

# CORRECTED VERSION

## LAW REFORM COMMITTEE

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

Melbourne — 8 September 2011

#### Members

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#### Witnesses

Dr L. Hale, IVF Directors Group, and  
Dr P. Foster, Fertility Society of Australia.

**The CHAIR** — Thank you very much for coming to this hearing today. This is a cross-party parliamentary committee, so we have representatives from the Labor and Liberal parties. I need to warn you that all evidence taken at this hearing is protected by parliamentary privilege as provided by the *Constitution Act 1975* and further subject to the provisions of the *Parliamentary Committees Act 2003*, the *Defamation Act 2005* and, where applicable, the provisions of reciprocal legislation in other Australian states and territories. In essence, what that is saying is that you are protected by parliamentary privilege in this room, but you are not protected outside this room. Journalists are taking some interest in this inquiry, so if you are asked questions, be aware that that protection is not provided out there.

Can you start by stating your full names and addresses?

**Dr HALE** — My name is Lyndon Hale.

**Dr FOSTER** — I am Penelope Foster.

**The CHAIR** — Are you both representing the Fertility Society of Australia?

**Dr HALE** — Yes.

**The CHAIR** — In what capacity are you representing the organisation?

**Dr HALE** — I am on the board of the Fertility Society of Australia. I am also the chair of the IVF Directors Group and was asked to coordinate the bringing together of the submission. It was suggested that some colleagues come along as well, so I asked Penny to come as the director responsible for donor services at the Royal Women's Hospital. My other colleagues at Monash were overseas, so I was not able to get them in at this stage.

**The CHAIR** — We will be recording all the evidence and that will become a public document in due course. Perhaps you could talk to your submission for 10 or 15 minutes. Generally we have been firing questions as they arise in the course of presentations. If you are happy to deal with the questions like that, it would be good.

**Dr HALE** — By way of introduction, and then I will perhaps go to the executive summary and we can take it from there, the Fertility Society of Australia is a multidisciplinary group that includes IVF doctors, scientists who work in the area, the Australian and New Zealand Infertility Counsellors' Association and also the Fertility Nurses of Australasia. It is very much a multidisciplinary group, and they were all asked for input to this. This area of discussion is not unfamiliar to us, because we recently had to do a similar submission to the federal legislation.

**The CHAIR** — Could I ask what is the status of the organisation? Is it funded by government or is it purely privately funded?

**Dr HALE** — It is funded by the subscriptions of the membership.

**Dr FOSTER** — But it is also a lobby group, is it not, for infertility patients?

**Dr HALE** — Yes, for patients — and we make representations to government, particularly the federal government with regard to funding. We have made multiple submissions in the past to the different acts that have come through. I suppose where we would have our major concern is with the legislation being retrospective. We would strongly advise against or oppose the release of any identifying information about donors without their consent. But trying to marry up those two concepts that we would like people to have information about their origins as opposed to respecting the privacy and the consenting issues from the past, we would make all representations and try — in actual fact if we had a request for identifying information — to have a process in place for that to occur.

**The CHAIR** — In essence what you are saying is that the right of the donors to anonymity outweighs the right of the child to be aware of their origins?

**Dr HALE** — Yes. Those people who donated sperm 20 years ago did so with an absolute understanding that it was private and confidential information. We have had some experience with going back to those donors and

saying, 'We have had this request. It is a deep-seated request. Would you consider relooking at the consent that you gave to releasing the information?'. We have had examples where that has occurred and the donor has consented to that process. I am also aware of a medical situation where it did not occur. I would like Penny to explain that situation, which will explain some of the difficulties and pitfalls that could occur.

**Dr FOSTER** — Shall I explain that now? We had contact from one of our donors who had donated pre-1988 and who had four offspring who were all aged about 29 or 30. This situation arose about four years ago, so they are all in their early 30s now. He developed a heart condition which put him at risk of fainting and even sudden death and there was a 50 per cent chance that any offspring would have inherited this condition. So it was potentially a quite serious condition. You can do a medical screening test for it to see if you have inherited it, and if you have, then you can have either appropriate medication or intervention such as a pacemaker to try to prevent your dropping dead.

We thought this was a serious enough risk that we should try to contact his four offspring to let them know of this risk to their health and recommend that they have an investigation of their heart status. Because they would not necessarily have known of their donor conception, we chose to go back to each of their parents and ask if we could have their permission to talk to the children — the four offspring all in different families — about this issue. It took us four years to work through that process, because back then when these couples had been treated it was not usual for you to tell your children they were donor-conceived. In fact secrecy was the norm. Despite all the counselling efforts that disclosure was in everybody's best interests, secrecy was the absolute norm. In all these cases the adult children did not know they were donor-conceived.

