

CORRECTED VERSION

LAW REFORM COMMITTEE

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

Melbourne — 21 November 2011

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Ms E. Keleher, Manager of Strategic Projects, Registry of Births, Deaths and Marriages.

The CHAIR — Hello, Erin. Thanks very much for coming in this afternoon. My name is Clem Newton-Brown, I'm the Chair of the Law Reform Committee. This is a joint party committee set up by Parliament and we investigate references which are given to us by Parliament, this being one of three that we're working on at the moment. With me today is Jane Garrett, who is the Deputy Chair; Russell Northe, who is the member for Morwell and Donna Petrovich, who is the member for Northern Victoria. Anthony Carbines, the member for Ivanhoe, is also on the committee but he's an apology today.

You're protected by parliamentary privilege when you give evidence in a parliamentary inquiry but not outside the room. Everything gets recorded and if you could start with your name, professional address and who you represent before you begin your submission that would be great.

Ms KELEHER — My name is Erin Keleher, I represent the Registry of Births, Deaths and Marriages. My substantive position is as Manager of Strategic Projects and my professional address is Level 17, 595 Collins Street Melbourne.

The CHAIR — Do you want to talk us through your submission?

Ms KELEHER — Certainly. I believe everyone has been distributed the information. Your first question was in relation to the number of applications for access to information held on the voluntary register or the central register that the Registry of Births, Deaths and Marriages has received since it assumed responsibility. That was on 1 January 2010. The response to that is in the pre-1988 period, none to the central register because it's not applicable at that time, there was no central register pre-legislation. For the voluntary register we've received 15. How many requests in the period 1988 to 1997? Central register, six; voluntary register, nine. How many requests have been for the post-1998 period? Central register, 15; voluntary register, 35.

You sought information in relation to the numbers of requests by donors, recipients and donor-conceived people respectively for each of these periods. For the purposes of the recording it's probably easier just to refer to the written submission. In essence, I would like to draw your attention to the applications, the number of requests from donor-conceived people for both the central register applications and the voluntary register applications. You will see in the post-1988 period there have been nil, and that's because those people have not yet reached maturity so they will only apply when they become adults.

What is the process currently employed by BDM to establish whether consent has been obtained to release identifying information from the central register where consent was given in that period 1 July 1988 and 31 December 1997? I've outlined the process and I'll take you through each of the steps. The relevant BDM officer checks what consent, if any, is recorded on the central register. The first step is the officer then seeks to obtain the current consent, which is to confirm the donor's current address details. In order to do this, she'll check the donor's recorded address. If the donor is listed on the voluntary register she notes the donor's address and the date it was entered. She will telephone the relevant ART clinic to confirm the date that the donor consented to the use of his or her gametes in the treatment procedure, and also

whether the donor consented to the release of information. She will confirm the donor's address as recorded by the clinic and whether the donor provided an e-mail address. So you see already by this stage we have the potential for three or four addresses to have been identified for one individual, but we always aim to identify when that address was provided to see which is the most current. We ascertain when the clinic last updated the donor's address information because the clinics ask their donors to keep them apprised of any changes of address.

If the ART clinic advises that the donor has consented to release identifying information, the BDM officer requests this information in writing. The officer then checks our death register to establish whether the donor is deceased or not. If the donor is deceased, consent must be obtained from the senior next-of-kin in the family. This may involve seeking written information from the ART clinic that the donor's partner also signed the consent at the time the treatment was being undertaken.

The BDM officer also undertakes a process to confirm the donor's current address, including searching the Commonwealth Electoral Roll, the White Pages and Internet references. If she is unable to confirm a current address, the BDM officer sends a generic letter to each available address. Rather like the previous speaker from FIND, the letter is generic in nature and doesn't disclose anything that would alarm the recipient. I've given you a copy of the letter and it's to the effect of: the Registry has a record that may pertain to you, would you please contact us to discuss this matter.

