactly.

CHAIR: What about identifying information?

Mr MARTIN: Yes, that as well.

Mr NICK LALICH: I will ask this first question but it seems to be in total opposition to what I just heard the witness say. In your submission you say that International Social Service Australia does not support the provision of mandatory counselling for donor-conceived adults to access their information. Can you comment on this point?

Mr MARTIN: We believe it is a basic human right to have access to information. We believe counselling and support services are really important but I would not go so far as to say it has to be mandatory.

CHAIR: We know from the Victorian model that if you were to go to the Registry of Births, Deaths and Marriages the first tick would mean you would have to go off to counselling, which could be tick-a-box counselling rather than genuine counselling. That process is to make sure you have had some sort of support before you are given that information. I accept that you do not think it should be mandatory but there is a process for counselling to prepare somebody for information that is technically life-changing, especially if one gets that information in one's later years.

Mr MARTIN: I agree. In terms of the adoption field we have four different government-funded post-adoption providers and they are non-government organisations, and they can go through their adoption agency as well. We really do promote support. It is an emotional rollercoaster journey in terms of coming to terms with your identity and your family history. We do really promote using intermediaries, using support services, having support.

CHAIR: But you do not use that as an obstacle to stopping one from getting that information early on.

Mr MARTIN: Yes.

Mr GUY ZANGARI: Can you give the Committee an overview of the steps your organisation takes, in particular what your organisation does to protect the privacy of both parties when initiating contact in adoption reunions?

Mr MARTIN: We are all for—the practice is not just for ISS Australia but for all the adoption providers in New South Wales—we really promote using an intermediary service. We believe it is the least intrusive approach and we believe that it respects the other party's privacy. Basically if you are counselling someone prior to them trying to have contact with another party you are going to be talking to them about outcomes and things like that. These are all adults we are dealing with. People do not go up and try and force themselves on people because they know that is not going to get a good outcome, but if you can have an intermediary to really share the point of view of the other party so they can understand what the person's motivation is.

For instance, in adoption you might be approaching a birthmother who has just gone, "Look, I can't handle any contact. My child was forced from me 30 or 40 years ago. This is deeply traumatising for me." But it is also for them to understand the adoptee's need and to have a skilled professional say, "Look, this adoptee has never seen anyone that looks like them. They do not know anything about their family or medical history. They do not know who they are or what they are about. Is there any way that some information can be passed through whilst still protecting your privacy and making sure you have some support at the other end?" We really promote intermediary services. We think it is the least intrusive way and it respects both people's lives.

Mr GARRY EDWARDS: Your submission on behalf of the NSW Committee on Adoption and Permanent Care notes that some donor-conceived adults are accessing adoption-support services. Can you give the Committee an idea as to how many might be doing this? Do you feel that post-adoption support agencies are able to offer counselling and support services to donor-conceived adults?

Mr MARTIN: They have not got any actual numbers. In terms of our organisation it has been a handful—I know that the Post Adoption Resource Centre [PARK] with whom we work very closely it is probably more than a handful. The fact is that there is not a funded-support service out there for donor-conceived people. Through the adoption world we have had years and years of facilitating contact, reunions—I know they might not use the term "reunions" per se. I should probably backtrack and say that some have been talking in this hearing today about the adoption model being perfect; it is still far from perfect. We have major issues with birth fathers because birth fathers are not named on birth certificates probably 95 per cent of the time in adoption cases so they are not able to access their information.

Adoptees are only going on identifying information down their maternal line. So there is still a real issue there—very similar to donor-conception in the same sense. You have got a lot of fathers in the adoption world, one-night stands who cannot remember. We are still trying to work with them in terms of facilitating that form of contact. Adoption professionals understand the needs of adoptees in a lot of these contact situations—very similar to donor-conceived people. It is no coincidence that in the UK they set up a model: UK DonorLink. That was set up within After Adoption Yorkshire. There are a lot of differences and you would need extra training to understand the unique differences in the needs of donor-conceived people but I think post-adoption professionals are the closet equivalent field.

Mr GARRY EDWARDS: Do you think you are able to deal with donor-conceived adults adequately or should we be looking at some other agency?

Mr MARTIN: I think we are. As I said, we need extra training to understand the unique differences and needs of donor-conceived people. There are a lot of similarities between the two but there are some differences. In terms of understanding facilitating contact and issues around identity, these are things that the post-adoption professionals have done for decades and we are still dealing with it in terms of late discovery adoptees coming to us when they are 50 or 60 and they found out only last week that they were adopted. That is continuing to happen. It is going to happen with donor-conceived people too because at different stages throughout their lives they are going to find out that they were donor conceived.

Mr GARRY EDWARDS: Are those adults who find out later in life that they were donor-conceived normally from heterosexual families?

Mr MARTIN: Our expertise is around adoptions so I haven’t had, in terms of firsthand experience, very few with donor-conceived people. As the Committee has heard today, there is not much formal support out there for donor-conceived people. The evidence the Committee has been hearing I suppose has been from a group like the Donor Conception Support Group. People are going to find out at some stage in their lives—we know from adoptions that these are just ticking time bombs waiting to go off. Lots of people know within the family and it will usually come out. Then they are going to have deal with: I am now not who I think I am. Why have my parents held this information from me? We have learnt from adoption that we would never repeat the mistake of not telling a child. That is something that happened 30 or 40 years ago and it would not even be considered now. We know that adoptees need to know from the time they are born, from as young as possible. The best case scenario is when you speak to an adult adoptee and they say, "I can't even remember being told. I have always known." The same applies to donor-conceived people.

CHAIR: If the Committee were to put a system in place that allowed all of that to happen then the real concern would be about retrospectivity and we have seen retrospectivity happen in the adoption field. The Committee has also heard arguments for and against retrospectivity. The anguish is all about retrospectivity and that is the battle that this Committee faces. For instance, donors who donated anonymously 30 years ago and now there may be a breach of that privacy—you heard the evidence of the professor who gave evidence before you about a breach of that privacy.

Mr MARTIN: That is why contact vetos are probably the safest way. In adoption there are virtually no breaches. As I said, people are adults and they respect each other. They are not going to try and force themselves upon someone who does not want to have contact. I think we have got to make a difference between getting information and contact—they are two completely separate things. Having the support of an intermediary service to facilitate contact is helpful.

CHAIR: The NSW Committee on Adoption and Permanent Care has submitted that assisted reproductive technology clinics should retain birth records. The Committee has also heard evidence of the importance of collecting and collating all donor-conception information in one place regardless of any future decisions about how that information may be accessed. What would that involve in your view?

Mr MARTIN: We found that question probably quite hard. I do not know where the best place to keep records is. On the one hand we are saying that BDM is quite a good place to keep records but they are not counsellors, they are not able to share that information. When people go to BDM for adoption stuff they have to go to Community Services first to get what they call a supply authority to get their original birth certificate.