It took a lot of negotiating with the couples involved to discuss with them whether they would tell their children this. In one particular case, where the 30-year-old son was a pilot, there was huge resistance to telling him because they thought it was going to tear the family apart for him to find out at this late stage that he was donor-conceived. It was four years from when we started to when he was actually told of this risk. He was tested and he does have a heart anomaly. He is a pilot, not of a big plane but a little plane, so it was a very serious medical condition.

The other issue that arose was that as all this evolved with the help of his parents we wrote a letter to his mother explaining the situation — she wanted something in writing — but she still was not ready to tell her son. While the mother was away on holiday she had asked her daughter-in-law, her son's wife, to come to collect the mail. She said, 'Come and collect the mail, and open anything that looks urgent'. The daughter-in-law opened the mail and read the letter explaining the heart condition in her husband, who did not know he had a heart condition and did not know he was donor-conceived.

I thought I would tell you this just to show you the difficulties of doing something retrospectively from a time when conditions were very, very different and when people did not expect to have this thrust upon them. Even though it was a life-threatening condition for their son, it took them four years to get around to acknowledging they were going to have to expose this secret in their family and all the risks that that entailed to family relationships. But it also tells of the risk of just sending a letter cold to somebody. I think if we are ever to do something in terms of donor linking, we have to have very good processes in place, because you cannot simply send a letter and assume that however it is marked it will not be opened by somebody inappropriate.

**Dr HALE** — There are two other comments about that. We had gotten to the place where we had said to the parents, 'We can't wait'. We had advice, we took it to the ethics committee and we took it to a lot of places, and we said, 'We actually can't wait and we are going to tell your son whether you like it or not'.

**Dr FOSTER** — And that is what that letter was about.

**Mr NORTHE** — I suppose one of the conundrums we face as a committee is how do you provide that confidential information to the donor or even the donor-conceived person, making sure that you are not breaching privacy and that somebody is not going to get that surprise in the mail, as you have just outlined. Do you have any ideas and thinking about how you might do that?

**Dr HALE** — They are difficult, but essentially it revolves around personal contact.

**Dr FOSTER** — And you need counsellors who are used to doing that and who have had contact with patients before in similar situations.

**Dr HALE** — It can be very difficult, because it is a mobile population — they may be overseas — and each individual situation will need its own resources.

**Dr FOSTER** — We had to search electoral rolls to track down these four parents. One other point I was going to make is that when the wife found out, or read the letter, she rang the mother-in-law and the mother-in-law said, 'Please don't tell our son'. So she hung up and immediately rang the son.

**The CHAIR** — That issue you described, though, would not be confined to pre-88, because you would still have the same situation with somebody post-88 if they had not been informed.

**Dr FOSTER** — Yes, you could, but post-88 there was the possibility of contact if they consented; pre-88 it was never going to be told.

**Mr NORTHE** — The subsequent question I ask is who, in your mind, might be a better controlling authority to deal with this? Who should it be? Should it be a doctor? Should it be an authority?

**Dr HALE** — In our clinic we have taken the attitude that that is our responsibility, because we provided the treatment. So where we have had the request, our counsellors have done that.

**Dr FOSTER** — We think that is appropriate, because they have those skills.

**Ms GARRETT** — Unpacking that, which is a very good illustration of some of the issues, is it your basis that the anonymity derives from a contractual arrangement entered into with the donor at the time? And when you said the ethical obligation would then override that, what is that obligation to override that anonymity pinned on, and how is that determined and when?

**Dr FOSTER** — In this case it was a very big step for us to contact the patients, and we had several ethics committee appearances to discuss what was right and what was wrong and how far we could go in asking these parents to tell their children what was going on. We were not breaching the donor's confidentiality because they did not get identifying information about him.

**Ms GARRETT** — That is right.

**Dr FOSTER** — We disclosed a medical condition but no identifying information about the donor, and that was never part of the picture. We did not ask him for that. In fact he did not want that; he had made it perfectly clear.

**Ms GARRETT** — So your obligation that you sought to say that your ethics required you to act on was to the parents, the women — —

**Dr HALE** — No, to the donor-conceived child because there was an imminent or possible serious — —

**Ms GARRETT** — Sorry, of course to the child, but the obligation that you would have normally to the parent would be the same, that this was all confidential?

**Dr HALE** — Yes.

**Ms GARRETT** — So it arises from the same — —

**Dr FOSTER** — Yes.

**Ms GARRETT** — That they are all anonymous?

**Dr FOSTER** — But you are quite correct when you say that we feel an overriding obligation to preserve the confidentiality of the donor, because that is the condition under which he agreed to donate sperm in our clinic.

**The CHAIR** — Would you believe the anonymity agreement would be breached if there was a requirement for the records to be provided to a third party, an agency which holds all those records?

**Dr HALE** — Our concern would be that we as a clinic had provided that undertaking and then would be handing it off to a third party.

