CORRECTED VERSION

LAW REFORM COMMITTEE

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

Melbourne— 17 October 2011

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Witnesses

Ms R. Alesi, Counselling Manager, and

Ms M. Gabbe, Donor Coordinator, Monash IVF.

The CHAIR — Thank you very much for coming in today. You're aware this is a joint Committee where we're reporting back to Parliament.

Ms ALESI — Yes.

The CHAIR — And I think you've met us all before.

Ms ALESI — Yes.

The CHAIR — Thank you for coming in. Anything you say here you're protected by Parliamentary privilege but not outside the room, so just be aware if you're being asked to comment that you won't have that protection outside the hearing room. If you could start with your name and professional addresses and launch into it.

Ms ALESI — I'm Rita Alesi, and I'm the Manager of the Counselling Service at Monash. I'm based at the Clayton facility, which is at 252 Clayton Road, Clayton.

Ms GABBE — I'm Maria Gabbe and I'm the Donor Coordinator at Monash IVF, the sperm donor coordinator, and I'm based at the Hawthorn premises at 50 Burwood Road, Hawthorn.

The CHAIR — Would you like to talk us through your submission.

Ms ALESI — Yes. I've just made a very short summary of the submission. We've already been introduced, so I'm Rita and this is Maria. I've been with Monash IVF for 18 years and Maria has been with Monash IVF for 21 years so together we bring quite a number of years of experience in the context of donor procedures and donor conception.

Monash IVF has met previously informally with some members of this Committee on 15 August 2011. In summary the key points Monash IVF would like to reiterate from that meeting are: 1. Monash IVF would not be supporting disclosing the identifying details of donors who had provided their genetic material on the condition or assumption that their personal details would remain anonymous; however Monash IVF is willing to cooperate to assist with a voluntary register. 2. Monash IVF would be very supportive of a reactivation of the previous ITA model for matching donors and donor-conceived offspring. 3. Monash IVF strongly suggests that dedicated resources should be allocated by the Government to the task of assisting the matching of donors and donor-conceived people, where the desire and appropriateness of such matching exists.

To further extrapolate on the above points, the following recommendations are made:

Provisions of counselling and legal services for pre-1988 donors, which will help assist them in dealing with possible requests for contact and address any concerns they may have.

To reinstate the model of donor linking counselling service as previously offered by the Infertility Treatment Authority which had a system that reflected the complex and long-term needs of this population; unlike the ART Act 2008 which actually diminishes the type of support offered to these people, further disenfranchising them. This could be a role that VARTA could fulfill through the provision of specialist counselling services to address the needs of all parties involved such as the donor-conceived person, the parents, the donors and their families. By giving powers back to VARTA to manage donor linking counselling, they will be able to help the service providers, which are the ART clinics and the ART doctors, the parents, the donors and the donor-conceived people manage these enquiries.

VARTA has the experience and expertise to manage donor linking. A good example of this is the Time to Tell campaign previously run by the ITA and now VARTA which has established high standards of practice addressing issues around donor linking. The Time to Tell campaign recognised that people will deal with their anxieties about this subject in different ways and that people need time to process information. It may take months or even years from making an initial enquiry to actually wanting to set up contact with one's donor, if at all.

Another recommendation is to remove funding from the Adoption and Family Record Services for the provision of the one mandated counselling session for applicants to the central register and redirect funds back to VARTA. Those who are born after 1988 do have provision under legislation to make contact with their donors; however, the current system is inadequate and does not take into consideration that people need time to process information and need to revisit the subject again and again over a period of time. The current system providing one counselling session does not address the needs of these applicants.

Also to further develop a voluntary register where donor-conceived people, or parents of donor-conceived people, can make a request, and a third party contacts the original donor and acts as an intermediary to assist with providing information and liaison to help establish contact. A voluntary register still exists under current legislation; however it should be managed and coordinated like the model that was in operation under ITA, where there was provision of counselling and liaison for all parties.

And finally, to set up support systems for doctors who may still have the records from the pre-legislation days, to help them with this voluntary register process, such as providing them with proforma letters to send to donors and potentially access to legal services and advice. And that's it. Open for questions.

Mr NORTHE — Rita with respect to, I guess, a central voluntary register, and there is obviously records that are kept in a myriad of places at the moment, having said that and trying to have that linkage, if you like, from Monash's perspective or other medical facilities, what do we do with the records? Are you suggesting that they still remain in the hands of the medical practices or can they be passed onto a central register who can access it?