CHAIR: Your submission talked about the clinics retaining that information but the clinics are not mandated. There are guidelines about the type of information you hold and collect and how long you hold it for. In some cases these clinics are in the hands of private businesses or they are closed doors or get taken over by others. There is a push for a central register regardless of where we go. If you consider the three steps: firstly, we have a responsibility to collect and collate all that information today for the future regardless of what we do with that information; secondly, who has access to that information; and thirdly, contact at a later stage. The Committee has heard that a central register is the only way forward—and many would like a national register rather than a State-by-State register.

Mr MARTIN: Maybe a similar agency to VARTA in New South Wales but even a non-government organisation basically that can setup and be a centralised spot to hold records, provide educational seminars, share information, facilitate contact and become an expert in that area. In saying about a national register, we are very much for something happening nationally. That is one of the other major problems in adoption—it is all State-based.

CHAIR: There is no national register?

Mr MARTIN: There is no national register. Something I have been interested in for the past couple of years is a national voluntary DNA database. Notwithstanding what the Committee is going through today, I still think that it needs to be held essentially by the State—people have to have access to their information and things like that. For all those donor-conceived people for whom there is no information and they cannot get any information because it has been destroyed or whatever, here is an opportunity for them to voluntarily put their DNA on a national register—hopefully we will get enough donors on there—and have the opportunity to be linked with their half siblings, which maybe the next best thing to having contact with their donors.

Dr Allan talked this morning about different models around the world. She spoke about one in the Netherlands. That model is run by International Social Service in the Netherlands. I have been looking at that model here on a federal level and I have been liaising with all the State post-adoption providers that are non-government organisations. They are all keen to be involved, to be that intermediary service. That is another option for people who have got nowhere else to go and especially with people moving from State to State.

CHAIR: Donors are a very new sector. In the adoption field, where we have learnt some lessons from the past, are we seeing some States wanting uniform regulation laws and opportunities going forward?

Mr MARTIN: Yes. As to a national voluntary DNA database, all the State non-government organisation post-adoption providers have basically said to me that they would like to come on board with the idea. I have written something very brief on it which I can basically give you as well.

CHAIR: Thank you.

Mr NICK LALICH: Some submissions have proposed that non-government organisations could provide counselling or support services in the same way that non-government offices currently provide counselling and support services for post-adoption issues. Would you like to elaborate on that?

Mr MARTIN: I am basically saying that we are the closet equivalent but we need that extra training. There are already established post-adoption providers providing support in every State. Basically in this State we have already got four-funded post-adoption providers. We understand all the issues around identity and grief and loss and we understand facilitating contact. I think it is something we could work on in terms of the donor-conception field.

Mr GUY ZANGARI: The Committee has received evidence that compares the situation of donor-conceived individuals wanting access to their genetic information with that of adopted people. Can you outline your understanding of the main differences and the similarities? I acknowledge that you have already touched on some aspects of that question but is there anything else you would like to add?

Mr MARTIN: Obviously the difference with adoptees is that they are not biologically related to both their parents and I suppose for a donor-conceived person they are at least going to know half their genetic history, but you cannot underestimate how important knowing that other half must be for adoptees and donor-conceived people. I think it is very similar. They talk about grief and loss in terms of adoptees, and with donor-conceived people I suppose there is still grief and loss. It might not be the same in terms of relinquishing or forced adoptions, or things like that, but there are still issues around how was I conceived and how was it facilitated, or was money used, what was the motivation of my sperm donor and things like that. These are all questions around trying to fill in the pieces of who am I, and it is very similar in that respect.

Mr GARRY EDWARDS: The Committee has received some evidence stating that the United Nations Convention on the Rights of the Child, frequently cited as providing grounds for children to access information about their parents, applies only to children, not adult donor offspring. What is your response to this?

Mr MARTIN: As I said earlier, I think it is a basic human right to know your family and medical history. I heard some arguments earlier today by different people giving evidence that these donors came in and donated their sperm under the premise that they were going to remain anonymous, but the fact is that the donor-conceived people were not part of this deal or contract, per se, so their needs, their rights and their wishes

I think need to be paramount. For a child to grow up and not know that, to know that you cannot access that information, will continue to ingrain identity issues throughout your life, especially if you know that there is information being held in a drawer in a filing cabinet at an IVF clinic and this is your family, this is information about you that you are not entitled to get. It has to be hard.

Mr NICK LALICH: There is a legal problem as well in that if it was ever tested in court and the donor won, that would then close the door for all other recipients.

Mr MARTIN: But we know from adoption that we did not have a backlash in terms of relinquishing mums or mums that had their babies forced from them—and dads as well—when they did the retrospective Adoption Information Act in 1990. I should probably stress too that we are about respecting donors' privacy and respecting their wishes as well, but I do not think that should stop donor-conceived people from obtaining that information, both identifying and non-identifying. I think I heard a comment earlier this morning asking are they going to go after inheritance and things like that. Adoptees do not do that. Their legal parents are on their adopted birth certificate, the same as with donor-conceived parents, so they are not going to. From our understanding, that is not their motivation. Their motivation is really around "Who am I? What ethnicity am I?" All that family history is very, very important, but the medical history is undeniable—that should just be a given.

CHAIR: Are you aware of the Nuffield Council on Bioethics report that was released recently?

Mr MARTIN: I am. I think Professor Millbank sent me that and I have skimmed over it, I have not read it.

CHAIR: The report recommends that, rather than governments mandating or legislating retrospective access to donor information, we should just provide an environment of counselling, transparency and so on.

Mr MARTIN: Our view is that I think people sometimes have the very best intentions to tell, it just becomes too hard—even if you are a donor, like "I will tell my current wife and kids that I donated sperm. I will do it in six more months." I suppose having extractions of birth certifications, it is very coercive but I think unfortunately you have to put that in place.

CHAIR: So your preference would be for governments to mandate or legislate?

Mr MARTIN: Yes. I think then it kind of forces families and donors to be upfront and honest, and to be open. In the long run, as you have heard other people talk about today, it might be devastating and traumatic to hear that you are not related to your father, and we know from adoptees that it is traumatic, but they would rather know than not know. I just think if you can facilitate a way to encourage openness—we already have legislation that encourages that, but even more so, like the Victorian legislation which has the birth certificate extract but also retrospective release. We have done that in adoption and it just ends all secrets and lies.

Mr NICK LALICH: Are you aware of any figures of donor-conceived people born in Australia prior to the prohibition of donor anonymity in 2010?

