

CORRECTED VERSION

LAW REFORM COMMITTEE

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

Melbourne — 12 September 2011

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Witnesses

Ms Marianne Tome, and
Ms Rita Alesi, Victorian Infertility Counsellors Group.

The CHAIR — Thank very much for coming in. My name is Clem Newton-Brown, I'm the Chair of the Law Reform Committee. This is a committee which is convened by Parliament to investigate various issues in relation to law reform, this is one of three references that we're looking at. It's a multiparty committee so I've got Jane Garrett, who's the Deputy Chair; Russell Northe and Anthony Carbines.

Basically everything you say will be taken down and we'll end up preparing a report which will recommend changes to Parliament as a result of the inquiry. Anything you say here is protected by Parliamentary Privilege but outside of this room you can be sued for what you say, if someone so chooses, so just be aware of that if you're speaking to journalists as a result of your evidence today. So if you can start by giving us your names and addresses and who you represent and then after that if you could launch into your verbal summary of your submission and we'll ask some questions along the way.

Ms TOME — I'm Marianne Tome, I'm from Melbourne IVF. Do you want the Melbourne IVF address?

The CHAIR — Yes.

Ms TOME — 344 Victoria Parade, East Melbourne.

Ms ALESI — I'm Rita Alesi from Monash IVF and I'm from Suite 1, 252-256 Clayton Road, Clayton.

The CHAIR — And your role at Melbourne IVF?

Ms ALESI — Monash IVF. I'm the Manager of Counselling Services at Monash IVF.

The CHAIR — What have you got to tell us?

Ms TOME — As I said, I'm from the Melbourne IVF, Manager of the Counselling Department, and Rita is the Manager of the Counselling Department at Monash IVF. We're speaking today on behalf of the Victorian Infertility Counsellors Group, a group of approximately 25 social workers and psychologists who work in the assisted reproductive field. We are representing the views of the Victorian Infertility Counsellors Group, not necessarily our employers.

The CHAIR — Can we presume from that that your views may not be the views of your employers?

Ms TOME — Our understanding is that we do share the same views as our employers but — —

The CHAIR — Is there any divergence you're aware of that we should be — —

Ms TOME — No. But you never know. The VICG welcomes the opportunity for the establishment of uniform Victorian legislation that recognises the rights of donor-conceived persons to information about their biological parents and genetic siblings regardless of when they were born and it protects the individual needs of all parties involved.

We also strongly argue for the inclusion of a comprehensive and integrated donor linkage counselling service that forms an integral part of donor linking for both those seeking information and for those who information is being sought about.

The CHAIR — Just on that point, at the moment your respective organisations do the work of the linking and the counselling?

Ms TOME — Melbourne IVF does it for those who were born pre-88, we do it routinely for that and — —

Ms ALESI — And we've started doing it again since the ITA was dismantled.

The CHAIR — Do you only act for your own clients or do you act for people who have been at Queen Vic?

Ms TOME — We don't have access to those records.

Ms ALESI — A lot are through Monash. We have some.

Ms TOME — We don't have any, we only have Melbourne IVF and the Royal Women's.

Ms ALESI — And we have some Prince Henry's ones as well.

The CHAIR — Who falls through the gaps then in terms of people who have come from other services?

Ms TOME — Queen Vic, Prince Henry's.

Ms ALESI — And I guess it also depends too if there's some people who maybe are retired or perhaps no longer alive and if they've had records as private patients and the clinic no longer has them. I know we have some records but not necessarily all of the records.

The CHAIR — So if someone comes to you and you don't have those records, can you take on the role of trying to seek those records?

Ms ALESI — Not necessarily, no. We maybe try and direct them in the right direction. Sometimes they don't know where their parents had their treatment so we go through a process of elimination and we may direct them to Melbourne or elsewhere.

Ms TOME — We have. If we're aware of who the doctor is, we in the past have tried to make contact with the doctor to see if they'll release information but at doctors' clinics, my understanding is there were often no records. Keep going?

The CHAIR — Yes.