**The CHAIR** — So you think that it would breach anonymity if we were to recommend that all the information from prior to 1988 that is held be collated into the one space?

**Dr HALE** — I suppose our concern would be who the best person to do it would be given the clinics are still running. Yes, there is a situation in Victoria where Prince Henry's Institute closed down, but if we look at the two major clinics that provide these services, which is Monash and Melbourne, they have been going since the mid-1970s and there have been several changes of the act. In actual fact they have been the more constant feature of the landscape as opposed to the act and the authority because we have had the SRACI, which is the Standing Review and Advisory Committee on Infertility. That has been rolled up and sent somewhere else. The ITA has been rolled up and morphed into VARTA, so in actual fact there have been three iterations but the clinics are still there and doing their work.

**Dr FOSTER** — I think there are two issues. One is of course information and who provides the counselling to link in, and it is quite difficult to separate them. They probably belong together, so if you give one body the information but do not provide them with the staff and the skills to use that information properly, I think there is a risk that we are running a very poor service with very bad outcomes. If people are approached in an insensitive or in an appropriate way — —

**Mrs PETROVICH** — One of the concerns I have is that a couple of major agencies have participated in this. From our investigation it seems anecdotally there has been a plethora of people who were involved prior to 1988 when it was very unregulated. If we were to have a centralised register, which I think would be fairly difficult anyway because of the disparity of the information, but if we were to have something of that nature and there was a protection of those donors as per the agreement, would it work if we were to have a campaign to ask some of those people who donated to come forward? Would people be willing to give that information now — 20 years or more on — to that centralised register, perhaps to ease the pain of some of these people who were donor-conceived?

**Dr FOSTER** — There have been campaigns.

**Dr HALE** — There have been, and some people have come forward and some have not. I suppose that with a mobile population the campaign would need to be Australia-wide and almost worldwide, because some of these donors will have moved to other parts of the world.

**Mrs PETROVICH** — And obviously we can only deal with what is within the sphere of the state government.

**Dr FOSTER** — In previous campaigns people did come forward and put their names on the voluntary register so that if contact was made from an offspring, his details were there and he was happy to provide other identifying or non-identifying information. That has been done, and people did come forward.

**Mrs PETROVICH** — Do we know how efficiently that was done?

**Dr FOSTER** — No. I think it was run by the ITA, which was the predecessor of the current VARTA. I think it was fairly widespread in Victoria. Certainly I saw it in Melbourne, but I do not know how they did in country towns; I do not think they did a lot. It was more like public notices in newspapers and there might have been a little bit of radio, but I do not think it was huge, and it may not have been funded very well either.

**Dr HALE** — Anecdotally, that has worked quite well. I saw a patient earlier this week who is having an operation this afternoon. She showed me a picture of her donor-conceived child, the two children from another donor-conceived family and the two children from the donor's family. They were all having a picnic somewhere here in Melbourne, and the kids are all in their teen years, I would say.

I think where there is a willingness and a desire — and it can flow both ways as well; the person who has provided the donor sperm or the donor material — —

**Mrs PETROVICH** — I do not think it can work any other way.

**Dr FOSTER** — Even the man who had the cardiac condition is a doctor now. He had donated as a young medical student. Although he knew this was a really serious condition and he was prepared to come and tell us and make the information available so we could contact his offspring, given all that and the fact he was a doctor

who should be concerned about the wellbeing of other people — perhaps slightly more than others, who knows? — he still did not want his identifying information made available to his offspring. That was the condition under which he donated. He would do everything possible to make sure they had the medical information, but he still wanted his family life protected. He had a wife and some children around the same age as his donor offspring and he did not want any threat to that.

**Ms GARRETT** — Did you find that the children who had then been told wanted to see him, or was — —

**Dr FOSTER** — No, they did not ask for that. They were happy to have the information and happy to have the screening. I did not participate in the counselling process once they were contacted; I only had feedback from the counsellors. But my information is that they did not ask for identifying information. They may have been told, though, that he did not want — —

**Ms GARRETT** — Did not want it so it was not going any further.

**Dr FOSTER** — Yes, that he wanted to provide this but not that.

**Dr HALE** — As I said, we do not do that counselling but the feedback from the counsellors would be that there are different levels of information that they would like. There is a level where they get nothing or they just get height and health, whereas when the donors are approached, some of them are quite happy to provide a much more extensive list of characteristics, hobbies and those sorts of things but not stuff that would identify them.

**The CHAIR** — As I see it, there are two main issues that we are facing. The first is what you do with the information in terms of whether it is released and how it is released. Then you have the collection and safekeeping of the information. There is no point in coming to a conclusion on the first if you have not got the information stored and able to be accessed. You have given us some evidence that your organisation is particularly good at recordkeeping. My understanding is that back in the 1980s there were a lot of smaller clinics and doctors who assisted with donor conception. I am particularly concerned that if you have got the information sitting in boxes in garages in the suburbs. In that circumstance it is my view it would be better to have it stored somewhere centrally even if it is not a requirement when you have a well-run institution that is keeping good records.