When the recipients receive the letter, they respond to that generic letter, the BDM officer uses a process of shared secrets to confirm that the person is the donor before revealing any information in relation to the enquiry. The shared secret process is something that we use throughout the maintenance of our Births, Deaths and Marriages registers. It's a question, or series of questions, that only the individual themselves would be able to answer. If the donor's identity is confirmed the BDM officer advises that a registered person-to-person letter will be sent seeking their consent to the release of information, and I've attached a copy of that letter as well. For applications received pertaining to this particular period, BDM must not release identifying information on the central register without the consent of the person to whom the information pertains, or if that person withdraws their consent in writing before the information is disclosed.

In relation to the question about whether BDM is able to provide information regarding applications for access to information pertaining to the ITA, that is before BDM assumed responsibility for the registers, the answer is no. The donor register database that the Infertility Treatment Authority provided to us only had two applications in the period prior to 1 January 2010. What we understand is that the ITA did not use their database for the management of applications to either the central or the voluntary register. However, the ITA did report the number of applications for access to information as part of their annual reports so that information would be available from them. The corollary of that applies, the Registry does use its databases now for all applications to the voluntary and central registers, and that allows for the automatic matching of data.

How is the voluntary register currently operated, and how is the matching of applicants performed and verified, and how many staff operate the register? When an application is received for the voluntary register, the Births, Deaths and Marriages officer verifies, firstly, that the applicant is eligible to place their details on the voluntary register, that is the person themselves is either a donor-conceived person, a recipient parent, a donor or a donor's relative, or a relative of the donor-conceived person. She will telephone the ART clinic where the treatment occurred. If this is unknown by the applicant, because on occasion applicants will come to us and they will just say: I believe I'm donor-conceived but I really have no information. She will contact all of the ART clinics or search the closed records at the Public Records Office of Victoria to confirm the donor code. That's significant because the donor code is the matching key for all of the records.

The BDM officer keys the application into the voluntary register, at which point the system automatically matches any other records with the same donor code. She will examine the hard copy of the application form for each of the matched parties and then contact each of the matched parties to advise that there's been a match and to clarify this person's instructions in relation to the release of their information to the other person. It's a very labour intensive process.

If the matched parties have requested identifying information about each other, the Births, Deaths and Marriages officer refers both of those matched parties to the mandatory counselling operated by FIND. Once we receive written confirmation from FIND that that mandatory counselling has been undertaken by both parties, then the officer will post a statement of information to each party with the details that each person has agreed to release. We post these statements by registered person-to-person post, with a delivery confirmation received back to Births, Deaths and Marriages so we can be assured that the right person is getting the information and they've received it. If the matched parties have requested non-identifying information about each other, then the BDM officer offers them the opportunity to attend counselling at FIND, but they're not obliged to do that, and then we post a statement of information to each party, again by registered person-to-person post with a delivery confirmation coming back to us.

Our donor treatment registers are maintained separately to the Births, Deaths and Marriages register and access is restricted to four staff within the registry. There's one person responsible for the maintenance of the donor registers, including adding new records for birth notifications, processing applications, corresponding with customers and liaising with ART clinics and FIND. This person is supported by a manager — that's my position — a legal team and a communications team.

The next question is in relation to how many donors, recipients and donor-conceived people respectively are currently listed on the voluntary register? How many of these people were conceived from, provided or received donations prior to 1988? The table at question six outlines the responses there. You will see that the voluntary register is very small — 353 records as of 21 October when this data was extracted. Of that 353, 125 of those records were people pertaining to the pre-1988 period. The greatest number of parties recorded on the voluntary register are actually donors.

