CORRECTED VERSION

LAW REFORM COMMITTEE

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

Melbourne — 10 October 2011

Members

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Witnesses

Mr A. Othen, Managing Director,
Ms J. McCann, Operations Manager, and
Ms R. Varady, Donor Program Manager, Melbourne IVF.

The CHAIR — Thank you very much for coming in today. My name is Clem Newton-Brown; I am the Chair of the Law Reform Committee. This is an all party committee which is meeting on this term of reference to report back to Parliament. My Deputy Chair is Jane Garrett, Anthony Carbines, Donna Petrovich and Russell Northe.

Anything you say in the Committee hearing is protected by privilege but you are not protected outside the room; so just be aware of that in case you are contacted by a journalist to make a comment on things, you do not have that protection that you enjoy in this room.

If you could start by going through your names and addresses and then talk us through your submission and we will ask questions as you go.

Mr OTHEN — Andrew Othen, Managing Director of Melbourne IVF, 23 Clarendon Street, East Melbourne.

Ms VARADY — Rachael Varady, Donor Program Manager at Melbourne IVF and I am at suite 10, 344 Victoria Parade, East Melbourne.

Ms McCANN — Joanne McCann, Operations Manager, Melbourne IVF and suite 10, 344 Victoria Parade.

The CHAIR — Would you start by explaining what Melbourne IVF is and how it operates?

Mr OTHEN — Melbourne IVF is a fertility clinic. We have seven locations throughout Victoria. We deal with all types of fertility and IVF issues. We also have day hospitals and also diagnostics; so pretty much the full supply chain of fertility.

The CHAIR — It is in essence a business?

Mr OTHEN — Yes it is a for-profit business. It is owned roughly 50 per cent by the fertility specialist clinicians who started Melbourne IVF. The rest of it is owned by private entity.

The CHAIR — Would you take us through your submission please?

Ms VARADY — Firstly, Melbourne IVF through our submission, we still recognise the importance of donor-conceived children to have access to information regarding their donor; however we believe that the rights of the donor-conceived individual should never override that of the donor’s rights to privacy and control over the release of the information under which they consented at the time.

The pre-1988 donors who consented to be anonymous, we still believe that that consent should be true and held unless we are contacted by donor-conceived individuals and then would individually as a clinic contact that donor to see whether or not they would be willing to provide any information, whether that be anonymous information, non-identifying information or any identifying information to that individual.

The CHAIR — How long has Melbourne IVF been around? Were you part of this whole pre-1988 industry?

Ms VARADY — Yes we were, in conjunction with the Royal Women's Reproductive Services Unit from the 70s.

Ms GARRETT — Just a couple of questions, the records that you hold for pre-1988 are pretty good?

Ms VARADY — Yes.

Ms GARRETT — We have had evidence here before that obviously the Prince Henry records are extremely problematic and there are private doctors who have maybe not kept records or there is no access to the records. What sort of numbers of records would you have for pre-1988? What numbers are we talking about people?

Ms McCANN — It would have to be thousands. I would have to confirm with you.

Ms GARRETT — Thousands of donors?

Ms McCANN — No, recipients and then offspring born of a number of donors.

Ms GARRETT — Thousands?

Ms McCANN — There would be thousands of recipients but there would be tens of in terms of donors.

Ms GARRETT — But thousands of donor-conceived?

The CHAIR — Tens of thousands or tens?

Ms McCANN — Tens, so as in less than 100 I think there would be in terms of donors.

The CHAIR —Total donors?

Ms McCANN — Yes. Because Melbourne IVF was born out of the doctors that stemmed out of the reproductive services at the Women's Hospital, the records primarily were kept at the Women's Hospital and they still remain in storage at the Women's Hospital. So anything beyond the starting point of Melbourne IVF is all stored at the Women's Hospital, which we have access through our contract with them. So that information is accessible on a daily basis to us.

The CHAIR — Given the small numbers of donors, have you considered whether it would be worth contacting each of them and asking for their consent, even if you have not had a request from a child?

Ms McCANN — Well, they are not all active donors and I think that there needs to be a distinction between active and non-active. The active donors are the ones whereby there are new families being created through those donors. The past ones, we would only do that if there were reasons to get in contact with them. For example, if a genetic issue was raised with one of the offspring and we were notified about that.