**Dr HALE** — I would have to look at the historical part of it, but the Fertility Society of Australia began as a donor-conception program because that was one of the initial treatments it did. Part of that arose out of the fact that when HIV/AIDS came along it became an absolute requirement to quarantine sperm. This is well before my time; I was probably still in medical school or even in high school when donor material was used fresh. That would have been a private arrangement in doctors' surgeries.

As it became more formalised and there was a requirement for laboratories to be involved to freeze the sperm for the tracking of information, that is when you then had Monash, Melbourne and Prince Henry's Medical Centre. As I said, Melbourne, which I am associated with, has a very strong record, and I believe the same is true at Monash. One of the other things about the Fertility Society of Australia is that we have an accreditation process which is recognised in legislation federally. One of the requirements is in regard to the keeping of information and the identity and all those matters. I think that is quite good.

Getting back to your point about whether there would be donor-conceived individuals who there are not records available for, it is very possibly so.

**The CHAIR** — Is there any merit in the idea of requiring those doctors who were small-scale contributors to the whole process being required to provide those records if they still have them?

**Dr HALE** — You may have to help me here, Penny, but Ian Johnston was the chair of the Melbourne IVF — in fact he was the founding president of the FSA — started the donor program at the Women's Hospital, but sadly he is deceased. Before that it was Carl Wood, who sadly has Alzheimer's. I do not know where one would — do you have a thought on that?

**Dr FOSTER** — I think the institutions would hold the records about a donor's identity rather than the doctor who was the treating doctor. The experience I had in looking for the offspring of this particular man with the heart problem was that we had all that information, not anybody else.

**The CHAIR** — So even pre-1988 one of those three institutions would have all the information.

**Dr FOSTER** — Yes. These were from about 1979, so yes, the institution had the records, and they certainly had a record of who the donor was.

**Dr HALE** — But if the donor-conceived sperm was frozen sperm, absolutely; the institutions had to have had that, but with their private arrangements in the 1950s and before, I do not know.

**Dr FOSTER** — I do not think that is the issue, though. It is not the children born in the 1950s, it is from the 70s and 80s onwards.

**Ms GARRETT** — What sorts of numbers are we talking out of, for example, Royal Melbourne, in that period?

**Dr HALE** — Who wants to know, or who may want to know?

**Ms GARRETT** — Who were conceived? Do we know? And then what percentage have sought to know?

**Dr FOSTER** — I could give you an answer, but I could not say.

**Ms GARRETT** — That is okay, I am just interested in what figures we are talking about.

**Dr HALE** — It is not in the hundreds per year. It would be of the order of 20 to 50, but that is a bit of a guess.

**Ms GARRETT** — That is fine. How many requests do you deal with from people who are seeking information?

**Dr HALE** — We have had one request that has gone right through the whole process and they did get identifying information that was okay to be released, and we have had a handful who have sought lesser information, but not identifying. We would think it would be of the order of 1 to 2 per cent.

**Ms GARRETT** — Is that because they are the ones who are being advised, or is that just how it goes? A lot of people would not know for years, would they?

**Dr FOSTER** — That is right, a lot of people would not know.

**Ms GARRETT** — Given those were the prevailing conditions at the time.

**Dr FOSTER** — We would not know, now, how many were told by their parents of their donor origins, but I would suspect that from the 1970s and 1980s many were not told and would still be unaware. I know that from counselling surveys of how many parents actually do tell.

**Mr CARBINES** — I just wanted to ask in relation to donors, what is your understanding of what choice they would have been given when making a decision to donate? Did they tick a box requesting full confidentiality and anonymity, or did they tick a box allowing full disclosure? Under what circumstances do you understand donors in that period pre-1988 would have been contributing to the program?

**Dr HALE** — I think the prevailing philosophy at the time was that it was going to be anonymous. It was not a tick-a-box-type situation in terms of disclosure.

**Mr CARBINES** — Do you think that they felt they were in a position to express a view or that they were entering a program where the conditions under which they were making a donation — that is, it was anonymous or information was not made available — were set? Was there a choice? Was it that they were happy to make a donation and those just happened to be the arrangements that were set in place, as opposed to a choice? I am just trying to get an understanding of that.

**Dr HALE** — For information on the counselling at the time, we would have to go back and talk to the senior counsellors of the time, but because it was an anonymous program the assumption would have been that the child would not be told and that it would not be disclosed to the children and, therefore, they would be contributing on that basis.

**Dr FOSTER** — I can confirm that, having spoken to counsellors from that era; it was not offered as a choice, it was just, 'These are the conditions of the donation'.

**Dr HALE** — The prevailing community idea was that this was anonymous and, therefore, the information would not be disclosed.

