

CORRECTED VERSION

LAW REFORM COMMITTEE

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

Melbourne — 8 September 2011

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Ms K. Mander, Chairperson,

Ms L. Johnson, Chief Executive Officer, and

Ms K. Bourne, Community Education Officer, Victorian Assisted Reproductive Treatment Authority (VARTA).

The CHAIR — Thank you very much for coming in. This is a joint parliamentary committee, so we have people from both sides of politics. We are investigating this issue in detail and will then present a report to Parliament with recommendations; so what we cover here may or may not result in legislative change. When giving evidence here you are protected in relation to parliamentary privilege. Evidence you give is protected under the *Constitution Act 1975*, the *Parliamentary Committees Act 2003* and the *Defamation Act 2005*, but you are not protected outside this room. Just be aware that if a journalist calls you up to ask for comment, you do not have the protection that you have in here — not that I expect you will be using it, but it is something to be aware of. Evidence will be taken down and will be made public in due course. For the purposes of the transcript can I get you to start with your full name, address and in what capacity you are attending the hearing.

Ms MANDER — I thank the Committee very much for inviting us along and giving us the opportunity to speak today. I am Kirsten Mander, Chairman of the Authority. Beside me is Louise Johnson, who is the CEO. She has been with the Authority for about the past six years in both its current capacity and when it was the former Infertility Treatment Authority, so she is very experienced. Kate Bourne is the Authority's Community Education Officer.

The CHAIR — What we have been doing is getting witnesses to talk through their submissions without reading them — just highlighting the main points. We have basically been firing questions as they arise. If you are happy to do it like that, we will proceed in that manner.

Ms JOHNSON — Sure; delighted to do so. I want to draw on the two submissions that we have made to the Law Reform Committee by pointing out some of the key points in both submissions. The Victorian Assisted Reproductive Treatment Authority is a statutory authority responsible for administering aspects of Victoria's *Assisted Reproductive Treatment Act 2008*. We were formerly the Infertility Treatment Authority, and because it is a mouthful of a name I am going to abbreviate and refer to 'the Authority'. Prior to the introduction of the act in January 2010, the Infertility Treatment Authority managed the donor registers under the *Infertility Treatment Act 1995*. This consisted of a central register which housed information about all donor-conceived births in Victoria since 1988, and a voluntary register. The donor registers are now managed by the Victorian Registry of Births, Deaths and Marriages.

I would like to start by giving you a little bit of historical context, because I think this is key. In 1984 Victoria and Sweden were the first places in the world to pass legislation to enable donor-conceived people to apply for identifying information about their donor, and Victoria's central register was a world first.

The CHAIR — Could I interrupt you there just to get the context. Kate Dobby, who previously gave us evidence, worked with the donor register service. Was that the precursor to your organisation, and how did it come about?

Ms BOURNE — Yes, it was the donor register service of the Infertility Treatment Authority.

The CHAIR — So what is the relationship between that and your organisation?

Ms JOHNSON — When the new act came into force at the beginning of 2010 the Infertility Treatment Authority became the Victorian Assisted Reproductive Treatment Authority. Staff and members transferred to the new authority, and our functions changed. Our major role now is public education. We now have a monitoring role, a community consultation role, and donor registers were transferred to the Registry of Births, Deaths and Marriages.

The CHAIR — So you have nothing to do with that any more?

Ms JOHNSON — No. Our public education role does involve a lot of contact with the Registry of Births, Deaths and Marriages and with the agency that does the counselling within the Department of Human Services. We have developed brochures for both agencies to use, which they distribute as part of their work. We meet with both agencies quarterly as part of our monitoring and public education roles to gather and exchange information.

The CHAIR — Do you assist people who come to you wanting to be matched? Do you simply give them the address and phone number for Births, Deaths and Marriages, and they go down and do it themselves, or do you have an ongoing role as an assistant?