With all of our consenting across the years we have had written information — I think we have provided that to you — regarding that we should be updated of any changes that might occur, but of course people choose to do that based on their own determination of whether it is relevant or not to advise us. We would act on that but to go back just as a routine matter of course to actually kind of interrupt that normal functioning of those families, the potential harm associated with that would probably override the benefit to any offspring at the moment. So we would do that on, as Rachael said, a case by case basis as the issues arise.

Ms GARRETT — To pick up with what you mentioned before about genetic issues, et cetera, is the current process where you would contact a donor, does that go through an Ethics Committee or is it a decision made by who?

Ms McCANN — Initially the contact would come via a number of sources I guess. It might come directly to the donor program at Melbourne IVF, it might come to a counsellor. So it might be that an offspring or a potential recipient with the offspring would contact us and talk about that problem. It might be reported to the doctor.

So it will come in via a number of channels and then it would be fed through our donor committee in the first instance. The discussion would be there on a medical basis. We would do all the preliminary research to try and find out if there are medical records associated with that.

Sometimes it is a very vague story to start with, so it might be the counsellor that has the first outreach to the patient to try and get some more information. So we would not take it to any formal committee until we kind of had all the facts.

We have had a case where we did go through the Ethics Committee through the Royal Women's Hospital and that was primarily because we were having difficulty getting in contact or getting the communication through to the offspring and we felt there was sufficient basis to do that and we got legal advice on the side to suggest that there was fair reason why we would actually need to make contact.

Some things are quite straightforward and others are much more severe. So depending on what the actual condition was, you might take a different tack.

The CHAIR — Just talking generally when an offspring approaches you to try to find the identity of their father, how do you make that approach without dropping a bomb on his family?

Ms VARADY — It is through our counselling department. We have a counsellor that is involved in the linking. First of all, we need to locate the donor if they have not been in contact with us, so that can be a bit of a laborious effort trying to go through the electoral roll, especially if they have got a common name. Trying to contact a donor with a common name, we do not want to send out information to people that is confidential. But it is a very vaguely worded letter in regards to treatment that they may have had in contact with the Women's Hospital during this particular year or years and to please contact us and give a direct number.

Sometimes we are able to have access to a telephone number and they may outreach on the telephone.

The CHAIR — How many of those would you have done?

Ms McCANN — They are quite low numbers.

Ms VARADY — Under five I would say.

Ms McCANN — Yes.

The CHAIR — Has the approach been considered sensitively done by those who have been approached?

Ms VARADY — Absolutely, yes.

Ms McCANN — Absolutely, yes.

Ms GARRETT — Has their response been generally positive?

Ms VARADY — Generally it has been positive, in the sense that pre-1988 donors, contacted donors may say yes, I am happy to provide non-identifying information, an update on my family's health and history but they will not provide the actual identifying names as their families may not necessarily know. Others will actually be quite excited that someone is actually trying to reach them.

The CHAIR — Of those five, how many have provided full details or had a meeting?

Ms VARADY — I have not got the actual numbers. I know that one of each at least, one has provided contact information and the other has declined identifying information but passed on other non-identifying information.

Ms McCANN — It is quite an intensive process though, so it is quite a number of counselling sessions. It could be more than 10 for that particular patient and then there are all elements of that. There might be the recipient, the partner of the recipient, any potential siblings that may or may not be donor-conceived, so it is quite a complicated process and it is not one or two letters and phone calls.

Ms VARADY — Some of the donor-conceived individuals are not asking for the identifying information, they are just asking for a bit more information in regards to family and genetic health.

The CHAIR — Have you ever had any donors asking for information about offspring?

Ms McCANN — Generally what they will be asking for is the number and the sex. So how many female offspring do I have, or how many males?

Ms VARADY — What we usually do is a family update.

Ms McCANN — It is not in-depth information usually that they are seeking, it is very superficial.

The CHAIR — Is it rare for a donor to be seeking contact with their offspring?

Ms VARADY — Yes, I would say so. It is more the donor-conceived individual that is requesting and not necessarily requesting contact, just information.