**The CHAIR** — Dr Hale, could you flesh out your comment about personal contact being the best way to try to contact people sensitively? How would that occur?

**Dr HALE** — We gave the example of sending a letter giving the actual condition, causing alarm and concern and then someone else reads it. It could be done by a phone call or a letter saying that the clinic wanted to talk to them, without specifying what it was about. There could be a number of different levels too. My understanding is it is initially done by personal phone call.

**Ms GARRETT** — Which avoids the complication of the daughter-in-law opening it.

**Dr HALE** — But if you were not able to do that, you would send them mail. You would be sending it from the clinic. In the case of the Royal Women's Hospital we would send it from the Royal Women's Hospital. It is a bit along the lines of when I have a medical certificate for one of my patients they will ask if they can have it without 'infertility specialist' on it. I accommodate that; it is just 'Dr Hale' so that their boss does not know they are going to an infertility practice.

**The CHAIR** — The costs of providing these matching services, is this something you absorb in the cost of the organisation? Can you estimate how many hours you would spend on an average inquiry where you have to track down the donor and seek permission and everything else?

**Dr HALE** — Dozens of hours, I would have thought, from the infertility counsellors. It has not been a queue going out the door. There have been odd requests. We, as an organisation, would think that we have a duty of care, given the treatment we offered in the past. If it is going to become more common, then that is part of the skill set that we expect our counsellors and doctors to have. The Fertility Society as well as the clinics — and I do not think I am speaking out of turn here — would think we are at the forefront of where this is all going and that, therefore, we are the experts and should be providing the advice. I think you would agree with that, wouldn't you?

**Dr FOSTER** — I would completely, on both counts. We feel a duty to provide that and to absorb the costs ourselves, because we have been the care providers in the first place. Yes, it should be provided by people who are able to do it, and do it well.

**The CHAIR** — Do you think it would be fair for you to have the obligation, if offspring contact you, to go that step towards contacting the donor, or is it something you do if you feel like it but you do not feel there is any great obligation to do it?

**Mr NORTHE** — Sorry, can I just preface that, if you do not mind: the obligations might be morally and socially right, but what about legally as well?

**Dr HALE** — There is not a legal obligation at this point in time. I cannot speak for all clinics on that matter, but as an example, at the organisation that I am with, we would consider that as being moral and ethical, and therefore we would do it, and have done it.

**The CHAIR** — Does the act of contacting for this purpose breach the anonymity?

**Dr HALE** — No. If we were contacting the donor, we would see there are privacy issues. We have had a relationship with the donor in the past, therefore we are not breaking that because we are contacting them directly.

**The CHAIR** — Just to clarify — and I think you answered this before — your concern would be that if you provide that information to another agency and they do the contact, that would breach that anonymity contract.

**Dr HALE** — That would breach the privacy, because we have handed their private information on to another organisation.

**Ms GARRETT** — Just to flesh out this concept of the privacy of the donor, in the example you gave, none of that was taken lightly. I think it was you, Dr Foster, who mentioned that contacting a donor many years hence can be very disruptive and unsettling. Given the contractual relationship at the time the donation was made, would it be yours or other clinic's view that the act of contacting the donor, given the donor-conceived child was seeking identifying information, would be problematic? If the donor thought they were walking away and they expressly did not want to know what happened to their donation, how does that fit in? Would that require legislative change, or do you think it is a discretionary issue?

**Dr HALE** — We have seen it as discretionary.

**Ms GARRETT** — You have, but others perhaps may not.

**Dr HALE** — They may not. That has not backfired, to date, for us.

**Ms GARRETT** — So you think that, given the contractual arrangements at the time and where donors are contacted, that is not beyond their understanding of what their role was at the time?

**Dr FOSTER** — I think some of them did not give it much thought at the time, it is fair to say.

**Dr HALE** — It is mentioned endlessly that medical students are sort of corralled.

**Ms GARRETT** — It is, yes.

**Dr HALE** — ‘Here you go — this is part of the prac in third year’. You would have to think that if you donated sperm and you actually read a paper occasionally, that there would not be too many who would not know of the debate in the community. Does that make sense? Whether you read the big paper or the little paper or listen to the commercial stations or the ABC, this has been discussed a multitude of times. You would have to recall having donated sperm, I would have thought.

I think you mentioned a community program of education. I would assume that if you have done something like donate sperm, you would be mildly interested when it came across the news, and therefore it would not be a surprise if you then got contacted. I think where they would rightfully get very upset is if we breach their privacy or went outside their consent parameters.

**Mrs PETROVICH** — Thank you very much for your presentation. When a person seeks information on their background, if the information available is non-identifying, is that information provided to the person automatically, and if it is, is the next step then to contact the donor to let them know that somebody is actually looking for them?