Mr MARTIN: I have looked. I have written a paper on the right to information for donor-conceived people and lessons learned from adoption, and I have tried to look at different things. There are varying degrees. You hear from 20,000 to 60,000, and I even read recently a woman from Western Australia said 100,000. It is just so hard to know because there are so many that are going to be informal private arrangements where records have not been kept. I think the fact is that it is just going to continue to grow. We know that adoptions basically slid right down. We used to have 10,000 adoptions per year in the 1970s and now we have about 350 across Australia, so they have gone right down, but you will be seeing donor conception continue to rise and rise and rise, so the numbers are just going to continue to grow. I do not really know—

Mr NICK LALICH: The exact figure.

Mr MARTIN: Yes, there are just so many ballpark estimates. I would probably be of the view to aim quite high because of what you know and in terms of current figures, maybe triple that. I do not know; it is a guess.

CHAIR: Do you have any concluding remarks?

Mr MARTIN: No, thank you for the time. It has been enjoyable listening to the questions and hearing the other evidence, so thank you for the opportunity.

CHAIR: Thank you for appearing today. We may have further questions, but we will write to you.

Mr MARTIN: That is fine.

CHAIR: And your responses will form part of your evidence. Are you comfortable with that?

Mr MARTIN: Yes, that is fine.

(**The witness withdrew**)

(**Short adjournment**)

JOEL BERNSTEIN, Medical Director, Fertility East, affirmed and examined:

CHAIR: I welcome Dr Joel Bernstein from Fertility East. Thank you for appearing in front of the Law and Safety Committee. My name is John Barilaro, the member for Monaro, and I am the Chair of this Committee. Will you please confirm that you have been provided with the Committee's terms of reference and the information about the standing orders that relate to the examination of witnesses, and do you have questions concerning these procedures?

Dr BERNSTEIN: Yes, I have been informed, and no questions, thanks.

CHAIR: Have you provided the Committee with a submission and do you want that submission to form part of the formal evidence?

Dr BERNSTEIN: Yes, I have provided it and am happy for it to form part of the formal evidence.

CHAIR: We have a series of questions, but we are more than happy for you to start with an opening statement, if you choose to do so.

Dr BERNSTEIN: Just to tell you who I am, what we do. Essentially, I am a fertility specialist, trained as an obstetrician and gynaecologist. I have been doing this for nearly 40 years. If you do your arithmetic, you will realise I started doing it before I was qualified as a specialist. I thank you for the invitation. I hope that I will be impartial, because our fertility clinic is a new clinic and we have really only functioned under the laws of identifiable donor, so I do not have any axe to grind with anybody. I really hope to be speaking on behalf of all the people who your decisions will impact upon. I am happy to answer any questions.

CHAIR: Thank you, doctor.

Mr NICK LALICH: Doctor, my name is Nick Lalich. I am the State member for Cabramatta. A number of submissions argue that the promise of anonymity given to donors in the past was invalid because a person born as a result of that donation was not represented when such an agreement was entered into. Will you comment on that?

Dr BERNSTEIN: Yes, my comment would be that parents who were not coerced into using donor sperm make decisions about their children all the time and the children have to bear the brunt of those decisions. You cannot, obviously, have somebody present with that kind of decision when they do not exist. I think children, as a result of parents' decisions, will either suffer or do very well and I think the parents do have a right in their decision-making process.

Mr GUY ZANGARI: The Committee has heard evidence of the importance of confidentiality and faith in the doctor-patient relationship. In relation to the issue of gamete donation, is the donor considered a patient in the same way as a person receiving fertility treatment?

Dr BERNSTEIN: Obviously I am speaking from my own personal experience and as someone who actually assesses sperm donors but did not assess them, obviously, at that stage, for what your Committee is looking. So they are my patients, and we assess them, provide them with all the legal information that we are supposed to give them, give them the counselling they need, assess their medical status and describe the whole process to them, so yes, very much they are seen as patients, as is— just to extend your question which you did not ask to me—the offspring of such. We have responsibilities as doctors to the outcome of offspring as well as the extended families of recipients.

CHAIR: You are classing offspring as patients as well?

Dr BERNSTEIN: Theoretically we have a duty of care to them, absolutely, although they are not physically a patient in as much as I have seen them, but in respect of our medical duty of care, whatever we do, yes, absolutely. It is a bit like an obstetrician where the baby is not quite his patient, but the mother's outcome will determine the baby's health, so yes.

Mr GARRY EDWARDS: Doctor, I am Garry Edwards, the member for Swansea. Will you clarify the status of the agreements made with the donors? For example, were they made with the doctor or the clinic, and do you have an example of such an agreement you can show the Committee?

Dr BERNSTEIN: As I said in my opening statement, when we started our clinic, it is at a time when we no longer use anonymous donors. As far as we currently function, and as we have always functioned, we do have donor agreements that have been drawn up by a legal team for us and, if it would help the Committee, you are more than welcome to have any copies of any of the agreements that we use, but these are post-2010, so they may not be of much value to you. Looking at it from a different point of view, to give you a bit of the history of our clinic, there used to be an IVF clinic in Bondi Junction. It was called IVF New South Wales. They used to do a lot of donor work. We opened an IVF unit, they closed down; the doctor had a stroke and could not continue to function.

The Fertility Society of Australia's [FSA] Reproductive Technology Accreditation Committee [RTAC] requested that we take over its records in an effort to try and manage any potential ongoing problems that could have arisen, and the problem is that their donor forms and donor information and recorded information is so variable that most of the information really does not exist. So one of the points I made—sorry to take such a roundabout route—with this submission is that if one tries to retrospectively change the law, you are going to be faced with a time when records really did not have to be kept. There is no law that says they had to be kept more than seven years. There is a National Health and Medical Research Council requirement that they should be kept indefinitely, but it is only a guideline, so there are lots of very poorly kept records, which means that a lot of people—or some people, depending on the clinic—may not be able to get information that a retrospective law would hope to give them. It is a major source of concern.

CHAIR: By us having a retrospective legislation where we are trying to retrieve that information, it may cause some clinics to destroy that information.

Dr BERNSTEIN: Yes. Well, you would not even know it existed.

CHAIR: That is right.

Dr BERNSTEIN: Absolutely. We are all grown up and one does not want to waste time, but the quality of this information that we have of this clinic is atrocious. It would be unacceptable today, so my concern is I do not know how it is being stored, who has got it. Would somebody destroy it? I have no idea.

CHAIR: And there are question marks concerning the integrity of that information.

Dr BERNSTEIN: Absolutely. It is not as if there are great records. Currently, because of the law which demands that we keep information for 50 years, that is the Assisted Reproductive Technology Act—from 2010 we have to keep it for 50 years, so records are now being—not photocopied, microfilmed, and we have special secure storage, et cetera, but that was not the case.

Mr GUY ZANGARI: Doctor, to add to that, if there was a legislative requirement where there is a central repository where it is mandated that all the clinics provide that information, would that mean better management of that information? However, that information, prior to 2010, as you have said, may be existent or non-existent as such, but would that be the way for us to go? It has been brought to our attention today that the Federal inquiry did not go the way of having a central repository, but if we were to do that in New South Wales, would having information stored in a central place be the way to go and have all the clinics being responsible for uploading that particular information?