The CHAIR — How would you deal with it if a donor said: Look, I don't have any other family, I have an intense desire to meet my offspring, if the child is under 18, would you then contact the parents and ask them?

Ms VARADY — Not necessarily. I think in that first instance we would refer them to the voluntary register to see whether there is other information contained on the voluntary register as to contact with the donor-conceived offspring.

Ms McCANN — But we would follow the same process though, we just do the reverse of that, but we certainly would not contact under-18 offspring directly. Our patient and our relationship is usually with the recipient, so the recipient is the point of contact to go to in any instance.

The CHAIR — You would contact the birth mother and ask whether she is interested?

Ms McCANN — That is right.

Ms VARADY — And also they can refer back to counselling notes as to whether that was something that they had wished for at that time and then make the phone call from there to say at the time of counselling you suggested that you were open to contact, are you still open to contact? We would not necessarily just release information.

The CHAIR — On that point, if you have counselling notes from many years ago saying definitely don't get in touch with me, do you take it that that is the view that is held forever more or do you take the view that might change in time?

Ms McCANN — That has not happened and I guess going back that far, the conversation was not really so much around that information, because at that point it was purely anonymous. So we would probably test the water. The worst that could happen is that they say no and we would do that in a sensitive way and support that recipient.

Ms VARADY — And also provide counselling around that potential outcome for the donor-conceived individual as well. So when Jo was saying that it is quite a long process, there is that counselling around the potential disappointment that they may end up with if the donor says no that they do not want to provide any information.

Ms PETROVICH — Just further to Clem's point, because we have perhaps not contacted donors directly, we do not know if their requirement for privacy is still the same and still required. I wonder as time moves on do you become a little less sensitive to what might have seemed onerous or perhaps culture has changed, is there a way to approach the donors in a sensitive and confidential way to see if there has been a change of attitude and they would be willing to provide that information?

Ms McCANN — I think to your first point about do we lose sensitivity, I would say absolutely not, the changes that have happened recently to the legislation have meant that unfortunately that we do need to get in contact with donors for any range of reasons.

Ms PETROVICH — I did mean from the donor's perspective as time marches on.

Ms McCANN — Yes, we do need to contact them for any range of reasons and the process that we have followed is to contact them through the counselling process, so they are having that support from the counsellors from the first point of contact and the follow up support team behind that is the administrative function. So the information that they require, they often ask for copies of their consent forms because they have disposed of them.

So we try and do everything as seamlessly as we can to make it as easy for them to gain that information.

Ms PETROVICH — From the donor's perspective, you would be contacting donors to see if they were willing to be accessed by the recipients?

Ms McCANN — We do if the offspring requests for us to do that but at the moment we are doing it for other reasons. For example, for extending storage periods, et cetera, because of the changes that have happened in the recent legislation, we have had to go back to them for things that they did not consent to I guess at that point in time. We are going through that process of explaining that things have changed in the legislation anyway and we need to get in contact with you. That in itself is a change and requires sensitivity.

Ms PETROVICH — The point I was really making was if there are tens of donors, not hundreds or thousands, is there a sensitive way of doing that to see whether they would be willing and open to either acknowledging or seeing or providing extra information, is that sort of something that is being done proactively?

Ms McCANN — Absolutely we have and I guess the way that we do it is make that first point of contact verbally, so try and get in contact with them using the contact details that we have and then follow up with written information. We would never just send out a letter unless we really needed to and we could not track them down in any other way.

Often phone numbers do change unfortunately and the donors are not always the best at keeping us up to date with those changes. We would try our very best to make that personal contact first.

The CHAIR — As far as donors go, is there an age limit for donors?

Ms McCANN — There is for us, it is clinic by clinic but ours is 25 to 45 years.

The CHAIR — Why do you have a lower limit of 25?

Ms McCANN — Largely it is around maturity and understanding of their life decisions. Also we find that donors in general can make decisions more informed if they have perhaps had a family themselves and know what the meaning of having offspring is. We have just found that that is a good age from a lot of history and the upper age obviously it is more physiological.

Mr CARBINES — With regard to pre-1988 donors, what would you say is the range of potential numbers of donor-conceived people per donor?

Ms VARADY — How many offspring per donor?

Mr CARBINES — Yes.