Your next question is in relation to how have enrolments with the voluntary register responded to media publicity and campaigns by BDM? Have we undertaken any promotion or media campaigns to publicise the existence of the voluntary register and how have these campaigns resulted in increased registrations? From our point of view, it's difficult to establish whether publicity results in increased applications to the registers as some people may be prompted to apply at the time of the media attention but may not follow through for some time. We even see this occur when people are referred for their counselling to FIND, the mandatory counselling for FIND, so they've applied for information, are referred and then they don't follow through, and it may be weeks or months before they make that call to FIND to undertake their mandatory counselling. BDM does not ask applicants why they have applied to the registers, so it's not possible for us to establish whether they applied in response to a media campaign.

In January 2011, there was substantial national media coverage in relation to the Kimberley Springfield case, a young woman who was conceived with gametes in the pre-legislation period who was seeking to find her donor, and had approached the Registry to seek out the donor and ask him to voluntarily put his information on the voluntary register. The Registrar declined to do that and that matter was upheld at VCAT. As a result of the substantial media coverage that we received in that case, in the two months following that coverage two people lodged information on the voluntary register and two people asked for their information to be removed. Was it related to the media? We couldn't say.

The CHAIR — Could you just explain why the Registrar refused the request?

Ms KELEHER — Yes, because it wasn't contained within her powers and further the objects of the Assisted Reproductive Treatment Act didn't consider that for us to go to a donor to seek him to volunteer information to the register, that that was within scope. What I've done is attached the VCAT findings which outline the arguments on both cases.

The CHAIR — That's the current practice, is it, that Births, Deaths and Marriages does not believe that it is its role to approach people and seek consent?

Ms KELEHER — Not to seek consent; first of all to identify who the person may be, locate them, contact them, and then ask them to volunteer their information to the register. We believe that there's a role in terms of advertising the existence and purpose of the voluntary register and have produced a media campaign, which we anticipate will roll out, so we will let the Victorian community know that it exists and that people can come forward to lodge their information but not that other more detailed approach.

The CHAIR — But you could have the details sitting there in a filing cabinet available?

Ms KELEHER — But we don't; that's not true. The voluntary register only holds information that's already in existence that's been given to us.

The CHAIR — But you hold records from some hospitals?

Ms KELEHER — No, we don't. The records from any hospitals and records from Prince Henry's Hospital, which are held at the Public Records Office of Victoria, are closed records and we can access them on a case-by-case basis. If you were the donor, for example, we could access your record from the Public Records Office.

The CHAIR — If the request is made by the donor?

Ms KELEHER — Yes. So we can go to the Public Records Office to firstly establish that you're eligible, that you were in fact a donor, so we would access your record and then we are able to lodge the information that you provide to us.

The CHAIR — What about with the person who was the recipient, do they not have similar status to look at the files surrounding the recipient of the material?

Ms KELEHER — So if you were a woman who was treated by Prince Henry's, there's a treatment file for you held at Prince Henry's, and if you came forward to us and said: I was treated in 1984 and I would like to lodge my details on the voluntary register — as 16 recipient parents have done — then we would go to Prince Henry's and seek Jane Smith's record.

The CHAIR — But that file wouldn't provide information as to the identity of the donor, though?

Ms KELEHER — No, that's correct; it would only provide the donor code and then that's what would be recorded on the voluntary register until such time as the donor who had the donor code came along. Say it was you and Jane, Jane was treated and her donor is N11. You're donor N11. Jane's record sits and waits on the voluntary register until you come along. And you say: I don't remember what my donor code was, I just know I donated and I've been reading the newspapers and I would like to come forward, I think it's important that I come forward. What's your name? Clem Newton-Brown. We'll go off to Prince Henry's, locate your record, which will have your donor code, N11. Matches N11 and a match has occurred on the voluntary register.

Ms GARRETT — Who are these letters being sent to then?

Ms KELEHER — Which letters?

Ms GARRETT — This letter that you've given us a copy of. We've got a record that may apply to you.

Ms KELEHER — That's in relation to the question when we're seeking consent and we're trying to find the donor, it's typically the donor, and we may have four Clem Newton-Browns and we can't distinguish — —

Ms GARRETT — I understand that, but when you're writing to four Clem Newton-Browns, is this to get consent to be put on the register?