Ms ALESI — You can help me answer this as well, Maria, but I think the clinicians would probably prefer to actually manage their own records, I think they will be open to actually facilitating some contact information but I think they need some support in that process. I think the idea of automatically handing information over in that context would — —

Mr NORTHE — Is problematic and potentially illegal.

Ms ALESI — Correct. I think there is anxiety about potential litigation and, as was mentioned earlier in the submissions, that consent was given to donate a number of years ago on the provision that it would remain anonymous, and that was the promise under which they actually donated. So that was, I suppose, the contract under which they donated and it's like we're going back to potentially changing those conditions of their original agreement, so there's enormous anxiety from the medical profession about what that might mean for them. Maybe that needs to be addressed in terms of what it would mean for them.

Mr NORTHE — From a practical application of that, how do you see that working out if somebody wanted to request information through Monash?

Ms ALESI — Do you want to answer that, Maria, because you do deal with this?

Ms GABBE — Yes. Under the previous ITA system, if they got a request from a donor or a donor-conceived child they would send me a letter saying Joe Bloggs from this was a donor at such and such a time, could you confirm this donor code, were there any children born as a result of his donation? I would look up our files, pull out Joe Bloggs' file, check that all the details were correct, that it really was the right Joe Bloggs. I would go back to archives and pull out the patient's history and check that the donor code that I had on my handwritten notes that were done at the time were the correct donor codes. So I will check the donor codes with the patient's history and then I would write back to the ITA and say: Joe Bloggs fathered X, Y, Z. These are the dates of birth that I've got and these were the family names. So that was the information that they would get back from us, and everything was checked as far as we could check it on our records.

Mr NORTHE — But in terms of making contact with the donor?

Ms GABBE — No, that's not part of our brief. They had the names, they had the dates of birth, the family names and then they would take it further from there.

Ms ALESI — And the ITA would initiate the contact.

Ms GABBE — Yes.

Ms GARRETT — Just to pick up on what you said before, you think that the primary concern from the medical profession is regarding concerns about litigation to do with the contracts that were entered into?

Ms ALESI — Potentially, around the issues of confidentiality because they were guaranteed complete anonymity in those days.

Ms GARRETT — So if the Parliament saw fit to change the legislation in a retrospective manner which wasn't in the control of the doctors, would that put the medical profession at ease, do you think?

Ms ALESI — Some yes, some no. I think there would be mixed reactions.

Ms GABBE — A lot of doctors' files don't go back that far. I'm assuming we have the file of every single donor that's come through Monash IVF, which sits in a filing cabinet behind my desk, so we have the files on the donors and those files, the early files, they are very incomplete. Some of them don't have dates of births, some of them have definitely no addresses, some of them didn't even have names because they've been cut out of the files, the signatures have been removed, and all I have is one small piece of paper. The information that they were asked to give in those days was very minimal.

The CHAIR — Would there be any benefit in going through a process of trying to build the records of the pre-88 donors and have them there sitting in your filing cabinet complete, or do you think the numbers of people searching or the task is such that you're better off waiting until you actually get an approach from an individual?

Ms GABBE — I usually wait until I get an approach from an individual because that's much easier to handle.

Ms ALESI — We've actually got some figures for you; we've been asked previously and now we have some numbers.

Ms GABBE — 928 offspring who potentially were born from pre-1988 donors.

Ms ALESI — These are ones we do have records of.

Ms GARRETT — Would they be similar figures across the different — —

Ms GABBE — Monash IVF donor records came from the Melbourne Family Medical Centre which were specifically dealing with donor insemination, and then later on a few of these may have been part of Monash IVF's IVF Program because that's merged there a little bit towards the end. Prince Henry's had a large insemination program as well, and a lot of doctors individually had insemination programs in their private practices.

Ms GARRETT — Just to extrapolate on that, if your predecessor, etcetera, was similar to Prince Henry's you would expect a similar amount?

Ms ALESI — Correct.

Ms GARRETT — So what you're looking at, and I know this is a guesstimate, but you would be looking at what, roughly?

Ms ALESI — A couple of thousand.

Ms GARRETT — 2,000 to 3,000 children born of possibly — —

Ms GABBE — Yes.

Ms GARRETT — Of that — and we've talked to other people who have given evidence — how many donors did you have on your records during pre-88?