**Mr NORTHE** — Dr Hale, just further to Donna's question, in your exec summary you talk about getting that non-identifying information and suggest the donor be asked. Should the donor be asked or required, in your view, to provide that information?

**Dr HALE** — I see what you are saying. If we were contacted, we would give them whatever information we have, because the reason we collect that information is to give it to them, and the donor would expect that. The next level up is further non-identifying information that the donor could reasonably provide without their identifying it. I am surmising — this is my opinion — that that would be not an unreasonable request, I would have thought, apart from, say, if their occupation happened to be — —

**Mr NORTHE** — There is a distinction between being asked and being required.

**Dr HALE** — Sure, but if you are setting something up that says, ‘You are required to give non-identifying information, such as occupation’, and you then have to write down ‘Prime Minister of Australia’, you could have a problem because it identifies you.

**Mrs PETROVICH** — My component of that was slightly different in that if they have the non-identifying information that is available — and you assume at that point it is to be provided — the next step for me would be do we then let the donor know there is somebody who is looking for them, not as a requirement but as information that may assist?

**Dr HALE** — It could be a requirement that we ask the donor, and then the next level up would be a requirement that the donor has to give it. I personally would be happy enough with a requirement for the donor to be contacted, respecting their privacy and consent issues. That is covered by the NHMRC guidelines, by the way. I do not know if ‘cover’ is a good word or not. Does that make sense? We are very much guided by NHMRC guidelines as part of our accreditation. That would be reasonable, but I think it would be unreasonable to compel the donor to release information they did not want to, because it goes against their privacy.

**Mr NORTHE** — I have a couple of questions. I do not know if this is factual or not, I am just curious about it. Do you think donors themselves, particularly those pre-88, may not come forward for a number of reasons or may not want to be contacted for a number of reasons? Obviously they might be living in a family situation now and do not want to disclose it. Is there evidence otherwise to suggest that they might be fearful of coming forward because there may be some legal obligations that might be imposed upon them, and do they understand the legalities that making contact through this particular forum might mean for them?

**Dr HALE** — It is possible, but they do not have any legal responsibilities, because most of their children would be above the age of 18. I think they would understand that. There may be some issues with regard to estate planning and those sorts of issues. Where we have then contacted them, that would be part of the counselling process to go over again all of those issues.

**The CHAIR** — Do you have an information sheet on the legal issues that you give to donors to address concerns such as claims on their estate or claims on maintenance?

**Dr HALE** — Yes, that is covered in the counselling process.

**The CHAIR** — I am interested to see what the situation is. Would you be able to provide us with a copy?

**Dr HALE** — We can provide that, yes.

**The CHAIR** — That will save you guys doing some research.

**Mr NORTHE** — Further, if I can just ask a subsequent question, you mentioned the counselling, and I guess one of the concerns you have raised in your submission is the transition from the ITA to the registrar now around counselling services. Did you want to briefly speak to that and how you see that those services through the registrar could be enhanced?

**Dr HALE** — It was transferred to the ITA, and the ITA took a lot of effort and went to a lot of protocols to set up quite a good counselling service — and we believed it was good because in actual fact it was some of our staff who did that — Helen Kane and Kate Bourne. In actual fact counsellors look at our program. You have to understand that this is quite a small area of medicine, so you would not expect a lot of expertise and there is a bit of speculation that goes on. I suppose one of the concerns we had transferring it to Births, Deaths and Marriages, where it just becomes much more of a tick-a-box perfunctory thing, was that without providing that deep understanding of counselling issues it is a major concern, yes.

**Ms GARRETT** — On that, if I could ask about the submission about the establishment of a service to assist all of those things.

**Dr HALE** — Sure. I think in Victoria you have the two programs that were there at the beginning, which are still going and seeing it as their obligation to do it. Then there is the Prince Henry’s, which closed down. There is a group of patients, and that is where we believe the resources should be put. If you are going to embark on this finding of information and passing it each way, you have to resource it.

**Ms GARRETT** — Would you see that you continue to do your thing, Monash continues to do its thing and then there would be a supplementary service, as there used to be for those who might have fallen through the cracks, or would you see consolidation as the key?

**Dr HALE** — I have not given that a lot of thought, but if expertise lays within the clinic, maybe it could be contracted back to the clinics to do that. What is your thought about that?

**Dr FOSTER** — I think that would be the best solution, because they are the counsellors with the civil setting, and it would make sense to use that.

**Dr HALE** — Rather than establish a completely different organisation that may get two referrals in three years.

**The CHAIR** — So are you suggesting having, for example, your organisation handle the inquiries in relation to the Prince Henry's conceptions?

**Dr HALE** — That would be one way to go. We would obviously want to make that a cost-neutral thing, but you do not want to set up a whole different organisation, I would have thought.