Dr BERNSTEIN: Assuming that the information stored is secured and—I do not know enough about the legal rights of people, about who stores what information, but it is a law that we have to store this information. Every clinic that is using a donor is storing information. It is being stored electronically, it is being stored in files under secure storage. It is being stored.

CHAIR: Would that be better stored centrally by government?

Dr BERNSTEIN: I am just thinking. Part of the story is we sometimes have to retrieve information, so the one thing we do have with the private storage is we can retrieve it pretty quickly. A patient may disappear and come back three or four years later, and we pay.

CHAIR: I am not talking about the clinics losing control of their database if we go to a central register.

Mr GUY ZANGARI: They would still have their info.

CHAIR: One would assume you have your own personal information and data available to you, but you would be updating the central register.

Dr BERNSTEIN: No, it is not as simple as that. Each doctor has a clinical record of the patient, but the clinic itself which provides a fertility service, which is unusual, has its own records. It is a bit like a public hospital. They have their own public hospital records and then the individual doctor has their own records, so what you would need are the copies of both. Does that transcend privacy? It is beyond my knowledge; I would not be able to say. The point is one would need safe and efficient storage and I think if one could do that, then I think it is a possibility that it could be done. I think most people, from a comfort point of view, and from a patient's point of view, may prefer their doctor to store the information. I think that is something for the public to answer.

CHAIR: Thank you. This is a bit of a strange question. Throughout holding this inquiry we have heard from a lot of donor-conceived individuals and from groups that represent that part of the sector. We have heard more from one side of the argument than the other. We have not heard a lot from donors, especially when we are talking about retrospective legislation and retrieving information from the past. We have struggled to engage and hear that side of the story. One of the questions I have is, could we ask clinics to get in contact with those donors to bring their attention or awareness to such an inquiry that could change the rules of the information they have provided in the past? Is that something you would be comfortable to facilitate on behalf of an inquiry?

Dr BERNSTEIN: Maybe I will answer that question slightly differently. The problem you face—as I was saying earlier to Guy—is that you in fact have opened up Pandora's box and you are sitting on the tip of the iceberg. If we look at the New South Wales registry, they are going to have to make this information available. I do not think they currently have a system—or whether it has been planned, I do not know—to deal with putting donors and recipients together. As I mentioned to Guy earlier, of course this has stimulated a great deal of interest in me, and I have now challenged a whole team, including counsellors, to put together protocols of how you actually do it. Everybody says they should have counselling. That is easy. It is like saying you need traffic lights, but it is where they have to be and how they operate. There is no literature. I have challenged everybody now that we have to put it together so we can handle it.

The fact that donors are anonymous would preclude them coming forward. This is a problem that everybody has faced and I am sure you have heard today about the Nuffield report. It is a massive report. I think fell asleep about ten times in the bath trying to read this thing. They deal with these issues. I do not know whether hearing from donors will help. There are some who wish to remain anonymous, and the mere thought of breaking their anonymity may have an impact on their current life. They may not have told their wives what they have done, their children, offspring, et cetera, so I do not know if you will get an honest attendance and whether you will get a proper representative view in trying to solve this problem. I have taken on this problem because it is something we all face—it is not unique to the Committee. The best we can do is follow up the opt-in system. As a point of some criticism, I do not believe that the State Government has done enough to attract people to opt-in. The fact that it appears on a website is meaningless. For the people you need to target, you need to get a message to them and regularly. I honestly believe that that would be the best approach to the problem.

A lot of information is missing. If the legislation is passed, the information will not be available or it could be conveniently lost. It may be already being lost because this inquiry is being held. As I said, it does not affect us. I do not want to be so bold as to say that you would think along those lines. We already have an opt-in system and a voluntary donor register. That is the most cost-effective and best method of attracting people who are interested. If they are not interested, they will duck and dive and you will not get them anyway. There is no simple answer to the question, but the mere fact that the majority are anonymous means they do not wish to be contacted, and least of all by government and even by the doctor.

CHAIR: When they made the donation 20 years ago they may have thought that they would never want to know the outcome. However, 20 years later their life is different and they may be more comfortable with it. Without having that contact what do we do? I know we have the voluntary register.

Dr BERNSTEIN: You have a massive tool that is being totally underutilised. It would save a lot of time, effort and money. I do not know whether you have read the Nuffield report, but it contains a very good recommendation. It says that governments should look not to legislate but to facilitate. By facilitating the whole to donor thing and laying it out I think you could attract many of the old people back into the fold. That would be the right method. However, the minute you legislate you get people's back up. You do not want these people to get their back up. How would we contact them? Would it be fair of me to send a letter to Joe Bloggs saying that we would like him to contact us apropos his donation? He already said that he wishes to have no contact. We may not be able to find him. How are we going to track him down? We might have the address he used 20 years ago. The mere practicality of doing this is enormous and how successful will it be? The opt-in system provides tremendous power and it is all positive.

Mr NICK LALICH: Such a letter would also telegraph the information to his wife if she opens his mail.

Dr BERNSTEIN: Yes. I did not even go down that track. What happens if his wife opens the letter and she never knew about it? Who takes responsibility for the implications of these decisions? Are we allowed to contact someone who has said he wanted to be an anonymous donor? You might be able to justify it if there were a critical illness or someone needed bone marrow. However, there is negative potential; we could be liable for some sort of breach. We do not have a process. We are all talking about the theory, but how do you translate it into real life? I am not saying the opt-in system is simple in any way, shape or form, but it is a lot easier to manage.

Mr NICK LALICH: The Committee has heard evidence about the importance of collecting and collating all donor conception information in one place. Regardless of any future decision about how the information may be accessed, what would that involve?

Dr BERNSTEIN: It is part of what we discussed. The law demands that once a child is born to a donor, the donor's details, the recipient's details and the child's details must be put on the New South Wales donor register. That already happens. While the donor has not had success he does not exist anywhere; he exists in limbo. Once there is success, he exists and the information goes to the New South Wales donor register. You are asking whether the donor's information should go to the New South Wales Government. If he is not successful, you do not need it and if he is by law he must be registered. Going backwards in time to donors prior to 2010, the difficulty will be in finding that information and the legal aspects. Ideally should it be in one place when children are born? That is already the law and it happens.

Mr NICK LALICH: Should it be a federal register and should the law be the same across Australia?

Dr BERNSTEIN: You highlight a really interesting point. The laws pertaining to assisted reproductive technology and donors seem to vary from State to State. Ultimately it would make sense to have a more comprehensive system.

Mr NICK LALICH: An umbrella system?

Dr BERNSTEIN: Yes. If that is the question, I agree.