Ms GABBE — That's one thing I didn't pull up.

Ms GARRETT — Because Melbourne gave evidence they had in the 10s rather than 100s. So less than 100?

Ms GABBE — Donors in those days could have as many families as they wanted to. Some of them had one family, some had 20 so it's difficult to say, depended on how successful they would be, but I could go back and theoretically pull the number of donors relating to this.

Ms GARRETT — It's been a useful exercise for us on this Committee to have a sense, and I think Donna asked a very pertinent question before about what is the size of this exercise. So to have a sense of we're talking about this number thousands of children and this number hundreds of donors, you can actually form a picture.

Ms GABBE — I can do that, that would be a very simple question to ask the database. But also you must understand that some of these donors were put down as fresh sperm, there's no information.

Ms GARRETT — I understand and I think in part of the things that we identify where there are gaps but just to have a sense of the size of the exercise. Chair, through you, just to follow on from a question the Chair asked. Given the difference in records and the fact that some of the records and some of the memories may be in people's heads and may be on a scrap piece of paper somewhere, is it a useful exercise to at least have some sort of a spreadsheet with standard questions across each possible donor-conceived child, that as many gaps are filled in as quickly as possible? Is that an exercise that perhaps a central registry, a VARTA type, could undertake which would require your cooperation, would that at least be trying to contain or get the integrity of this data, whether or not it's ever used if no one comes forward?

Ms GABBE — I actually have a database that has donor code, family, child.

Ms GARRETT — That could be replicated for other — —

Ms ALESI — If asked.

Ms GARRETT — So that system could be employed on the Prince Henry records which is, as we understand it, or we've been given evidence, that they're public records and they could be accessed?

Ms ALESI — Yes.

Ms GARRETT — So that same process could be gone through so that you've got, as best you can, knowing there's anomalies, knowing there's gaps, you have, as best you can, a standard record?

Ms ALESI — Yes.

Ms GARRETT — How big an exercise would that be, do you think?

Ms GABBE — It's definitely doable but they're not checked; I only check the donor code that relates to that family when I get an enquiry and I pull the records from archives. They did have a pregnancy book, when there was a pregnancy the nurses would fill in the patient name and the donor code they used and then they would come back and if the patient rang back and said: I had a little girl born on this time, they would fill in that detail as well so I've just taken that pregnancy book that was from 1979 to 1990 or whatever and I've just put it on the computer just to facilitate my speed at which I would answer these ITA queries. On that there were 95 pregnancies that were marked as unknown so they've marked them down as a pregnancy but never had anything back from the parents to say that the child has been born, or not born, or when they were born, or what sex they were or anything like that.

Ms GARRETT — Just to follow on from this. For example, if Parliament or this Committee was minded to recommend you could create a centralised system and you could create a committee of experts from yourself to others to devise at least a standardised, there will be gaps in those but that you could get present practices as best you can for saying what is our experience to most readily and most reliably identify both donor and donor-conceived?

Ms GABBE — Yes. Half the work is done already.

Ms GARRETT — It's bringing it together.

Ms ALESI — Yes.

Mrs PETROVICH — Thank you for your presentation. Even if we had a volunteer program where we actually promoted and asked for donors to come forward, could we piece together from those files — as you've said there is some very incomplete data and names, dates, signatures have been removed — could we in some cases ever complete those files without perhaps DNA matching at some point?

Ms GABBE — We would have names for all of the donor codes. Even though they're not on the files, there is provision to find a name for the donor code, it's a separate file, but we can't confirm the identity if we only have a name without a date of birth.

Mrs PETROVICH — Because that may have been a false name?

Ms GABBE — Exactly, it could have been a false name. Some practices in the early days was you could give any name that you wanted as a part of protecting the anonymity. But with a name that's a common name, and this is one of the problems we've had with an enquiry, we have a name, we can't give the name because we don't have any other identifier. You know, it could be — it's not exactly John Smith but it's as close to John Smith as you might want to get, and there might be 90 John Smiths floating around without a date of birth, you don't know which John Smith it's going to be, and you can't write to every John Smith and say: were you a donor at such and such a time?

Ms GARRETT — I know some may well just not be able to be completed but is that where it would be of assistance to contact the physician, contact whoever was there, it's a bit of detective work as best you can which is time intensive, but do you think at least some of those gaps would be filled in for those that are — and, sorry, I know I'm asking a lot of questions, but in rough percentage terms too of your cases and other cases, what percentage do you think you could get vaguely complete?