Ms KELEHER — That was in respect of the question about how do we get consent from the people from 1 July 1988 to 31 December 1997, and this is in relation to the central register not to the voluntary register.

Ms GARRETT — So you don't do any of that for people pre-88?

Ms KELEHER — No. The central register, we already hold the information because the clinics have provided it to us. For the voluntary register, it's a voluntary process; we hold none of it until someone comes forward and volunteers the information.

Ms GARRETT — So you're absolutely reliant on donors to come forward — —

Ms KELEHER — Absolutely.

Ms GARRETT — — — for donor-conceived people to ever have any chance of knowing?

Ms KELEHER — We're reliant on all of the parties to come forward because even if a donor comes forward and there's no matching donor-conceived person, who may not know they're donor-conceived, and is likely not to know that they're donor-conceived, there's no recipient parent, there's no one for the donor to match with.

Does BDM have any processes for, or play any role in, facilitating non-identifying contact between matching applicants on the voluntary register? No. What the Registry does is we provide information to eligible parties that's consistent with the consent of each of those parties and if there's mandatory counselling that needs to have been undertaken what we do is we provide the information. What our predecessors at the Infertility Treatment Authority did was they facilitated contact, which is the next step.

In June 2010, the Registrar refused a request, and I've spoken about this in relation to Kimberley Springfield's request to write to the donor to advise him of the existence of the voluntary register, and I've attached the VCAT information for your reference.

Has the Registrar received other requests to contact donors directly? No.

Currently records related to fertility treatment by Prince Henry's Hospital and Prince Henry's Institute of Medical Research are held by the Public Records Office of Victoria. The committee understands that these records are closed as, according to PROV, they contain personal and private information about persons that may still be living. BDM is the agency currently responsible for these documents. Under what circumstances, if any, will BDM grant access to these documents? As I said before, these documents that are held by PROV are closed and accordingly the registry is only able to access them in relation to managing specific applications to lodge information on the voluntary register. We don't have unfettered access to all of the records. We're not able to grant access to these documents either, that's not in our role, and individuals seeking access would need to apply to the Keeper of Public Records and

then BDM is advised that the individual would need to demonstrate compelling reasons for a grant of access and, if that access were granted, it would be subject to conditions. So we can access them to do our job to maintain the registers with the highest level of integrity because we need to be able to confirm that when people are placing information on the registers that they're in fact eligible to do so.

Mrs PETROVICH — Through you, Chair. The individual you're talking about who is seeking that information, that's a donor?

Ms KELEHER — Anyone who comes to us seeking information. We're only able to access the records in order to process an application to the voluntary register so if someone is making an application we need to determine that they're eligible to actually put their information on the voluntary register.

Mrs PETROVICH — What sort of conditions would you be talking about for either a donor or a recipient?

Ms KELEHER — No, no, we wouldn't apply any conditions. As I said before, if Clem was the donor in the case and came to us and said: look, I don't remember, I had treatment, I think it was on St Kilda Road, it was about 1984, I was a med student. Whatever the case may be. That's usually a giveaway, St Kilda Road in that year, but sometimes the BDM officer needs to do a bit of a hunt across all of the clinics to find whether the clinics themselves might hold that pre-legislation record, because not all of the records are in the Public Records Office of Victoria, only those closed Prince Henry records. The BDM officer would try and locate, okay, who has got Clem Newton-Brown, can we confirm absolutely it is this Clem Newton-Brown, to allow him to put his information on the register.

The other issue is that the Registry applies the same standards of record keeping that we do for our other records, so people need to prove that they are who they say they are, so they need to provide identity documents, three varieties. If they're showing us originals we can witness that ourselves, if they're copies they need to be certified by the police, so it's a high standard of proof that that person is the person who they purport to be.