Mr GUY ZANGARI: My question touches upon what you said about counselling. Your submission states that it is important for all parties to receive appropriate counselling, but that is almost impossible to achieve. Can you comment on the proposal put to the Committee that non-government organisations could provide counselling or support services in the same way that non-government organisations provide those services in respect of post-adoption issues? I refer to the comment you made to me about counselling and the way in which we provide support. It is not simply a matter of counselling but also the mechanisms. That was an interesting comment.

Dr BERNSTEIN: We must look at how it works practically. That is why I have challenged our counsellors to come to up with information. I know that it does not pertain to the Committee now, but I am happy two pass on that information because it is a problem we all face. I have had a brief chat with the counsellors concerned and they have said that there are no well-defined counselling models in this area. My concern is whether we actually know; is there a protocol? Adoption has been around for a long time. I am not a counsellor, but I presume that they have a protocol for that counselling. Will that model work in this area? I have no idea. Is there data showing that it does? According to my counsellors, they cannot find much information. We are very much flying by the seat of our pants and how many pairs of pants will we need? That is the problem.

What are the practical aspects involved in doing it? We need to address some sort of protocol. That is what I am trying to do in my own small way. We have had one or two people who want contact and we have spoken to a recipient who indicated in her initial submission that she was interested in doing so, so we were not breaking any confidentiality. However, we are now faced with how we do it. Must each person see a counsellor first and must the counsellor decide? What questions need to be asked? I do not know the answer, but that is part of what we have to define. What resources will you require? Will you need a psychiatrist or more than one or two counsellors and so on? A counselling session in private practice costs between $150 and $200. Who will pay and how many sessions will be required? There is a way to do it, but it does not exist right now. As I said to Mr Zangari, this Committee has dealt with only the tip of the iceberg. All these problems will hit the New South Wales donor register 18 years down the track. I hope whatever you do is working towards a lot of common goals.

Mr NICK LALICH: We hope so too.

Dr BERNSTEIN: I am happy to share whatever information our counsellors come up with. Our intention is to write to the people who run the massive private donor registry to see how they manage counselling. We will attempt to contact a number of people to get this information and the Committee will have to do the same thing.

Mr GARRY EDWARDS: Do you have any figures on the number of donors and donor-conceived people born before and since the anonymous donation laws were changed?

Dr BERNSTEIN: Unfortunately our clinic has been involved only since then. We have records pertaining to probably 100 or 200 couples, but I cannot tell you how many donors. I would have to establish whether that information exists. However, there are no comprehensive records.

CHAIR: Your clinic was established after that?

Dr BERNSTEIN: We are five years old.

CHAIR: We have heard other organisations talk about a drop off in donors when the law about anonymity was changed. We heard that one program closed. How do you survive if there is a lack of donors? I assume you are getting donors.

Dr BERNSTEIN: We have one staff member whose sole job it is to attract donors. We conduct lectures and public information evenings to attract them. We might be lucky to attract six donors a year. They are allowed to get only five women pregnant worldwide. Many of the recipients are older women and we never achieve those numbers; they are exceedingly difficult to achieve. The donor program is only one part of it.

We have been able to negotiate with one American clinic that fulfils the New South Wales regulations regarding counselling and so on. It provides us with a limited amount of donor sperm. Again, it is limited because the cost of finding a donor and testing them is so exorbitant. We also request that our patients purchase five vials of sperm per donor. The maximum amount of sperm available is 25 vials per donor, whether or not it is used. That must cover the finding costs and so on. I do not have an exact figure, but it costs us about $10,000 or more to get a donor in Australia to donate. That is the kind of cost involved and the results are horrific.

There has been a tremendous drop off worldwide. We saw what happened in England: The minute they passed the law about donors having to be identified suddenly the donation rate dramatically reduced. It is a fact of life and we do the best we can. I point out that it is a limited part of the work we do. We are a fertility clinic, but we try to maintain the service because there are people who desperately need it. There is an irony with the law and the problem is twofold. Individual women can get donor sperm from overseas perfectly legally, but we are not allowed to use it. The law controls the doctors, not the patients—they can do what they like. In addition, the more restrictive the law the easier it is for a patient to go down to the pub, to find a bloke and to have a baby. That is perfectly legal.

CHAIR: That is one of the Committee's concerns. I have said that regardless of the legislation we put in place there are many private arrangements.

Dr BERNSTEIN: That is happening more and more; you need only look at the internet to see what is available. We are becoming more and more restricted and we are chasing patients to what I call the dangerous options. Responsible reproduction is becoming less and less frequent and irresponsible reproduction is increasing. The Government of New South Wales could adopt a far more positive attitude by highlighting sperm donation, bringing it to the fore and making it more socially acceptable. That is an interesting part of the Nuffield report. We might see a lot of benefit coming out of that and donors might be more accepted in the community. The only other supply of donors that has increased is I think from 2010 gay males were allowed to donate sperm. They were not allowed to donate before for risk of transmission of disease, which is incorrect. We do have a few more gay males, and that information is available to recipients.

CHAIR: You mentioned earlier that Fertility East took over a clinical practice, IVF NSW, in 2007.

Dr BERNSTEIN: No, we made an agreement with a reproductive technology accreditation committee that we will assist in managing the records. We did not take over a practice. I am trying to help these people because otherwise these records could have been thrown out in the garbage and that could have been the end of the story.

CHAIR: That is the point I was making. You mentioned earlier that with a lot of the records the samples were incomplete or of poor quality. Will you expand on that?

Dr BERNSTEIN: There are two aspects, there is the date and there are samples. The samples can no longer be used because they have exceeded the various interim legislation which allowed older sperm to be used. So we got rid of almost all of the samples that existed because they cannot be used. They were collected at a time when the current testing was required. The records are incomplete so we do not use them. They were kept for a few people who, in the interim period, had had a baby and could still continue to use it up to the end of this year for donor sperm and the end of 2014 for embryos because they have been given an extension and that is it. The records that we have got from them are hopelessly incomplete both individually within the records, a lot of them, and then there are complete banks of records missing.

Mr NICK LALICH: You state that the Department of Health or the Fertility Society of Australia could manage donor conception information. Do you consider that both those organisations are equipped to do so?

Dr BERNSTEIN: I cannot speak for the Department of Health because I know nothing about the functions of the Department of Health. But I think what I was actually trying to say is that they each bring certain expertise to bear and you probably need expertise from both in order to effectively manage it. I think that was the point I was trying to make. Really from an impartial point of view, the problem we face is that the group of people involved are the children borne of donor sperm at any stage, their half siblings from the same donor, the parents and the extended family of the recipients and the actual clinic. These are all what I call stakeholders but that is not really a fair term to use, I just could not think of a better English word. All their requirements and interests, because they make one kind of very large family, need to be looked at in detail. One has to be aware of the impact of all of this. We see it all the way down the line.