Ms GABBE — There's not a lot of those that are incomplete, and I'm thinking not so much the ones that have had their names removed, because sometimes you've got a date of birth, I'm thinking about the ones that you don't have an identifier with that name. If you go to someone who did have a private practice, his records would not be in my files because they would have their own records and their own things.

Ms GARRETT — But that's a small percentage?

Ms GABBE — I'm just talking about the donors who came through Monash IVF that I've got the files of and it's no good going to a physician about those because they never saw a doctor and all of the inseminations were done as part of the Melbourne Family Medical Centre or as part of Monash IVF when they took it over because that was later on anyway so it doesn't matter. But those files are all the information we have on those donors so it's no point going to a doctor, they never saw the doctors, they just came straight to the clinic, filled in a little bit of paperwork, if they filled it in — I don't think they actually even did that then — they came in, produced the sample, the sample was coded, frozen and put away.

Ms GARRETT — But that's a small percentage and the overwhelming percentage from yours you will be able to — —

Ms GABBE — Most of the donors would be able to be identified.

Ms GARRETT — And you would think that would be similar for the other major clinics?

Ms ALESI — Possibly.

The CHAIR — How many approaches have you had pre-88?

Ms ALESI — We've had two this year.

Ms GABBE — That's right. Most of the donors or the ITA queries that I would get was a child asking or a parent asking or a donor asking were people who were on the central register, they were just confirming the donor code. Not many pre-1988. I've had a number of donors call in just out of the blue saying: I used to be a donor in 1975, or 1978 or whatever. And I can look it up and say: yes, your donations were used, you have x number of children, this is where you go, you go and get information on the voluntary register, this is the only way you're going to be able to know which children you've fathered because a lot of those children may not know that they're donor-conceived so I've steered them in that direction. When ITA was around it was really actually quite a lot better because you could say: ring this number, talk to this counsellor, they will give you extra information, they will guide you through whatever aspects that you could probably do in order to get further and find out if any of your children have made contact. But, no, I haven't had a lot of queries from Births, Deaths and Marriages; maybe about four or five since they took over. From the ITA I would get maybe one or two a month.

The CHAIR — Any questions?

Mr NORTHE — Does Monash offer counselling services?

Ms ALESI — Yes.

Mr NORTHE — Am I right to say I guess under a central voluntary register, if it is VARTA that operates it for example, that those counselling services would be under that one auspice?

Ms ALESI — Correct. At the moment, as I said, we've had two applications this year and I guess for us it will become a resource issue, so that's one of the areas of concern as well too.

We're setting up systems in place to obviously manage these enquiries that are coming forward now and doing the best we can to assist these people with the limited information we do have.

The CHAIR — Any other questions?

Mr NORTHE — I've got one. What is Monash's current practice for dealing with requests for information from donor-conceived people prior to 1988? Has this approach changed over time? How many people from this period, either donors, recipients or donor-conceived people have approached Monash IVF for more information?

Ms GABBE — I could find out for you; I would have to look up my records to see which ones were pre-1988. A lot of the enquiries, as I said, came from the ITA as it was then and I don't believe I've had many enquiries from Births, Deaths and Marriages since they've taken over the central register but I can look up my records and tell you how many people pre-1988.

Mr NORTHE — That was probably about a four question statement there. But on the first one, has the way you deal with requests for information from donor-conceived people changed over that time?

Ms GABBE — Not really. I try and get as much information back to the ITA, or whoever, as I possibly can so, as I said, if I did get a query from the donor or from the donor-conceived child it's a matter of checking all of the other families that were born from that donor, pulling all of the histories from archives, checking that the donor codes were correct, and giving them information, which is: I've made my check, donor XYZ has conceived this number of children with five families. So he's got 10 children, five families, these are the dates of births, these are the families' names and send that back.

Ms ALESI — And any other non-identifying information as well.

Ms GABBE — Yes, and non-identifying information, of course.

Ms ALESI — Like height, hair colour.

Ms GABBE — Yes. Sometimes they've got that information. From post-1988 all that information was part of the information that was given to the central register when a child was born for every donor, but pre-1988 sometimes they had that information, sometimes not, so if they ask me for the non-identifying information that's what I give them as well.

The CHAIR — Thank you very much for attending today; we really appreciate it.

Witnesses withdrew.