Ms JOHNSON — No. We refer them to the Registry of Births, Deaths and Marriages, but we do get questions about what it means. Sometimes people express fears over the phone about the process, and if they have questions in relation to that, we would answer them but refer them to the appropriate services and to the Registry in terms of making an application. We point them in the right direction and tell them a little bit about what is involved so that they are not starting from scratch again when they talk to the next person in the next agency.

The CHAIR — So VARTA is basically an agency for educating people as to where you can go and what you can do, but without actually doing that?

Ms JOHNSON — Yes, and our public education role is much broader than that. We provide education about the use of assisted reproductive treatment and highlight research in relation to infertility and fertility. We have a broad-ranging public education function.

Ms BOURNE — We developed those brochures there, we have podcasts on the website that talk about situations where people have been linked and we are running a donor-linking symposium at the end of the year in conjunction with the Donor Conception Support Group and the Australian and New Zealand Infertility Counsellors Association, of which I am the chair. I was also a counsellor whilst ITA was providing donor-linking services, and I have worked at Melbourne IVF, so I can comment a little bit about the counselling that was previously involved.

The CHAIR — Of particular interest, and you may want to answer this now or in the course of your submission, is how things are going under this new system, as opposed to how they operated under the old system.

Ms JOHNSON — I have some information to give you in relation to that.

Ms MANDER — In relation to our responsibilities, I might just add that education is the primary focus, but we also have responsibility for registering clinics, import and export of donor gametes, a reporting role and oversight of the legislation in a broad sense. But our primary function is education.

Ms JOHNSON — The Victorian central register was a world first implemented in 1988, whereas in Sweden information is held by the treating clinics. So some of the linking work that is currently being done in relation to the donor registers is really groundbreaking. It really is world-first work, and there is very little experience of this sort of work worldwide. I wanted to just provide that context.

Ms GARRETT — In your experience, would Victoria have a similar rate of donor-conceived children as anywhere else in comparable jurisdictions?

Ms JOHNSON — Worldwide, one in six couples have difficulty with infertility. In Australia the statistics are around the same, so you would expect the same sort of need in relation to male infertility, female infertility, a mix of both or indeterminate infertility.

Ms BOURNE — Australia and Melbourne were world leaders in fertility treatment. They really led the way and started providing treatment before a lot of places did, so we have a high level number.

Ms JOHNSON — I understand from Vaughn Koops that there is interest in some data as well, so I will just give you an idea. In Victoria there are now over 5000 donor-conceived persons on the central register. One of the unique aspects of the central registers in Victoria is that not only can donor-conceived persons apply for information but parents of younger children and donors can also apply for information, and information can be released to parents and donors with the consent of the other party. While the voluntary registers enable those born either prior to or after legislation to lodge and apply for information, information can only be exchanged if there is a match with a related party. Parents, donors and relatives can also lodge and apply for information, but in our experience substantial publicity is required to promote the voluntary registers before people come forward to register information, and it sometimes takes years after publicity for people to actually put that into action.

The *Assisted Reproductive Treatment Act 2008* provides for an addendum to the birth certificate of donor-conceived people born under this act. The addendum states that further information about the birth is

available from the Registry of Births, Deaths and Marriages, and this enhances the donor-conceived person's right to information.

VARTA believes there is an opportunity to build on world-first legislation to better consider the needs of young donor-conceived adults born prior to legislation, and this is the subject of this inquiry. It is not the role of the Authority to develop policy; that is the role of government. However, we are in a unique position to provide options for government consideration. In relation to the rights of access to information for donor-conceived people, in Victoria it varies according to when they were born and also what clinic their mother was treated at. Amending the legislation to allow all donor-conceived people to apply for identifying information about their donor would provide greater equity for donor-conceived people in Victoria.

In looking at this issue, obviously the rights and privacy of donors must also be considered and balanced with the rights of donor-conceived people. Prior to legislation being implemented in 1988, initially donors consented on the basis that their donation was anonymous. I want to talk very briefly about the quality of the records because I think this also needs to be taken into account. Most donor treatment occurred through major public hospitals and private centres. Private doctors also provided services from the 1940s, and the Infertility Treatment Authority received inquiries from people born as early as that.