Ms TOME — We feel that the counselling should be more than a single mandatory information provision session; that it should be available for all individuals involved throughout the linking process and tailor-made to meet individual needs.

We just wanted to highlight some of the following recommendations that we addressed in our submission. Donor-conceived individuals born before 1988 in Victoria should be given the same access to information about their donor-conceived origins as those born post 1988. For those born before 1988, the donor's consent should be required prior to the release of identifying information similar to the Infertility (Medical Procedures) Act.

The CHAIR — So in essence they have a right of veto?

Ms TOME — Yes. Having said that, and we'll talk about that a bit later, we feel if a donor is given the right support and information to make decisions, in Melbourne IVF's experience, for example, we find that most donors do agree to give information, even if they don't want to be identified, so I think even though we give the donors a say as to whether their information is released or not, I think there's ways you can do that, that can definitely facilitate a donor being happy about giving some information.

The CHAIR — From a counselling perspective of those donors who have refused the requests of the children, what's the impact like on those children who come up against that blank wall?

Ms TOME — In Melbourne IVF's experience the donor-conceived who come to us often have low expectations; they're aware of the circumstances under which the donation occurred and they're grateful for any information. We prepare them carefully for the chance that they might not be able to find their donor because we don't have access to really sophisticated means of finding their donor, basically the electoral roll, and often they've got a common name. If they don't respond to our letters then we don't know whether it's because it's not them or because they're refusing or avoiding. So, yes, we prepare them that they may not be able to find their donor, but they're prepared also that the donor may not want to identify who they are, and then we get them to think about what questions they might want to ask the donor, if the donor is willing to provide some answers to the questions that they have, and then prepare them for the fact they might not want any contact with them at all and not want to provide information. They're usually accepting of that; obviously they're devastated at not getting that information but they understand too. Obviously it's preferable if they were able to at least get some information from the donor.

Ms GARRETT — A few issues. The first is with respect to making contact with the donor in the initial sense. I know Melbourne does make that contact. We had a submission from PILCH who ran a case associated with Monash IVF at that time, I don't know whether it still continues, but Monash IVF said that they felt it's impacting the donor himself, just the contact was a breach of their initial contract to have privacy. Is that about where the statement of things are at at the moment?

Ms ALESI — I think things have progressed.

Ms GARRETT — So things have progressed. So that's from both of your perspectives but then the Births, Deaths and Marriages case demonstrated that the Registrar didn't believe she had the power to actually even contact the donor, so obviously that is something that maybe this committee will be looking at as to discrepancies.

Ms ALESI — Yes.

Ms GARRETT — And you would agree that that's something that needs to be looked at, I assume?

Ms ALESI — Absolutely.

Ms GARRETT — In terms of where you have contacted donors at Melbourne IVF and maybe at Monash, and we asked a similar question to the previous person giving evidence, in the main what's the percentage of donors who say: I'm not interested? Do you find most are open to contact, that's the overwhelming experience?

Ms TOME — Yes. We had one who didn't respond at all to the letters and the counsellor decided to give it one more go. I can't remember exactly why it happened but he rang up and said: I want to get more information, it is me but I want some more information. She spoke with him, she explained the motivation. He didn't want to have contact with her but agreed to answer her questions. It was a lovely exchange of the answers he gave her.

I should have said before that one of our experiences with the donor-conceived people is that they want the right — at least if someone tries to make contact with the donor and gives them that chance to have contact with their donor, it's when the doors are shut and you're told: no, you don't have a right to that information about you. I think that is the hardest thing — not wanting to speak on behalf of them, but our experience is that that's the hardest thing for them. If you at least try and do what you can to help them and make contact with the donor, when the donor says no they feel that at least that's been made and maybe it's opened up the possibility for future contact.

The CHAIR — What percentage of kids get to the point of finding that they've discovered who their donor is and contact is made, what's the expectation of starting a personal relationship with the donor?

Ms TOME — I think in our experience, and with the limited numbers because, a, they've got to be before 1988, know that they've been donor-conceived and then have the nous to think I will contact the clinic, but when they do it's usually just to get information and they're happy with that. We've had people who have gone on but the majority are probably just information.