Interaction between the agencies. The introduction of the ART Act split the functions that were previously carried out by the Infertility Treatment Authority, which is now VARTA, so between VARTA, Births, Deaths and Marriages, and FIND. To what extent does BDM have links with and liaise with VARTA and FIND and exchange information with them? We have quarterly meetings, the three agencies, to discuss matters of interest in relation to the operation and function of each of our organisations. I speak at the VARTA seminars, their Time to Tell seminars, to educate the public about the registers that we hold.

I've given an example in my written response that VARTA may, for example, discuss a proposed program of public education and might come to the Registry and seek information about the number of applicants to the registers upon completion of the program, so they want to know what kind of impact that media coverage has had in terms of applications.

Ms GARRETT — Through you, Chair. Just going back to the Public Records Office, we had previous people before the committee who talked about prior to the changes, that they were able to look at the records at Prince Henry's and there was a sharing of information and it was complicated at times but it wove the tapestry of what happened. When was everything shifted to the Public Records Office and the door shut, so to speak?

Ms KELEHER — Everything went in 2006. There were two tranches of information that Monash Medical Centre sent through to Prince Henry's.

Ms GARRETT — So VARTA wouldn't have been able to access them either; is that your understanding?

Ms KELEHER — My understanding is that VARTA did access the records and then they sought legal advice and then ceased accessing the records.

Ms GARRETT — When was that, do you know when they ceased accessing the records?

Ms KELEHER — Some time before they came to us. I could investigate but they would be able to provide that information to you. Perhaps there was a presumption of access that upon legal investigation didn't actually exist.

Ms GARRETT — So should recommendations be that that access be reallowed, or allowed for the first time? Would there need to be legislative change, in your view, because currently people can go to Monash or Melbourne and they will do some searches and see whether they can assist to achieve some voluntary outcome. Clearly your hands are tied in that you can't do that, and that's not an insignificant amount of people at Prince Henry's, isn't it?

Ms KELEHER — That's right. You asked two questions, whether I think it needed to be changed and whether there would need to be legislative amendment to do that. I think our access to the PROV records is sufficient for our purposes as they currently stand within the legislation. So if Clem turns up, we can confirm he has an entitlement and will go on. I think the provisions that sit around those records maintain people's privacy irrespective of the role that they played, whether you're the woman in treatment or whether you were the donor, so I think that is sufficient for our purposes as it currently stands.

The CHAIR — What happened when Lauren Burns — I understand that Professor de Kretser helped facilitate contact by writing a letter to her donor father. Was that through Births, Deaths and Marriages that that information was sought?

Ms KELEHER — No, that occurred when the registers were still held by the ITA and I believe that that occurred after the Infertility Treatment Authority had received legal advice that said that they couldn't access the information to provide information directly to Lauren and that the only option was for the treating doctor to conduct the outreach to the donor. In that instance, Professor de Kretser had access to the donor's details, he had his own records.

The CHAIR — In the case of Narelle Grech — are you familiar with her case?

Ms KELEHER — I am.

The CHAIR — I understand that an application was made by Professor Kovacs for access to his records, which was declined. Can you shed any light on the circumstances of that?

Ms KELEHER — Yes. Professor Kovacs believed that the Registry held the records in the proverbial filing cabinet and came to us and said: I would like to access these records, I've accessed them in the past. When we advised him that we didn't hold the records, that they were with the Public Records Office of Victoria, that we would need to investigate how we would be able to access them to accede to his request, he's not an eligible applicant to the voluntary register, he's the treating doctor, so it can only be the donor-conceived, the donor, or the recipient parent, so he doesn't play one of the roles so he's not actually eligible to apply to the voluntary register. The two options available to him would be a Freedom of Information request, or a request directly to the Keeper of Public Records. A Freedom of Information request is also problematic. In fact, it wasn't refused, he withdrew his application because he said it was likely that it wouldn't succeed, the information he was seeking was personal information about another person, so the personal information exemption would apply, so he withdrew his FOI request.

The CHAIR — When was that?