From an end user who read your initial submission, the feeling was very much that this Committee is looking—this is my perception—at the rights of the donor-conceived child. I think, and I am sure you have come to the same conclusion, that there are a lot more people involved than just the donor-conceived child. There is a terrible lack of knowledge which I find quite frustrating.

CHAIR: The point was made that the word "rights" probably should not be used because we are almost pitching one against the other as competing interests where really they are all part of the one family.

Dr BERNSTEIN: I refer to it as a kinship but truly that is the case. It is just as difficult for us. Currently this is the type of problem we face. I have patient who I mentioned earlier, the donor agreed to be in contact but he did not say with whom, he just said he agrees to be in contact, not with the child, with the mother, or the parents, or both, we do not know. The actual semantics are important. The female who I will now see, who I do not know, it is a patient of this old clinic, she just wishes to meet the donor. The child does not wish to meet the donor. Is that correct? I am not asking for an answer, I am just saying I do not know. How do we manage this? What if the child does not want the mother to meet the donor, but the mother wants to meet the donor?

Nobody is being difficult it is just an incredibly difficult problem and how do we solve it? Essentially we are going to have to get a questionnaire done by the child, assuming the child is aware of what the mother wants to do. Maybe the child is not, am I right to get a questionnaire there? A questionnaire of the mother, a questionnaire from the actual donor and then probably we will have to get our legal team to see whether we are allowed to ask those questions. This is just one couple and I have not solved their question.

CHAIR: Last week a couple told the Committee last week that when choosing a donor one of their requirements was they wanted a donor who was prepared not to remain anonymous and that that information would be passed on to the child at some stage. That change the situation and instead of having 20 or 30 donors there was only about four from whom to choose. They all agreed and the child was conceived and born and then four years on the donor rescinded his consent. Again it leaves us in the position who has a right for information and who does not?

Dr BERNSTEIN: I am sharing a problem, there is no criticism, I just do not know what to do. This is the first problem that has arisen. As a result of this, we are trying to work on it but there are vast problems ahead. In relation to the availability of donor sperm, there are identifiable donors available in the United States of America. I spoke to, I think it is called, Fairfax recently. They said why do we not use them. I said "Because your requirements do not fulfil the New South Wales State law". The current requirement of the Act is that you are only allowed to get five women pregnant worldwide. I do not know where the number came from because there is no scientific evidence to show that that makes any difference but because it is five it has limited the availability of sperm.

The bloke wrote back to me, his name is Dr Poole, to say, "We cannot provide you 25 vials for worldwide use only as a one-off. We cannot afford to do that." We have actually cut short another supply. My comment to the Committee, and I know that is not what you are dealing with, is that because of our current law, we are actually driving patients to irresponsible reproduction. We need to do something about that.

Mr GUY ZANGARI: The Committee has received evidence which compares the situation of the donor-conceived individual wanting access to genetic information with that of adopted people. Will you outline your basic understanding of the main differences and similarities in those cases?

Dr BERNSTEIN: My first question would be, "What is genetic information?" The genetic information may be the outward physical appearance of the donor, fair enough, hair colour, eye colour, height, et cetera. Non-identifiable information: education, background, we offer religious—this is all available not as anonymous—orientation. Does he want to know about family history? My submission says that the genetic history of the donor is relatively immaterial. A lot is made of this but in reality it is not functional. You will see in the report they come to the same conclusion. Donors are screened and in order to be a donor, if you have a particular genetic disease we may not accept you as a donor. You literally have to be as close to perfect as possible. These are highly selective people. What other genetic disease information, blood group maybe? A lot of those records still exist, maybe not the social aspect, education et cetera, but basic physical features.

We are the only donor clinic in Australia and probably one of the few in the world but our local donors all undergo a 90-plus pre-natal genetic screen. A test called Counsyl. We pay for $US510 for it. It looks for additional diseases and we recommend that all our recipients—it is not a requirement of law—have that as well because the current law demands they have a cystic fibrosis screen. That is inadequate with what is available today. In terms of genetics, just to show you there is a different aspect to it, that is what we are currently doing. If a recipient has an abnormal gene, is a carrier of an abnormal gene, say, cystic fibrosis, we then have the ability of requesting from the donor bank to re-test or test further their donor specifically for cystic fibrosis, so we avoid that. The American bank that we use retains all the information. If we have any information about an abnormal child, that is brought to the recipient's attention.

Mr GARRY EDWARDS: What do you think of the model used in managing adoption information where there are several different agencies, both government and non-government involved in the process of releasing information and providing counselling to adopted people and their families?

Dr BERNSTEIN: I really do not know what is involved with adoption. The fact that there is multiple agencies would be better than if it was related to one single agency. The only request would be that you would get a lot of mileage and it would be very valuable if you had some fertility specialists who deal with this every day involved in providing that information. Obviously we see it from a very specific point of view but we also bring a lot of experience to bear and a reasonable amount of knowledge of the subject.

CHAIR: The Committee may have a series of other questions that it will send you. If you respond to those questions they will form part of your formal evidence. Are you happy with that?

Dr BERNSTEIN: I would be more than happy. At the end of the day we are trying to help people through really difficult situations but, more importantly, leave a very good system in place for the future. It is impartial. It does not really directly involve me and I am more than happy to give up my time to help at any time.

(The witness withdrew)

AMY LOUISA CORDEROY, appearing as a private citizen, affirmed and examined:

CHAIR: Thank you for appearing before the Committee. Can you confirm that you have been provided with the Committee's terms of reference and information about the standing orders that relate to the examination of witnesses, and do you have any questions?

Ms CORDEROY: I have received them and I have no questions.

CHAIR: In what capacity are you appearing?

Ms CORDEROY: I am appearing as a private citizen who was conceived through donor sperm.

CHAIR: Have you provided the Committee with a submission and do you want that submission to form part of your formal evidence?

Ms CORDEROY: Yes.

CHAIR: Would you like to make an opening statement or speak to your submission?

Ms CORDEROY: Yes. I have not thought about exactly what I wanted to say. I think it is all there in my submission. What prompted me to put in a submission is that I have seen this issue play out for a while. I was involved in it in my job, writing about it, and it prompted me to take a look at my own circumstances. I feel like we are developing this incredible cultural mythology around sperm donation and what it means for people to know their sperm donor and what this genetic connection means for them in their life. I think it is quite harmful the way the story is heading so I wanted to put my hand up and say not all children conceived through donor egg and sperm feel the way some children do and not all of them feel upset about it or that there is anything missing. There is another side that probably does not get heard quite so often. That is what prompted me to put in my submission.

Mr NICK LALICH: Some submissions have argued that a donor's decision to donate anonymously should be preserved. What is your opinion on that?