Ms GARRETT — What numbers are we talking about that you have dealt with?

Ms TOME — I think it's probably about — the pre-88s, maybe five to 10 a year.

Ms ALESI — We've got a small number; we've only had two come forward this year.

Mr NORTHE — Through you, Mr Chairman, just interested in your thoughts with respect to the register itself and obviously understanding the clinics operate the way they do at the moment, are we better to have a central register where the clinics can filter information or are we better to keep it in-house with clinics, understanding obviously we do have a central register, there's some privacy and legal issues associated with that?

Ms TOME — You mean having a central place where information is kept about those born pre-1988?

Mr NORTHE — Yes, correct.

Ms TOME — I think there's two ways you can go: the clinics hold that information or there's a central register and what we've been recommending is that there be a process put in place to help facilitate that. At the moment obviously with the current ones Births, Deaths and Marriage hold that information and then if you apply you get one counselling session to prepare you for that. We don't think the current system works but probably if it's not the clinics then Births, Deaths and Marriages hold that information but then you have another group like VARTA that facilitates that and you can have access to that information.

Ms ALESI — I like the idea of having a central register because there is uniformity and consistency across all sites and everyone has access to the same level of rights and I think then there's a system in place to deal with all sorts of challenges. One of the biggest challenges that I've been facing is accessing records but the records have either been tampered with, information is missing or information, if it is intact, is actually very minimal.

The CHAIR — This is information that Melbourne holds?

Ms ALESI — Monash. All records. So the information where there has been details crossed out, and I can think of some historically where I've actually seen sections where there's a name and address, it's actually been cut out.

The CHAIR — I can't remember who it was we saw last week but there seemed to be some resistance to the idea of an independent body getting hold of your records and maintaining those records.

Ms TOME — Melbourne IVF. I think they've advocated that the clinics are responsible for that, and I thought that was great that they were taking responsibility for that, but I just wonder in the long-term how that would work just with commercial pressures.

Ms ALESI — That's right and businesses change and our one's a commercial business as well and interest can shift over time so I think having something consistent is really important.

Ms TOME — And I would be concerned that we wouldn't be resourced adequately and obviously the clinics wouldn't be resourced, they need to be resourced through government funding, but whether that would be adequate to do the job properly.

The CHAIR — So rather than having one or two, your two organisations that are well resourced and able to deal with the enquiries, one model being using your facilities to bring in all the others, that model as opposed to having a central body off to the side that you provide all your records to and you don't have to worry about it anymore?

Ms ALESI — It's what we did under the ITA system pretty much. There would be a request for information and then the clinics would co-operate — our clinic did — we would co-operate with the ITA and provide information across, and that seemed to work quite well. Yes, the clinics are well resourced but it's also run in the context of a business model so it's fitting that into the daily operations of the business and then how is that going to be resourced? And being a commercial operation what will come of that is that will then start becoming a fee for service issues.

The CHAIR — Physically what does it look like, you've got paper records in filing cabinets?

Ms ALESI — Pretty much, yes.

The CHAIR — What sort of volume?

Ms TOME — Archived away. I think there's two ways to do it. One is all the records get handed over centrally or we keep them and there is a request.

Ms ALESI — And the clinic co-operates.

Mr NORTHE — My point was going to be, Rita, along the lines of in an ideal world we have a central register, what are the practical, legal and privacy implications of that because I would imagine that you would need some form of authority from the people involved?

Ms ALESI — Yes, which means we would have to contact them anyway, which would be interesting. But can legislation not be made retrospective, as it has in other instances like in the adoption laws?

Ms GARRETT — So that you can hand over the — —

Ms ALESI — Yes.

Ms GARRETT — Yes.

Ms ALESI — Clinics would be anxious about that issue and about the repercussions, that's a big concern, that there would be consequences legally from the donors if that's a breach of privacy.

Ms TOME — We've never had that issue with the donors that we have contacted, no one has ever questioned our right to do that.

Ms ALESI — And I guess it's also the way in which you manage that information and how you approach people and how you facilitate that contact.