Ms KELEHER — He came to the Registry in September and by October — I could provide the exact dates — he withdrew that request.

Ms GARRETT — But the donor-conceived person can't make that application either?

Ms KELEHER — Yes.

Ms GARRETT — To the Public Records for access for identifying information obviously?

Ms KELEHER — In fact that's the recommendation, that Ms Grech does apply to the Keeper of Public Records for the release of that information.

The CHAIR — Has she done that?

Ms KELEHER — I don't know. She's never made an application to the Registry of Births, Deaths and Marriages.

Ms GARRETT — Just go back a step. For release of identifying information of her donor, that's the donor father?

Ms KELEHER — Yes. So under the response to 11, under what circumstances will access be granted, we're advised that the individual would need to apply to the Keeper of Public Records and demonstrate compelling reasons for a grant of access,

and that if access were granted it would be subject to conditions. They are not conditions that we would place; we have no role in what the Public Records Office of Victoria does in terms of its records management.

Ms GARRETT — But presumably given the current system, the Public Records are not going to release the name or some of the personal medical records to the applicant?

Ms KELEHER — That's the advice we've got. So Ms Grech has never come to us, has not made an application, but there is one sitting on our system waiting for the matching donor code.

The CHAIR — Could you explain that again?

Ms KELEHER — She applied to the voluntary register when the ITA managed the voluntary register, and that application has been waiting until such time as anyone else with that donor code comes along. It could be another donor-conceived person with a matching donor code, it could be the donor themselves, it could be a recipient parent, a woman who was also treated with that donor code.

The CHAIR — When you say she's never contacted you, are you saying that she should be contacting you if she wants to progress things?

Ms KELEHER — No, no, that's not necessary. As soon as we had any match to that donor code our system would automatically match it and we would be in contact with her.

The CHAIR — What about her mother, is she likely to get anything further than anybody else in terms of trying to identify the donor?

Ms KELEHER — If her mother applied to the voluntary register it would only be about putting her own information on, and she would be in the same situation as Narelle, waiting until somebody matched with the donor code.

The CHAIR — Her donor code, is that a certainty that that's her donor code or is that based on what her doctor has told her is the donor code?

Ms KELEHER — Professor Kovacs indicated that there was a great deal of secrecy about protecting donors' identities and that information was recorded on the treatment files in a particular way. But the Registry is aware that he has written to the donor, has written three letters to contact the donor in the past, and in each case it's the same donor code, so at least from his point of view he's absolutely sure he knows what the donor code is.

The CHAIR — To be certain, there would be some value then in her mother seeking her file so that she can cross-check that the donor code is the same?

Ms KELEHER — She could. She could. Yes, of course.

Lastly, one of the criticisms that has been made of the current system is that counsellors at FIND are unable to access information on the registers when providing their counselling service, so they have no background about the person whom they are counselling. Is this correct? Is there any current mechanism that will allow counsellors to access this information? As the previous speaker indicated, FIND can actually ask the person that information as part of the counselling session. What's been your journey in coming here? I'm a woman who received treatment; or I'm a sperm donor; I'm an egg donor.

The Registrar is only able to disclose information from the central register on receipt of an application from a donor-conceived person, their parents or the donors associated with that donor-conceived person. This disclosure is made to the applicant, so we're not able to disclose anything to FIND, and we can only do that when the requirements for consent and counselling have been met so there's no capacity for us to release anything other than a person's name, someone has been referred and they will contact you to set up an appointment.

With respect to information on the voluntary register, the Registrar may disclose information about the person from the voluntary register. Again, only in accordance with the wishes of that person. We know that one of the things is that people change their mind over time so as each new application comes in, our BDM officer will contact the parties concerned to confirm what exactly they wish in relation to this application, what they're happy to release.

The CHAIR — That concludes your submission?

Ms KELEHER — Yes.

The CHAIR — Any further questions? Thank you very much for coming in, we really appreciate it.

Committee adjourned.