Ms CORDEROY: I believe it should be preserved. I preface this by saying I do not want to discount the very real and genuine feelings that a lot of people have and the pain and terrible things they have experienced related to their donor conception, but I believe they are sort of social problems and they are created by our attitudes towards donor conception. I do not think they are going to be solved by making this connection between donors and children. Considering there are these kinds of problems with the way all this emphasis is being put on the genetic relationship between the two parties it would be unfair to them to disclose the identities of men who donated anonymously in good faith and who could have some bad side effects from having their identities revealed or being contacted and having it found out through some other means. When you weigh up the two things you need to prioritise the rights of the men who donated on the understanding they would be kept anonymous.

Mr NICK LALICH: If you do not want to answer this question, do not answer it. At what age did you know you were a donor-conceived person and was it paramount that you try to find out any of your genetic connections?

Ms CORDEROY: I guess I have always known. I do not remember Mum specifically telling me. She says that I first told her when I came home from preschool and said, "So-and-so has a daddy and so-and-so has a daddy but I don't have a daddy." She explained it to me but I do not have any memory of that; it has always been there. I was thinking about it on the way here. I think that I am in a kind of unique position in that my Mum was adopted so when I was growing up I saw her dealing with her adoption and she felt very upset by the fact that she did not know her biological parents. She put so much investment and emotional energy into imagining what her relationship with them would be like and what the biological relationships would have meant for her sense of identity. Seeing that and how it played out in her life made me go, "Wow, this isn't actually that important to me", and these questions that people are asking are maybe not the right kinds of questions to be asking and are related to other emotional problems and ways of finding meaning in their life that maybe will never be solved by knowing the biological parent. For me it was never a big question.

Mr NICK LALICH: Do you know your biological father?

Ms CORDEROY: I found out later in life that it was a family friend, so I had met him when I was young although I do not really have any memory of him. I could meet him if I wanted. I do not think he lives in Australia now but we emailed a couple of years ago. I was not that keen to meet him so I never arranged it.

Mr NICK LALICH: There is no feeling of family tie to him?

Ms CORDEROY: No. I think he was actually keen to meet me. He wanted to meet me but I just did not feel I would get anything out of it. I did not feel there was anything I needed out of that relationship so I decided it would be a bit stressful. I also did not want to have any demands placed on me as a daughter so I never arranged it and never pursued it.

Mr NICK LALICH: If he pursued wanting to meet you would you be interested in that? We are thinking about what the children would like to know but sometimes the donor also wishes to know. Would you be interested and say, "Come home and we'll have a coffee with Mum?"

Ms CORDEROY: At this stage in my life I do not really want to. You never know, maybe when I have my own kids my feelings about that will change. It is not something I want and I think I would feel the pressure. It is a highly pressurised environment to go into. I have a few friends who were born by sperm donation and when they met their biological fathers it was a very emotionally laden experience. It was frustrating in a way because they felt that sometimes the fathers might claim credit for some personality trait they had or something they did. They found that a bit annoying because they were saying, "Hey, it's nothing to do with you." I guess because I do not have that desire I think about those negative things a bit more and think that I probably would not want to. If he contacted me and said, "I desperately want to meet you, it is really important to me", I would not refuse, but it is not something I want.

CHAIR: That leads me to a couple of questions. It is about choice, therefore when I look at the process and what this inquiry is looking at, first and foremost it is the collection, collation and record keeping of the data so that that information is held and stored somewhere so that in the future if you choose to go down that path that information is available. Then of course there is access to that information, which the Committee also is looking at. At some point that might lead to contact. Those are the three areas I am looking at. Do you believe we should at least put in place a process that collects and records all that data so it is ready for the generations to come so that a donor-conceived individual has a choice to pursue the information?

Ms CORDEROY: I guess it would depend on how you went about collecting the data. If it means sending letters to every man who donated I think that would be a fairly invasive process.

CHAIR: I think that is going to be very hard to do because that contact information is missing anyway.

Ms CORDEROY: Yes, absolutely. I would not want to impose my views on other people and I would be totally open and supportive of the Government setting up some kind of system for people to voluntarily register and put their contact details in there.

CHAIR: We have that.

Ms CORDEROY: Maybe publicising a little bit more could be a way of doing it. I think even the contacting of men who thought they would not be contacted and that it would be anonymous would have to be very carefully done because there are so many opportunities to potentially expose their identity when they do not want it exposed in that process that it is fraught with hazard.

Mr GUY ZANGARI: Thank you for your submission. You are very brave to put those comments down on paper and I can imagine how daunting it is for you to appear here. Going through your submission I was really interested in your thoughts. You say that while you have your genes the real person is you. That is quite an interesting point because we have not had that perspective in any submission from an individual before. It is very brave of you to put that out there and say, "I am a donor-conceived child but I am who I am." I think you talked about the love of camping and the comfort you get from the smell of your mother's perfume. You are who you are and you are really celebrating your life and enjoying who you are is most important to you. I would like to commend you on the fact that you are brave in putting that down.

Ms CORDEROY: Thank you.

Mr GUY ZANGARI: Of course, different perspectives have been put to us by donor-conceived individuals who have a different point of view. I commend you for that. You say the sperm donor can never give a person meaningful knowledge about their identity, which is what you have articulated throughout your submission.

Ms CORDEROY: Yes, I think that is really important for us collectively to acknowledge. I read through a lot of submissions that children of sperm donors made to the Victorian inquiry and the expectations they have around meeting their biological father are so high they are almost unachievable in most cases. I say that for my benefit and even that of people who do not agree with me we need to lower the expectation of what that connection will mean for someone.

Mr GUY ZANGARI: Can you expand on what you mean about the expectations of these donor-conceived individuals in finding out who their donor father is?

Ms CORDEROY: I read a submission from a woman—I cannot remember which country it was her family was from—who had grown up in a family knowing her parents were from this country. Then she found out that her father was not her biological father and she felt she had lost all connection to this country. Then she found out years later that her sperm donor was also from this country and she said, "Okay, now I will find I have a connection to this country"—it was Macedonia or somewhere. I just thought the idea that you could only have a connection to a country or a hobby or anything like that because it is passed down through your genes is so divorced from reality and anything we know from science about how genetics works. As I said in my submission, in terms of our society and what makes someone a citizen of Australia we do not say people have to be born here or that their family has to be born here.

We recognise that cultural values are things that you adopt through interaction with people and that you learn through life or from upbringing somewhere, and that once you come here you start interacting with people. You do not get those things from your biological parent. I am a health writer so even if we look at various health conditions or mental health conditions and we know they are heritable in some sense it does not mean you definitely got them from one parent or another. We all have risks for different conditions but it depends on the environment we are exposed to and choices we make through life. The idea that it is just as simple as, "I will learn this thing about myself from meeting my biological father" is not true and it is quite damaging because of the expectations it creates.

Mr GARRY EDWARDS: Do you have any ideas as to how the voluntary register might be better advertised? In other words, in trying to get donors back into the system?