The CHAIR — Have we diverged you from your submissions?

Ms GARRETT — I had another question given we're talking about how the matrix may or may not work. I guess if you have been getting five to 10 a year, you have had two, presumably more if there is an education campaign, but I suppose you're responsible for teams of expert counsellors that would deal with a range of infertility issues and that is one part of it, and that would give you, I would imagine, terrific expertise in dealing with people.

Ms ALESI — Yes.

Ms GARRETT — You wouldn't want to lose that kind of depth.

Ms ALESI — No.

Ms TOME — And it also helps us in preparing parties now because we get some insight into what it's like 20 years down the track.

Ms GARRETT — What you are dealing with now is, I think, important; you don't want to remove those privileges.

Ms ALESI — No.

The CHAIR — All right. We'll get back to your submission.

Ms TOME — We do not think that contacting a donor is in contradiction to the Charter of Human Rights or the NHMRC Guidelines, as long as it is undertaken in a respectful and confidential manner that acknowledges the context in which the donor originally consented to donation.

I was going to talk about, and we've already talked about, this can be achieved through the establishment of a system where donors are approached by a donor linking counsellor who can inform them of their options, including the particular details of the request for information and support them in their decision making and facilitate any contact or sharing of information between the donor and the donor-conceived person.

The CHAIR — The previous witness, Helen Kane, suggested that a registered letter was the most appropriate way of doing that. How do you do it?

Ms TOME — That's how we do it, we do send a registered letter and we ask if they were treated by the Royal Women's Hospital in this period of time, we don't use Melbourne IVF, and ask if they can contact this number.

Ms ALESI — It's a vague letter.

The CHAIR — So the blokes who had donated, if they get a letter in those words: were you treated by the Women's Hospital, that's enough for them to trigger what it is they've been contacted about?

Ms TOME — Yes. One of our concerns has been obviously with people with common names, especially if you've got family members who might have the same name, is then you're breaching their confidentiality if another family member has got the same letter.

Ms ALESI — Same initial, same surname.

MS TOME — So we've been in contact with the Electoral Commission and we're asking if we can get some further information from the Electoral Commission, not just rely on the address but rely on birth date also to help us to make sure we're getting a hit and we're accurate right at the start, and it looks as though they've agreed to that. They want to send a letter on our behalf and say that Melbourne IVF is trying to get in contact with them, we've got back in touch with them and said: can you say a health provider so that it doesn't identify them right from the start? We're just waiting on them to say yes or no but it looks like they will agree to that, which will mean we will be less likely to breach confidentiality and it will be a much quicker process for finding the donor.

The CHAIR — As far as the assistance you get from the Electoral Commission, do you think that there is any legislative change required to achieve what you want to achieve? Are you concerned that

the ground you've made up is going to be lost some time in the future if someone decides they are not going to assist in that way anymore?

Ms TOME — If it went to a central body like VARTA to do the searching instead of us?

The CHAIR — It seems that the Electoral Roll is a key tool that we use to find — whether we need to be looking at putting in a framework as to who and how and when.

Ms TOME — You would need to because if you just go on the address and a name, you've got John Smith, where he lived 20 years ago is definitely not at the same place so there's some that we just scratch our head and go: hey, we're not going to find this person.

The CHAIR — Does the Electoral Commission provide historical information, 20 years ago this person was at this address?

Ms TOME — All we're able to get at the moment, hopefully what will happen probably this week, is just the date of birth; at least that will give us a match of name and date of birth. We don't get any further information. All we've been getting is just a current address of all the people with that name.

The CHAIR — Why not the date of birth?

Ms TOME — You have to get special permission to get the date of birth. We can publicly access that information but any further information you have to go through a process for getting permission so we've just been going through that process now to get the date of birth but they won't give us the date of birth, they will send a letter on our behalf to people who match that date of birth.

The CHAIR — I suppose if you've got multiple agencies performing a service then it's more difficult to control the provision of that private information.