Once sperm freezing was possible in the late 1970s and IVF in the early 1980s, more women could receive donor treatment. The quality of records prior to legislation is mixed; however, there is a vast number of records kept at major centres that are in good condition. I really want to emphasise that. In some cases there may be gaps and no records may exist, particularly where treatment was carried out by private doctors, and the records that were kept at the Queen Victoria Medical Centre have been destroyed.

One of our roles as the Infertility Treatment Authority was to license the IVF clinics, and we used to inspect records on a regular basis as part of an audit process. Sometimes donors who were used prior to legislation were also used after legislation, so we did inspect records. Having viewed a number of records, I know there are substantial records in good condition. There were also 1500 women treated through Prince Henry's Institute, which closed. Those women were treated in the 1980s and in the first couple of years after legislation was introduced and implemented in 1988, so there are a substantial number of records that have been maintained. Those records are located at the Public Records Office Victoria, and the Registrar of Births, Deaths and Marriages has access to that information.

The CHAIR — How do you go about accessing that? If you come off the street and say, 'I want information about my background', what rights do you have to actually get that information?

Ms JOHNSON — If you were born prior to the legislation and your mother was treated at Prince Henry's Institute for Medical Research, you could only make an application to the voluntary register through the Registry of Births, Deaths and Marriages. The Infertility Treatment Authority and the Registry of Births, Deaths and Marriages explored the scope to proactively use those records, and under the legislation that is not possible. If your mother was treated at the Royal Women's Hospital, for example, it may be possible for a treating doctor to actually seek contact with the donor and see whether the donor is prepared to provide consent to release non-identifying information to a young person making an inquiry. The problem is that the legislation does not enable the Registry of Births, Deaths and Marriages to proactively make that same inquiry in relation to the Prince Henry's Institute records.

The CHAIR — But you think it should be able to do that?

Ms JOHNSON — I think it is a positive opportunity. I think the system as a whole needs to be well thought out, and there needs to be some sort of mechanism for people born prior to legislation to be able to apply for information.

The CHAIR — What do you think should be done? What would an ideal system look like?

Ms JOHNSON — In our paper, which we provided to the Committee, we presented three potential options. I can talk about those. In the first option all donors could be contacted and asked to re-consent to being identified. This strategy would require all data to be retrieved and stored in one place. It could provide opportunities to promote the voluntary register; however, this option is likely to prove cumbersome, as many donors would be needlessly contacted regardless of whether there had been an application for information. It

would also be very time consuming, resource intensive and legislatively difficult for the organisation charged with the duty. Information would need to be transferred from clinics to the central agency charged with this task, and current contact details would need to be detailed. Privacy issues in relation to the transfer of information would need to be considered.

A second option would be that donors' identifying details could be released without consent, as occurs with retrospective access to identifying information about birth details for adoptees. Open access to information could be available to all donor-conceived persons, giving people born prior to 1995 legislation the same rights as those born under the *Infertility Treatment Act 1995* and the *Assisted Reproductive Treatment Act 2008* — that is, consent does not have to be sought from the donor prior to releasing information to the donor-conceived person. If this option is introduced, both donor-conceived people and donors would require adequate counselling support. Donors would require counselling support, as they may be apprehensive about contact for a number of donor-conceived people, and this would need to be handled sensitively. Public education will also be required to publicise the changes to enable people to prepare for potential contact.

However, there are risks associated with the strategy given the mixed quality of pre-legislation records, and good outcomes may not result despite good intentions. If people's details are provided without seeking consent, they may be more reluctant and unprepared to provide information to a donor-conceived person. As Kate often puts it, you cannot force people to dance with you if they do not want to get up on the dance floor. As donor-conceived persons often want non-identifying information, some may not want to have direct contact with the donor; they may just want non-identifying information. They may want to know about medical history, for example, or what the donor looks like but not actually have that contact. It will vary from person to person, and that was our experience when we managed the registers as the Infertility Treatment Authority.