Ms CORDEROY: I do not know—this is totally outside of my area of expertise—but obviously it is a small group of people so maybe television advertising and that type of thing is not the way to go. We have heard anecdotally that a lot of people through the registered sperm donor system were medical students, so maybe trying to identify those types of people and advertising among doctors and in publications for doctors might be a useful way of doing it.

Mr NICK LALICH: You probably saw the story in yesterday's paper about sperm donors?

Ms CORDEROY: No, I did not see that.

Mr NICK LALICH: Please take this copy. That sort of advertising could possibly help some donors. There were quite a few journalists here listening to the evidence today. If this gets into the paper more often we may get the donors with anonymity—those donors before 2010—to come forward and give their information, if they wish, so it can be given to those children who want it.

CHAIR: This is about the record keeping. There is a serious gap before 2010.

Ms CORDEROY: Absolutely.

Mr NICK LALICH: In having that as an advertising medium, which hopefully will work, and advertising in medical journals and so on, what is your view of the importance of collecting and holding all the information in one place?

Ms CORDEROY: I would say that you need to keep it as simple as possible, particularly for those donor-conceived children who feel traumatised or upset about their experience. I would say also that it would be a good idea to have some kind of counselling service or other things available through that process so that you are automatically given that option if you are trying to go through the process.

CHAIR: In the Victorian model, Births, Deaths and Marriages hold the information. If there was an addendum to seek further information an individual would have to go through a counselling process—in Victoria that is done through VARTA.

Ms CORDEROY: The problem is—are you talking about actually putting that into someone's records so if they did not know that they were donor conceived they would then go to their records and find they had a little note there?

CHAIR: On a birth certificate there would be a marking or something to show there may be further information.

Ms CORDEROY: I would be very anti putting it on a birth certificate. I think it is incredibly invasive to put something like that without having the child seek it out for two reasons. Firstly, you are essentially disclosing to them without their permission—if you see something like that on your birth certificate you are going to go and check it out. Secondly, in my case I did not have a father listed on my birth certificate at all. My mum was a lesbian so she was not allowed to have an official sperm donation. It was all done off the books, the old-fashioned way. I have had sort of official people look at my documents and accuse me of having them forged because they did not have a father listed on them. It is quite stigmatising potentially to have that kind of thing on your official documents so I would not be in favour of it.

CHAIR: Regardless of what government does, regardless of what legislation or processes are put in place, many children are conceived, to use your term, the old-fashioned way—through private arrangement. Are we going to push more people into private arrangements and lose complete control of what is possible the more we try to legislate in this area?

Ms CORDEROY: The problem is that it seems that we are trying to deal with a problem that is really complicated and things were done in a very different way. You cannot undo those private arrangements and you cannot undo the fact that people were told they could do it anonymously or that records were not kept. In a way as a government you do not want to try and overreach too far and make promises that you cannot keep or try and fix problems that can't be fixed. That is a sort of thing worth thinking about.

Mr GUY ZANGARI: In your final thoughts you say, "We as a society have created this mess; we should fix it." Can you expand on what the mess is and how should we fix it? Many of the people who have made submissions to the Committee would not hold that view. I know where you are coming from but it is quite harsh for someone who is finding out after 18 or 19 years perhaps that their dad is not really their dad. It can be quite confronting to say that to someone who at 18 or 19 is finding that information out.

Ms CORDEROY: That is what I mean by it is a mess. It is a really messy situation because emotions run so strong and it is so upsetting for some people. That is why I am hesitant because it is easy for me to say that I am not upset by this but I cannot appreciate how hard it is for some people when I do not feel the same way as them. I really do think it is important that those people get access to counselling and that everything possible is done for them, but I do not think that should mean that we also inflict unfair things on other people like the anonymous sperm donors who do not want their identities revealed.

Part of that fix is providing those services for people but what promoted me to write to the Committee is that I feel that part of that fix is also having a really honest conversation about what we are actually going to be able to achieve by putting people together with their donors and what that relationship actually means. That is why I think the Committee's role and report is important to shaping the debate about what biology actually means in terms of the relationships these people have and what kind of meaning people are actually going to find if they do meet a biological parent, particularly a biological parent who is reluctant to meet them, who really does not want to be a part of it, and what that will mean for them. I think it is really important that it is dealt with sensitively and that we don't just buy lock, stock and barrel the idea that people have a right to know and their identify is tied up in this biological parent and all that kind of thing. That is really what I meant by that.

Mr GUY ZANGARI: If someone was of a religious background that could stir up the whole idea about creation and the way in which creation should occur. We well know that in our society there are people who cannot conceive naturally and they need assistance. That could also be misconstrued in that concept as well. I wanted to clarification on that point and you have said about the mess we are in as a result of people—

Ms CORDEROY: I did not mean the mess of allowing people to meddle with IVF or anything.

Mr GUY ZANGARI: That could also be something that many people have campaigned and championed the cause about for years and years. We know that in our society there are avenues in which people can be given the gift of life by other methods when they cannot conceive naturally, and that is a wonderful thing.

Ms CORDEROY: I am a product of that. I am obviously grateful because I would not be here if my mother had not gone about having a child in a very unconventional way, particularly for that time. I am very happy that happened obviously.

CHAIR: The mess could also be related to the lack of transparency, the cloak of darkness that was used in this sector for many years. This inquiry is looking at two things. Firstly, retrospectivity, if we were to go down that path. Secondly, with the information we have heard from the experts and the child knowing that they are donor conceived as part of their life—what you have enjoyed as part of your life—going forward we can probably have a process that works a lot better and does not have all that secrecy. The real concern will be the retrospective changes and the effect on the anonymous donors who willing came to the party at a time when they thought they would remain anonymous.

Mr NICK LALICH: It sounds as though you were not particularly perturbed about finding out who your father was. You found out but you were not really worried about it.

Ms CORDEROY: Yes.

Mr NICK LALICH: How do you think you will go when you have children and your son or daughter wants to know who grandpa is? They will know who grandma is but what about grandpa? As a donor-conceived child would you be prepared to tell your child, no matter how they are conceived, that grandpa was Joe Blogs, a friend of the family?

Ms CORDEROY: I would say to them probably what I say to most people when they ask me about my father. I would say, "You don't have a grandpa; you have a grandma and God willing that is the person you see every day of your life. A grandpa is someone who helps to raise you, who is part of your life and who does this and that. Your mum did not have someone like that and that is her life. But you have got these other people; you have got this aunty and uncle." That is probably how I would go about explaining it, and if they wanted more information when they were older I could tell them who the person was. I very much want to make it clear that I did not have a father and there was nothing missing because you do not miss something that you don't have.

CHAIR: Thank you for appearing before the Committee today. The Committee may have some additional questions for you and, if so, your answers to those questions will form part of the formal evidence you have given.

Ms CORDEROY: Thank you.

(The witnesses withdrew)

(The Committee adjourned at 4.56 p.m.)