**The CHAIR** — So it is really either you or Monash.

**Dr HALE** — The other IVF group in Melbourne now is City Fertility, but they have only been around for six years or so, so they are not going to do it. None of their patients are going to be under the old legislation. In terms of the old legislation you are talking about Melbourne and Monash and Prince Henry's.

**The CHAIR** — Do you think people who are donor-conceived children would have a better experience and have more likelihood of success if, for example, you were resourced to handle the Prince Henry's records rather than going to Births, Deaths and Marriages? We had some evidence this morning of a bad experience that someone had going through that process and how they would be better going to you or Monash and going through your counselling service and having an easier flow of information.

**Dr HALE** — Yes.

**Ms GARRETT** — Sorry, on that, the only people now who would be butting up against Births, Deaths and Marriages would be the Prince Henry people. Is that right, or could other people be coming through you?

**Dr HALE** — I cannot speak for Monash personally, but people who had treatment at the Women's Hospital — —

**Ms GARRETT** — Would be coming through you.

**Dr HALE** — We would look after them.

**The CHAIR** — If someone is told that they are donor-conceived but they do not know anything else, what would they do? Would they call you and say, 'Can you help me?', or would they go to the Victorian Registry of Births, Deaths and Marriages first?

**Dr HALE** — Presumably they would be told by their parents who would remember where they had treatment. How else would they get the information?

**Dr FOSTER** — They would say, 'Where were you treated?' and they would go back there.

**Dr HALE** — That has been our experience. They have turned up saying, 'My mum had treatment here. Can you help me?'.

**The CHAIR** — In general terms is your submission today that everything — the way you operate, the whole system — is working quite well and there is no need for any legislative change?

**Dr HALE** — In summary, yes, you could say that. I suppose what we are saying is that this problem has occurred, we have addressed it, and to my knowledge there have not been any bad outcomes as a result of that. If there are systems in place, why do we then need to start a whole new system, if that makes sense? Our major concern with the terms of reference was that bit about whether we should change the law and make this retrospective.

**Ms GARRETT** — To go further with the evidence this morning from PILCH, they acted for a Ms Springfield who was conceived following treatment at Monash IVF. She wrote to Monash IVF requesting that they contact her biological father, and the doctor there refused to act as an intermediary on the basis that the donor had elected to remain anonymous, which goes back to what we were talking about with the breadth of anonymity. At Melbourne you obviously take the view that you are able to contact the doctor, but it does not appear that Monash takes the same view. Are you aware of that?

**Dr HALE** — I had heard some of that, but I was not aware whether that was a Prince Henry's Institute or a Monash issue.

**Ms GARRETT** — That was a Monash issue according to this case.

**Dr HALE** — Certainly the document was prepared and circulated to all the clinics for input.

**Ms GARRETT** — That is how this woman ended up pursuing her contact with Births, Deaths and Marriages, and then they said they had no power to take it any further. There are obviously some discrepancies between the clinics.

**Dr HALE** — There may need to be further discussion and education on all levels, remembering also with the IVF or ART units that we have 20 doctors in our clinic and Monash would have a similar number.

**The CHAIR** — So there may not be consistency applied between doctors?

**Dr HALE** — Potentially. I don't know. I cannot speak for them.

**The CHAIR** — Do you have a written policy as to how you handle these requests, or it is just an understanding that you help out where you can?

**Dr HALE** — Our policy is written down, I think, isn't it? It is an understanding. It wouldn't take long to make a policy. Certainly our counsellors follow the executive guidelines, which we could give you a copy of.

**Mrs PETROVICH** — From the perspective of a donor-conceived person whose mum has not told them where the treatment was given, what is the starting point, and is there a sufficient process for that person to follow?

**Dr HALE** — Presumably they would find out because there has been some DNA typing for some medical reason and they have found out that way. I suppose you may be alluding to the scenario where their parents may be deceased. Where would they go next? I suppose they would go to Births, Deaths and Marriages if they were aware of that link, or they would know from reading the papers and things that there were only two clinics that did it — Melbourne or Monash.

**Mrs PETROVICH** — But there is no go-to agency, apart from Births, Deaths and Marriages, to assist these people?

**Dr HALE** — No, not that I am aware of.

**Mr CARBINES** — We talked earlier about the different ways in which the media provides some prominence or provides an opportunity for people who were either donor-conceived or were donors to follow community discussions over a long period of time. Obviously we have advertised extensively, not on just this occasion but also in the past, the terms of reference for the matters we are discussing. You alluded to some of our terms of references that you want to address or comment on, particularly around retrospectivity. Do you have a view as to why, I think it would be fair to say, it has been more difficult to get donors to choose to make a contribution to the Committee's work so far.