Ms TOME — Yes. The donors can be anxious or reluctant to initially give consent to the release of any information. However, once they understand the motivations behind the application, and are supported in exploring the options available to them, they're usually comfortable and willing to participate in either providing further contemporary information about themselves, for example medical information, or initiating contact with the donor-conceived person, usually via e-mail or letter. Then the counsellor usually works with the donor-conceived offspring prior to contacting the donor to compile a list of questions that they have for their donor.

We've talked about Prince Henry's. One of the things we did also think about is sometimes because of the inaccurate or just the missing information we may not be absolutely sure that this is the donor for this donor-conceived person, so we feel there needs to be a DNA bank where they can help connect and make sure we are getting the correct linking.

Ms GARRETT — It seems to be the evidence we've got from a couple of people now that the vast majority of donors are happy to, at the very least, provide some more information and a lot of them, and I know we're just talking small numbers, but the majority are willing to have contact made. Is that fair?

Ms TOME — Pre-1988, yes.

Ms GARRETT — So what's the major gap missing then, who is the cohort that is being left out in the cold? Most people who find out they're donor-conceived will make contact?

Ms ALESI — Not necessarily.

Ms GARRETT — So that's another group of people? So they may want to make contact in the future but the concern is the records are then not there?

Ms ALESI — That's right.

Ms GARRETT — So that would be quite a bulk of people.

Ms ALESI — Yes.

Ms TOME — Even for those born post 1988, we know that just giving them information isn't enough so they're finding the current process daunting where they're just given one counselling session, given the name of the donor, for example, and have to undertake a search themselves. It's daunting enough for them without having that support to think about what they want to ask, to prepare them for it, to do what ITA used to do which was actually to facilitate that initial contact, they're being left to their own devices. You can imagine too that it would just get so daunting to start that process and make that initial contact. And for the donor too, they know that there's someone who potentially is going to make that contact with them but in terms of preparing themselves without even thinking about the outcome they'd like to have from that contact and to having any of their concerns or fears allayed so that they get the best chance of that initial contact going well, it's just missing at the moment.

Ms GARRETT — What would your response be to a suggestion that there should be proactive contact with donors even if there hadn't been a request from a donor-conceived child for the purpose of records? And what sort of size and task would that be?

Ms ALESI — I think it's a great idea because then you're pre-empting possible requests for information in the future and hopefully giving time for that person to get used to the idea, do some preparation, to possibly link in to some supportive counselling.

Ms GARRETT — What size are we talking about here?

Ms TOME — I don't know.

Ms ALESI — I think it would be hundreds.

Ms GARRETT — You would be talking in excess of 1,000 people maybe?

Ms ALESI — Possibly.

Ms TOME — It's an interesting point because even the donors that have donated in the current environment, they know that they're going to be contacted but when you make contact with them, for some reason they're just blown away to think they actually have a child. It's like it doesn't really connect with them that there are going to be children born from this donation.

We had one just this week where he donated years ago and we contacted him for another reason and he said: so how many do I have? He rang the minute he got the letter — he had 20 plus — but was just blown away and so excited. He said: I haven't been able to sleep, I'm been so excited, and it's just amazing. So this is someone who hasn't really thought about it and then when he's informed, that's the reaction that we often get, even when they've maybe only donated two years ago and find out that there's been a birth; they're very positive about it by and large.

The CHAIR — How do you deal with donors who initiate the contact, or want to initiate contact with their offspring, when the offspring hasn't actually sought it out?

Ms TOME — We refer them to Births, Deaths and Marriages and they get to know about the voluntary register where they can get their information.

The CHAIR — There's no process whereby children can be contacted to let them know that they're interested?

Ms TOME — No. Pre-88, no. Now the donors can make contact with the donor-conceived child's parents if they're under 18, or the donor-conceived person if they're over 18, but it's up to them to say yes or no.

The CHAIR — Pre-88 have you ever had a donor contact you?

Ms TOME — No. Do you?

Ms ALESI — I'm not aware of it.

The CHAIR — Do you think if the rules would be different in that circumstance that you wouldn't be sending letters to offspring in the same manner to try to facilitate a match?