Ms VARADY — I could not say off the top of my head.

Ms McCANN — The limit was 10, so 10 families. At that point in time, I guess if you say 2.5 to three children per donor, it could be 30 offspring from a donor roughly.

Ms GARRETT — At the opening you reaffirmed what is in your submission that you believed that the donor's right to privacy, given the agreements that were entered into, were paramount. Obviously things that were happening at that point clearly did not envisage some of the complexities and legislation change. We have had some quite extraordinary testimony from donor-conceived children about the impact on their lives of not knowing and not being able to find out. Certainly the testimony received is that it is a fundamental impact on their life.

We have just had evidence from the Equal Opportunity Commission saying in balance the rights of the child need to outweigh the rights of the donor in these circumstances. You obviously have a different view, what is your view on the rights of the child?

Ms VARADY — I am specifically talking to the pre-1988 legislation.

Ms GARRETT — Me too.

Ms VARADY — Everything else is perfectly fine.

Ms GARRETT — Me too, I am talking pre-1988, the testimony is from pre-1988.

Ms VARADY — I think what they were counselled for, what they believed that they were consenting to, I still believe that that needs to be taken into consideration because the implications of advising donors now that all of their information is going to be released and the impact on their families and even their children, and the emotional impact as well where they have not informed their families, could be just as great as those of the donor-conceived offspring who have no information.

I am saying that we can give information with consent of a donor from those times but we would have to get the consent of the donor rather than passing on information without their consent, as they did not have the belief and the understanding of that at that time.

Ms McCANN — And support for the donor during that process. At a previous hearing you heard our medical director, Lyndon Hale, speak to a case where we actually did go through the process of getting legal advice to contact known offspring directly because of a known medical issue and that was based on the potential harm to that person.

So when there is a medical reason we certainly would make an exception to that and based on advice. We took into consideration the potential offspring, the other offspring that we knew of and also the potential siblings of that offspring and the family dynamics that were created at that point in time, but the overarching decision to contact was based on the medical condition which we knew was a significant medical condition.

Whilst we are saying this is what we believe, there are times where we would override that based on the health of an individual.

Mr OTHEN — I think the other thing also too is the risk to prospective donors, if they are aware that the legislation changed or the rules changed from when they decide to be a donor, it might limit or make people think twice that otherwise would be willing to be donors under the current legislation.

Ms VARADY — Definitely. In saying that we think the rights of the donor should not be overridden. We are not saying that we would not be willing if a donor-conceived individual contacts us and wishes to make contact or have some information, we are not saying as a clinic we would not go back to that. I believe that Melbourne IVF has been the only clinic in Victoria that will assist donor-conceived individuals in contacting their pre-1988 donors.

Ms McCANN — And on every request we have made that contact, so we have not refused any request.

The CHAIR —When you say you are the only one, are you referring to Monash being less enthusiastic to do that?

Ms McCANN — All of the other clinics.

Ms VARADY — And previously with the Infertility Treatment Authority, they had that ability to do the linking as well, so as a clinic we also assisted our patients.

The CHAIR — Your view would be presumably that everybody should do what you do?

Ms McCANN — It is best practice. We believe it is best practice and that is why we have adopted it.

Ms VARADY — We treated these women and the donor-conceived offspring are just as much our responsibility.

Mr NORTHE — What about a centralised service; you have articulated that pretty well in recommendation 5. I guess having access to registers but the information itself where should that be held and I think there are differing viewpoints of whether it be held in the Public Records Office and somebody control that register. What is your sense on the information that is available to you? Do you feel that it is best kept in your clinic and a centralised body would be able to access that to make those linkages?

Ms McCANN — From a state perspective obviously you need to have one body that can control and manage, and make sure there is quality around that. When you start getting one particular clinic to manage that, there are potential issues with the quality of how that is managed. Any information that for example, Births Deaths & Marriages have, we absolutely have in our records now, so it is a double up.

But there would be risks I guess associated with not having that managed by one body. But the information that is available to the clinics to be able to provide that counselling and genetic linkage is really important. So the best process would really be to have those sitting alongside of each other, but I guess the current problem that we have is that the support just is not there to provide that donor linking alongside the information.