I would like to talk about the third option in a little bit more depth. It is that donors could be contacted and asked to consent to release information only when a donor-conceived person makes an application for information to the central register. Under this option people born prior to 1988 would have equivalent access to information to those born under 1984 legislation — that is, from 1988 to 1996, and that consent must be sought from the donor before identifying information is released to the donor-conceived person. In practice the Infertility Treatment Authority found that this legislative approach has really worked well. The Authority had extensive experience in linking donor-conceived people with their donors, and from 2006 to 2009 there were 43 outreaches to donors as a result of applications to the central register from parents or young donor-conceived adults.

In all but a very few cases the donor agreed to release information to the applicants. This usually resulted in the exchange of letters forwarded to each party using the Authority as an intermediary to protect privacy. In time some chose to exchange identifying details and correspond directly, and some later met in person. We found that while donors might have had some initial reservations about being contacted, with sensitive counselling and discussion these were usually able to be resolved.

I would also like to talk about some of the issues that relate to the constraints of current agencies under the current Act, which is the content of our second submission. Obviously agencies need to work within the parameters of the legislation, but one of the difficulties is that the Act does not provide for the ability to share information about potential genetic diseases or genetic abnormalities from donors to the people they have helped to conceive, and vice versa. This lack of information can have serious health implications for donor-conceived people. In the last 12 months we know of three cases where people, either donors or young adults, have found out that they have serious diseases, and they have not been able to apply for information or make related parties aware of that serious medical information.

In addition, the services provided to those affected by donor conception are less than those provided to people affected by adoption, yet there are significant complexities in donor conception practice due to the number of families created by one donor — up to 10 in Victoria and possibly more prior to legislation.

There is no provision in the Act for counselling for the subject of an application to the central register. If, for example, a donor makes an application to the central register and consent is required from a donor-conceived person, there is a risk that they may find out that they are donor-conceived through a letter from the registrar. This and a lack of available counselling support may have long-term impacts on the donor-conceived person's mental, emotional and social wellbeing. VARTA believes the scope for policy change could potentially be explored, but this would obviously have resource implications. Practice change does not have to be onerous.

Counselling sessions for the applicant and the subject of the application and follow-up email or telephone contact could be sufficient. But at the moment the act allows for the counselling of the applicant — that is, one of the two parties — unless it is an application to the voluntary register, and then, because both parties are making an application to the voluntary register, both parties would receive counselling.

There is no provision in the act for the Victorian Registry of Births, Deaths and Marriages to release information about the application to the counsellors at Family Information Networks and Discovery, or FIND, which is within the Department of Human Services. As a result, counsellors receive no information prior to a counselling session about the content of an application, including whether the applicant they will be seeing is a donor, a donor-conceived person or a recipient parent. Counsellors are also unable to relay information provided by an applicant to the subject of the application even if the applicant gave consent. This means the subject of the application has no information on which to base their decision to give or not give consent for the release of their identifying information. Counsellors are also unable to give information to the registrar regarding the outcomes of counselling. If a person counselled has particular wishes as to how they would like information exchange or contact to proceed, this cannot be provided to the registrar.

Due to the act's restrictions on information release, a letterbox service that enabled the secure transmission of non-identifying information from one party to the other under the *Infertility Treatment Act 1995* no longer operates. This method was a highly popular way for parties to begin to communicate with each other in a safe way, and it has been widely used as a communication method within the adoption reunion field.

In addition, at the moment there is no follow-up support available for those who are unable to access information from the donor registers or for those who are initiating information exchange or contact. At the moment donor-conceived people, donors and recipient parents are needing to navigate between several government agencies which need to operate within the parameters of the law.