Ms TOME — We had a situation where we had a donor contact us saying they had a genetic condition and that was really difficult.

Ms GARRETT — But the children didn't know they were donor-conceived in that situation.

Ms TOME — No.

Ms ALESI — It's a tricky one and it's one that probably needs to be fleshed out a little bit more but in principle I can't see why the parents, at least initially, obviously the primary sort of people who were involved in the treatment, to contact them and to put forward the request in the same way that we've put forward the request to the donors. I can't see why it can't happen in reverse. But then obviously if that hasn't been disclosed then there's going to be ramifications, so that family needs time to prepare for what that might mean or possibly even be in a position, I suppose like the donors, to be able to say yes or no or what kind of information does this person want? And have support systems in place for the donors as well.

The CHAIR — What about siblings, have you ever had any requests from donor-conceived kids to find out who their siblings are?

Ms ALESI — Yes.

Ms TOME — Yes. And I think Helen spoke about giving information about the year and the sex.

The CHAIR — So you wouldn't provide the service of writing to siblings?

Ms TOME — No. Merely because we know for that age group it was still very much an air of secrecy and a lot of them aren't aware that they were donor-conceived. If there was a medical reason we would but in most situations we would refer them to the voluntary register.

The CHAIR — So there is a register for siblings?

Ms ALESI — The voluntary register would help take care of that. So it could be the donor, it could be the donor-conceived person, it could be donor-conceived people who might want to find out if there are genetic siblings out there. But it's a fairly passive process, it's not an active register where someone is constantly monitoring that, it's only when there's a match that there's a connection there. But at least it's something.

Ms TOME — VARTA used to assist with that.

Ms ALESI — Yes. They're the ones that actually established the voluntary register.

Mr NORTHE — Mr Chairman, if I can just ask the ladies, with respect to counselling services themselves, and obviously we've heard time and time again the situation that exists at the moment in counselling services. In an ideal world how should this be undertaken, obviously irrespective of the

various clinics who undertake some form of counselling and a suggestion has been put forward that VARTA have those counselling services provided. Can you just maybe give us your thoughts on that?

Ms ALESI — My feeling is I think we should have a model back like we did with the previous ITA, because that was a system that worked really well, it was specifically dedicated for this group of people and it was able to concentrate particularly on the issues and they established an excellent system in place. I guess with the clinics, the clinics can do it, that's not to say that it can't happen, and we're in the process obviously of trying to deal with that, but it's part of everything else that we're doing as well.

Mr NORTHE — Trying to centralise it into one.

Ms ALESI — Exactly. But there is consistency, and I think that's the important issue.

Mr NORTHE — Do we have any sense of understanding of how many people you might be talking about in terms of delivering the counselling services?

Ms TOME — The number that ITA had before was 2.2 counsellors. However, I think what we would hope is with community education that that would increase too, but you don't need a huge number of counsellors to do it and do it well.

Ms ALESI — And I guess also, as you say, having that centralised system too where they can facilitate the communication, link them and being the central body to deal with all the enquiries, and also then to send out that information as well.

Ms TOME — The thing that takes up the most time for us at the moment is actually finding the donor. We find that really an arduous and time-consuming process and an anxious time too because we want to make sure we get it right and we don't breach anyone's confidentiality. But if you put in place processes that streamlined that it would be much easier; the counselling part is the simple part really compared to actually finding the donor.

The CHAIR — Do you have anymore?

Ms TOME — No, I think we've covered it all. I think the one thing, just wanting to stress the vulnerability of all parties involved and we really need for them to be supported through it so that they can actually follow it through and have the best outcome possible. I think Victoria leads the world in terms of donor linking so it's really important to capture our knowledge and research and evaluate that so that that can inform our practices and make sure that we're providing world best service to all parties involved, and that includes the donor-conceived parents who I think they get forgotten and it's a very difficult process for them, their fears, and what it means for their child to be contacted by the donor and siblings too. I think we need to make sure that we're doing the best by all parties involved.

The CHAIR — Thank you very much.

Ms TOME — Thank you.

Ms ALESI — Thank you.

Witnesses withdrew.