That may change as we continue along. But in trying to get a sense of it, is it that they feel their position is being advocated by other groups, that they have their fingers crossed or that they feel, 'Wait and see what happens'? I am just trying to get a sense if there is anything that we need to do to try to elicit further comments or viewpoints so as to get some further empathy as to how donors feel in relation to the terms of reference. I accept the point that if you were a donor, perhaps you would not be aware the entire time of these matters that bob up in the community consciousness and get discussed.

**Dr HALE** — It is difficult to give you a clear answer on that as we do not have much contact with the donors because they have moved on. Certainly the media, as you will be aware, can be a very powerful tool for good and can be a powerful tool for plain idiocy. I suppose that is another thing.

Just to give an example, I had a patient yesterday who was looking to do sex selection for autism, which is not in fact permissible. I said, 'If you want to do it, you have to go to the Patient Review Panel'. Her comment then was, 'Does that mean it will be all over the news with my name?', because all she could remember was the fact that there was a couple that did sex selection when they conceived and then they terminated the pregnancy. Her perception of dealing with a government body was that basically her private information would go onto page 1 or page 3 of the *Herald Sun* and she would be a pariah. That is just one example of the perception of patients who do not have a lot of contact with media.

**Mr CARBINES** — I suppose, despite the fact that we can potentially have closed hearings at different times and have other mechanisms available to us, the alternative to their not making a contribution can be how we then may choose to address the terms of reference. They may be making a judgement. We can only speculate.

**Dr FOSTER** — May I add something? We have had a couple of our donors come and talk to our doctors' meetings at lunchtimes, and they were very articulate and extremely interesting to listen to but they did not want to do anything apart from talk to us. For example, they did not want to go on any advertising material for more donors. If you wanted to get a view from the middle, you would almost have to do it through the clinics and say, 'Could you circulate this to your donors and see if there are any of them who would want to come and talk to a committee like us about what it meant to be a donor?'. I think they would be more likely to respond to a very personalised approach through one of the infertility groups. I think it would be worth hearing from them, though.

**Mr CARBINES** — Yes, that probably picks up that sometimes the contributions made by organisations like yourselves can be based a bit on the fact that sometimes donors would choose to have a conversation with you about things and that may inform some of your thoughts. I think we are always looking for ways in which we can elicit some further contributions from donors in our deliberations.

**Dr HALE** — Just in addition to that, we are actually running our annual world conference here in November in combination with Human Reproduction. One of our programs is around this linkaging stuff. The case that was going to be put forward was actually a Monash case, which I was bit surprised by. They did contact the donor and find out, so there has been contact between the donor and the donor-conceived individual, and that donor was happy to participate but only by video link with their face blacked out.

**Ms GARRETT** — Just quickly, in terms of the contractual obligations that your institutions had pre-88, has there been a suggestion that you are facing legal action from any donors or what the legal position of those donors may be in protecting their anonymity? Has that ever been a question, or would you just imagine that they would have a legal — —

**Dr HALE** — Not that I am aware of.

**Dr FOSTER** — We have not explored that capacity.

**Dr HALE** — I suppose because we have taken the attitude that we will protect their anonymity and their privacy.

**Dr FOSTER** — We did take legal advice, though, when we were contacting these four donor offspring — or rather their mothers — about the father of these four offspring, with the father with the heart problem. We took some advice about whether we were breaching any privacy issues in that.

**Dr HALE** — And the advice was that we were on strong grounds to do what we did.

**The CHAIR** — Thank you very much; that was really helpful. You have put a lot of work into that.

**Dr FOSTER** — If you are interested in talking to donors, I do not know how long you are sitting for but it probably would not be too late for us, through our counsellors, to see if we could find one or two who would be interested in coming to talk to you.

**The CHAIR** — Yes, all right. We will get Vaughn to contact you.

**Dr FOSTER** — The ones who spoke to us, for example, are here.

**Mrs PETROVICH** — We could do it in a closed hearing.

**Ms GARRETT** — Are these current donors or donors from pre-88?

**Dr FOSTER** — I do not think they are from pre-88; I think they might be from that middle period. I know one of them has been in contact with one of his offspring. They might be quite happy to come to talk in a session like this upon invitation. That would not be impossible if you thought it would be valuable.

**Dr HALE** — Certainly given that we have contacted several from pre-88, maybe we could contact them again.

**Dr FOSTER** — No, but I think one or both of the ones who talked at our meeting would be very likely to say yes, given that they were happy to come to talk to the Melbourne IVF doctor group.

**The CHAIR** — And they are donors who have gone through the process of being sought out by their offspring?

**Dr FOSTER** — One of them has. I think the other one has but in a non-identifying way. One has done identification, one has not. They were fascinating.

**The CHAIR** — Vaughn, would you follow that up?

**Dr KOOPS** — Sure.

**Dr HALE** — In summary, we believe there is a good system and, given that we are the people who provide the treatment, we are the best ones to deal with the consequences of treatment.

**The CHAIR** — Thank you.

**Witnesses withdrew.**