VARTA has an excellent working relationship with the Victorian Registry of Births, Deaths and Marriages and FIND, and we have been involving those agencies in our public education program and providing written material and brochures for the agencies to use as part of their work. However, in addition to exploring the scope of policy change, it is possible that simple amendments to legislation could resolve some of these issues.

From talking to Vaughn Koops I understand the Committee may also be interested in information about emerging research on whether the interest in searching out a donor is a worldwide phenomenon. If you like, I can provide a little bit of information about that. In the information packs we have provided to you we have put copies of some research articles as well as some of the resource materials that we have developed for people in this area.

Internationally evidence is emerging that supports the desire amongst donor-conceived people for open contact with their donor. The most recent study involved 741 donor-conceived participants through the Donor Sibling Registry in the US. In this study 82 per cent indicated a desire to be in contact with the donor. The most frequently stated reason was to see what they look like, followed by to learn about ancestry and medical history.

In another survey conducted by the University of Cambridge Centre for Family Research in partnership with the Donor Sibling Registry in the US, 70 per cent of donor-conceived persons described their meeting with the donor as very positive. 'Curiosity' was the most common reason given, followed by, 'To know and understand a "missing" part of me'. A study of 85 donor-conceived persons in further research revealed 76 per cent wanted to reach, attain identifying information on or develop relationships with their donors. This research is certainly congruent with the experience that the Authority had when we were managing the donor registers as the Infertility Treatment Authority, which was that linkages were very positive for both parties involved.

The other piece of information I would like to provide you with is a little bit of data which may be of interest. Our annual report will be made public soon, and there is further data that will be available in that report and also on our website, but I wanted to provide you with some brief data. There are currently around 1000 women annually receiving donor eggs, sperm or embryos through assisted reproductive treatment in Victoria. In the last couple of years over 500 children have been born through donor treatment in Victoria. Previously around 200 children per year have been born through donor treatment in Victoria. That gives you an idea of the order of magnitude.

I mentioned the number of women treated in relation to prior legislation. In the first year of establishment of the donor registers in 1988 there were about 100 donor-conceived children, and those young people are now in their early 20s. Young adults who are born through donor treatment prior to legislation are now largely in their 20s and 30s. In the adoption field the experience of Adoption and Family Records Service is that people often wait until their mid-20s before they apply for information. That was when they were perhaps starting families, thinking about life in a different way and seeking this sort of information. It is still very early days in relation to interest from young donor-conceived persons.

The CHAIR — Louise, we only have about 8 minutes left.

Ms JOHNSON — That is okay.

The CHAIR — Perhaps I might cut you short. I am sure there are plenty of questions.

Mr NORTHE — Thank you, Louise; that was excellent. The counselling services, details of which have been provided with a number of submissions, have identified the way the system works currently and that it is probably not adequate in terms of counselling. In your opinion, who is best to deliver the services? You talked about resources. In your view, what is required as a resource to deliver adequate counselling services?

Ms JOHNSON — First of all, I would say that obviously that is a policy decision for the government, but I think in the view of the Authority, given its past experience, it is important that a counselling service is comprehensive, that it can be linked with public education initiatives, that all the parties have a capacity to apply for information — those born prior to the legislation as well as those born after the legislation — and that the counselling, support and information are available to not only the person applying but also the other party where an outreach is made to see whether they are prepared to provide consent.

I might ask Kate to say something about the way the system worked previously, but obviously decisions around this are decisions for government. It is not for us to say who should be running the services, but we can provide you with information about what we think is really important and about a system that could possibly work. The other thing I would add is that evaluation to improve service provision and to cater for the needs of this group is really important given this is such a new area. So allowing that sort of research to be undertaken as part of the work would be important.

Mr NORTHE — While I appreciate your comments, it is also very important for our Committee to understand from you, because you work at that grassroots level with these people, what your opinion and feedback is, because we really require that in the context of what we are doing.