Previously, I know you have heard it said before, the Infertility Treatment Authority had a very comprehensive counselling service that sat alongside the keeping of that information and that was effective, but now that that has been separated, that can cause a problem I guess in terms of the information that is available.

Ms VARADY — And the Infertility Treatment Authority with their donor linkage counselling, would also provide counselling to both parties, not just the person that was requesting the information, which is what currently happens, it is only the person with the request under BDM and we believe that that is a downfall in the system.

The CHAIR — Have you ever had donor offspring seeking information about siblings?

Ms McCANN — Yes.

The CHAIR — What happens there?

Ms VARADY — We do not actually provide the information about the siblings. We will provide a family update, such as year of birth, sex of children but we will not provide the actual details. Again, we will refer them to the voluntary registers or whoever holds the registers; now it is Births Deaths & Marriages.

The CHAIR — So a child who has contacted you, they put themselves on a register in the hope that another offspring has done the same process and put themselves on the register?

Ms McCANN — That’s right.

The CHAIR — Why is that treated differently to when the offspring are trying to contact the donor?

Ms McCANN — Under the legislation they actually do not have the right to have that information, so again it is really encouraging and supporting the individuals to go through the process to provide that information. We may or may not have contact with obviously the other offspring and so we would do our best to make sure that they can provide as comprehensive information as they can to put on the register to have it accessible.

Ms VARADY — We do not know that they are aware that they are donor-conceived. We are not going to go head on into something like that when there is no action from both sides.

Ms GARRETT — If the law was changed to allow retrospective access pre-1988, would you see the practical application of that being that it would be better to notify the donors on your books and other books that this has been a change in the law and to be prepared for it or would you see it case by case as the most practical?

Ms McCANN — Again if you are blanket mailing people, there are risks associated with that. We know that other people open other people’s mail — whether that is right or wrong. It is very sensitive information and we would prefer that that is a personal touch by an individual to individual rather than just mail.

Ms GARRETT — I did not mean it is necessarily in the mail or that they are written to and said to contact because you need to be aware that there has been a change in the law and you need to be clear that you may be affected.

Ms McCANN — Yes, we have just completed that process whereby with the recent changes to the legislation we wrote to all of our donors for that reason but we followed up with individuals with phone calls.

I guess the point around this is that Melbourne IVF have chosen to take on this responsibility because we believe we have a responsibility to the recipients and their potential offspring, but it is a very resource intensive workload. So some of the things that you are describing would be fantastic but we have a service to provide to our current patients and with a finite resource, that is where the difficulty lies. We are not provided any funding to provide this service and we are really stepping in on what is currently taken on by the government but it is not being provided. We could do better if we had more money to do it.

Ms VARADY — The resource, yes.

Mr CARBINES — Chair, picking up on some of what Jane is saying. You have taken the position around greater access for donor-conceived people. Are there other measures that you would seek to recommend in that space that you think would be particularly useful for donor-conceived people?

Ms VARADY — I think definitely there needs to be access to donor linkage counselling; that would have to be the ultimate.

Mr CARBINES — It is not so much looking at what you might prescribe as you think how it should be done.

Mr OTHEN — More than just a personal request.

Ms VARADY — I think there has to be counsellors. It is similar to what the Infertility Treatment Authority used to do in that contact with donors and donor-conceived individuals, providing not just one counselling session for the person that has put in the application to find either their donor or their donor-conceived child, there has to be some sort of prescribed counselling that must be attended prior to obtaining the information and also some sort of counselling with the donor if they are pre-1988, thought they would be anonymous, have not told their family.

It is around the same sort of principle that the Time to Tell campaign a couple of years ago, where they had the ability to contact donor-conceived individuals' parents to try and tell them that we may be sending a letter to do linkage, so in a way, how to prepare your family for this information if it has not been already provided. I think the prescription of counselling and how that should be done is a definite requirement.

Ms McCANN — I think the other thing is if it is on a larger scale then we have very great success with our support groups, often linking individuals in the same circumstances is a great way to support them outside of the regular counselling sessions with the counsellor's support. If this was to happen on a larger scale, something of that nature would be effective as well.

The CHAIR — Thank you very much for coming. It has been very helpful.

Witnesses withdrew.