Ms BOURNE — The ITA employed two counsellors; one at 0.8 and one at 0.4. I think with that we provided a very good service. Making an application to the Donor Register gives rise to a lot of issues. First of all, someone is thinking about putting in an application to register, and this is a big decision for them. They also want to talk to someone who has had experience with previous linkages and how they have gone.

Under the current system there is no potential to have ongoing counselling contact, because it is a one-off service and also because it is not an intermediary counselling service. There is no ability to relay the wishes from one party to the other and to work towards a mutually satisfactory arrangement. I think that is a big drawback. You want your practice to keep being informed. You want it being informed by the really positive results, and that is what we saw in the majority. But there were also some issues there, and you want to be able to alert people to be careful of this and to be careful of that. If you do not have that informed practice, then you are not able to do that.

I had a phone call from a woman on Monday who had applied to the central register. The donor had released his identifying details, and she was petrified about what she should do with them. She wanted some guidance about what she should say in her first email. She was really worried. Her daughter was five years old, and this was uncharted territory. You really want a service where you can give advice to that mother or to that young donor-conceived person who is perhaps writing a letter for the first time to their donor. They do not know what to say, and the donor does not know what to say either; often he has not told his kids.

The CHAIR — As far as getting the matches pre-1988, would you get more successful matches by having a model such as when you had Kate Dobby out there doing the legwork to make the matches happen, as opposed to how the system is now?

Ms BOURNE — One is that you need good information. But the constraint of pre-1988 legislation was that ITA was not legally able to write to donors. When we were able to write to donors, once the legislation changed in 1988, often initially donors were very apprehensive and nervous about contact. But it was different when you could convey to them why the person applied, what information they would like, what they would like to see in the short term, what their goal is in the long term and that we could provide them with a way of communicating in a non-identifying way if they were interested in receiving a letter from them and if they were so motivated to write back would they be interested — then if you could reassure them they did not have to reveal identifying details they were often prepared to provide comprehensive non-identifying information.

The CHAIR — Does ITA do that function now?

Ms BOURNE — No, it has all gone.

The CHAIR — Nobody does it?

Ms BOURNE — No. It is all split up. A person would have to ring BDM, and it is not a counsellor who answers the phone. They would say, ‘This is how you make the application’. Then they make the application, then they go to FIND for counselling and then they get a letter saying, ‘Your donor has agreed, and this is the address’. This is post-1988. We are not talking about pre-1988.

The CHAIR — With the pre-1988 it is clear that there is information everywhere.

Ms BOURNE — Yes.

The CHAIR — And that if you do not know, then you are never going to know where to look. Was there benefit in having someone like Kate Dobby out there and available to those people who needed help pre-1988?

Ms BOURNE — It was useful in terms of getting records together, but of course Kate was not then able to pass that information on; none of us was. The only person who can do that is the treating doctor, who has access to that. Some of those treating doctors are not alive, are unwell or do not have the commitment because they are retired or the clinic has closed down. Even if the clinic is functioning, they do not see it as a priority to assist, and also they do not know how to do it.

Mrs PETROVICH — Louise, you mentioned a mailbox system which worked for communicating between donors and the organisations and children. Could that be reinstated in any way?

Ms JOHNSON — It worked really well. Kate was the one who was managing that letterbox system. It was incredibly successful as an intermediary step for people to work out whether they wanted to have further contact with the donor and vice versa — or a parent and a donor, if there was a young child. It could be reinstituted, but under the current act it cannot because of the information exchange systems. I guess one of the other things I would say is that the Authority would be more than happy to work with the government to explore options in a very practical sense as to how to set up a comprehensive system. Kate is the best one to talk about the letterbox system.

Mrs PETROVICH — Louise or Kate — whoever is the best one to answer — can you give us a bit of an overview, because you know what it is, but I do not.

Ms BOURNE — It is a beautifully simple system. Often people would not want to release identifying information straight off — either the donor-conceived person or the donor. Both of them were quite nervous and apprehensive when they did not know the other person. Often it was very useful to be able to offer them a secure way of passing on information privately to the other person in a way that did not reveal those details. They could put whatever they liked; we did not read them. It was still private; we did not vet them. If they wanted it, it was a secure way of passing photos or letters. In the course of time, perhaps once they had exchanged letters, they might then include a mobile phone number or their full name and contact details.

Ms GARRETT — Thank you very much; this is very helpful. We have had some really good submissions today. Some of the evidence given by the Fertility Society and Dr Hale and Dr Foster, who are working out of Melbourne IVF, is that in their view it is very important that the clinics maintain jurisdiction, if you like, over the patients who are treated by them and that they see the counselling function and the record-keeping as issues of confidentiality and anonymity for donors, particularly pre-1988, et cetera. When you look at the submissions from PILCH, though, there are obviously discrepancies in relation to, for example, Monash IVF when they are requested to approach a donor. That was the case that PILCH ran, so there are clearly inconsistencies. Would you see a system working whereby the clinics would continue that role, perhaps with broader legislative or administrative changes needed to ensure information access, and the Registry of Births, Deaths and Marriages or ITA, or whatever, would then pick up those people who did not fall within those clinics; would that be a system you would agree with?

Ms JOHNSON — Melbourne IVF does this sort of work very well and has a commitment to it, but there is not expertise at all clinics in relation to the skills involved in this sort of work. I think there is a role for an independent agency that provides service provision to do that work on behalf of clinics if they wish. It may be that if a young person born prior to the legislation made an application, a service agency could contact the clinic and work with the clinic to do that outreach — to seek consent from the donor.

Ms GARRETT — Through the clinic.

Ms BOURNE — Yes. It was one of the recommendations by the Victorian Law Reform Commission in its 130 recommendations some years ago that there be some sort of service that enabled this to happen. This is because there is a certain expertise involved with this sort of work and Melbourne IVF has invested extensively in its counselling team. It has quite an extensive number of counsellors, but not all clinics have that capacity in terms of their counselling team or the particular expertise that is required to provide that sort of service. There is some skill that is also gained through the practice of donor linking with the sort of work which is required and which can be built on with time.

Mr NORTHE — On that point, Louise, does that create any privacy issues from where you stand? The clinic, I guess, could contact the person we are referring to, but once you employ an independent person or organisation to do it, would it not require some authority from the person?

Ms JOHNSON — Obviously this area of work would need to be informed by legal advice, and I notice the Privacy Commissioner is going to be speaking to you about some of those issues. I know that some of the clinics are particularly nervous about delving into this area and they would certainly need to be assisted by a service agency that had the expertise in the way that the previous Infertility Treatment Authority had the expertise in this type of work.

Ms BOURNE — They also need access to specific electoral rolls with dates of birth. If you do not have that, you have to write to a number of people with the same name until you find the right person. Obviously if they have similar names they might be related and this increases the breach of privacy. When you write your letter you need to make very sure that you are reaching the right person, so the clinics need to be assisted if they are the ones that are doing it to ensure they have access to information and they can be very confident that they are writing to the right person.

Mr NORTHE — I am interested from a donor perspective, and mindful of your public education campaign you have at the moment, whether you get a sense that donors might be reluctant to come forward because they might be worried about the legal ramifications in terms of the donor-conceived person accessing estates and so forth? What information does VARTA provide potentially to alleviate some of the concerns that might exist?

Ms BOURNE — That was always the first question. There was often a concern about ‘Could they claim on my estate?’. There is often a misconception that the person wants them to assume a dad role when they actually do not. Often their partners or their wives are very concerned at the impact on the family or on the kids; often that is an issue. We have developed pamphlets for people thinking about donating and making it very clear what the legal rights and responsibilities are. We also have information on our website.

The CHAIR — Would you be able to provide us with some of those pamphlets?

Ms BOURNE — Sure, but they are for people currently donating. We also have information though on the website.

The CHAIR — Thank you very much, that was very helpful.

Witnesses withdrew.