

# LAW REFORM COMMITTEE OF THE PARLIAMENT OF VICTORIA

## INQUIRY INTO ACCESS BY DONOR CONCEIVED PEOPLE TO INFORMATION ABOUT DONORS

**Submitted by Kate Dobby**

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Law Reform Committee

My name is Kate Dobby. I'm an Information Manager/Librarian by profession and I passionately believe in the importance of collecting and maintaining information to enhance future opportunities for access, and in the promotion of rights to access information. From 2005-2009 I was the Registers Officer at the Donor Registers Service at the former Infertility Treatment Authority in Victoria, my employment ending with the January 2010 enactment of the Assisted Reproductive Treatment Act 2008. My job was to maintain Registers and associated information relating to births occurring as a result of the use of donors, thus monitoring the use of these donors, and responding to information enquiries about the Registers and releasing information to donors, parents and the donor-conceived according to legislation. I believe I am possibly the only information professional to ever specialise in this field, and I have built up a wealth of knowledge in the area of donor conception, and more specifically on donor conception in Victoria and the condition of the records. Therefore I am in a unique position to comment on this inquiry. My purpose in making this submission is to draw upon my experiences with the interests and needs of those involved in donor treatment and draw the attention of the Committee to the difficulties relating to the records and associated data, the issues of surrounding donor consent and the practical problems involved in releasing information to donors, donor-conceived and recipient parents.

I also bring this Committee's attention to my recent submission to the Federal Senate Legal and Constitutive Committee's inquiry into donor conception in Australia which contains more general information about donor conception and where I address the issue of practice and records across jurisdictions. This document is public and available online but has also been submitted alongside this submission.

**Please note:** *unless otherwise stated, 'donor' relates to sperm donors. This is because this inquiry is based on achieving rights for people born prior to 1988. However, it is important to note that a small number of people born in Victoria prior to this time were born as a result of (anonymous) egg donation.*

## SUMMARY OF RECOMMENDATIONS

- The current legal situation for donor-conceived people in Victoria is inequitable, with different rights depending on when and where recipient parents were treated, when a donor-conceived person was born, and whether records were subsequently destroyed, de-identified or altered or inadequately kept. Some donor-conceived people conceived in Victoria are the result of donor's who donated interstate and some people conceived interstate are the result of donor's who donated in Victoria. The four Victorian legislative periods (prior to 1988, 1988-1998, 1998-2009, 2009/10+) have only added complexity to an already complicated issue. Granting equal rights to access information for the donor-conceived will reduce confusion and the administrative burden.
- Granting access to this information creates issues regarding past donor consent to being anonymous. However, sometimes evidence of this consent cannot be found or did not accurately represent the needs or wishes of the donor at the time. Counselling was not made available to donors until the implementation of the Infertility (Medical Procedures) Act in 1984. The historical context needs to be taken into account - what most people would consider to be informed consent now, is very different from the situation 20 or 30 years ago. Community attitudes towards assisted reproduction have changed, and people are now more likely to be open about their involvement in it.
- Granting equal rights to access information will require specialised service, in particular counselling for all these parties. The current legislation and resulting arrangements with multiple agencies providing service do not provide for the specific and sometimes intensive support needed by these people, before during and after an application for information. These people are vulnerable and need to receive individualised service.
- The situation concerning donor treatment records is complex. Some records are kept by agencies that still provide assisted reproduction, some are in limbo at the Public Records Office, and some may exist interstate. Agreements and arrangements need to be made between organisations and jurisdictions regarding access provisions. Simply engaging an agency or organisation to release information does not empower them to be able to search through records or data belonging to another agency for important information, or provide them with the authority to demand that their need for this information takes precedence over other legislation or the concerns of the organisation holding the records.
- The former Donor Registers Service at the Infertility Treatment Authority ran a successful information, counselling and community education service from 2006-2010 on less than 2.0 EFT. The ability to run this service was contingent on the fact that the information and administration officer (myself) and the counsellors were able to directly access the records in order to provide individualised service. The Assisted Reproductive Treatment Act 2008, acting on the recommendations made by a Victorian Law Reform Committee report (whose consultation period ended before the formation of the Donor Registers Service) dismantled this service, replacing it with a disjointed service system splintered between three government agencies in three different government departments. This service is confusing for consumers and incapable of providing individualised service due to the records being separated from the associated counselling. It is also contingent on complicated service agreements between the three agencies and is not overseen by one single agency or department. It has created a significant logistical and administrative burden.
- The Central and Voluntary Registers are now held by Births, Deaths and Marriages in Victoria. There is no evidence that the Registry has any excellence or expertise in dealing with these types of records or the service and information brokerage required for the successful operation of the Voluntary Registers. The records relating to the former clinic at the Prince Henry's Institute of Medical Research sit in the Public Records Office (Victoria) where they have been incorrectly catalogued, therefore decreasing opportunities for access and potential misinformation being provided. These records are permanently closed but for many donor-conceived represent the only evidence of their biological parentage. The inquiry needs to consider where and how these records should be best kept and accessed and by whom.

- The Donor Registers Service was able to provide specialised counselling and referral for people for whom there are no or incomplete records. The current 'service' arrangement only provides one-off counselling for a person making an application for information. People with no or incomplete information cannot receive any counselling, and people who, as a result of making an application, discover that there is no information are not provided with any specialised support in relation to this. The Committee needs to consider the concurrent Federal Senate Legal and Constitutive inquiry into donor conception in Australia, and whether they find in favour of creating conditions where a national DNA databank (like that in the United Kingdom) can be established

## TERMS OF REFERENCE

### ***a) The legal, practical and other issues that would arise if all donor-conceived people were given access to identifying information about their donors and their donor-conceived siblings, regardless of the date that the donation was made***

If all donor-conceived people are given access to identifying information about their donor and their donor-conceived siblings, the agency/ies entrusted with providing this access need to understand that most salient issue is in the quality of the records – which when they exist – they can be very poor, incomplete, inaccurate and deliberately misleading. This is not just the product of clinical practice or poor recordkeeping, but is also the result of information existing in different jurisdictions (and in different clinics within the same jurisdiction). Without access to information relating to interstate clinics and practices, an accurate amount of half-siblings cannot be ascertained. It has been practice for donors to donate in more than one state and for their donations to be sent interstate (from and to Victoria). This still occurs and is a significant problem for providing information, and for state-based attempts at regulating issues such as family limits. State-based legislation is hindered by the inability to access information outside of its jurisdiction. Interstate clinics or agencies holding records are either inhibited by their own legislation or reluctant to comply with requests due to clinical practice. The National Health and Medical Research Council provide guidelines but clinicians (especially in jurisdictions without any regulation in this area) are essentially self-regulating.

Some Clinics, Hospitals and Doctors may oppose the granting of equal rights to access information for the donor-conceived, not only because it exposes the weaknesses and inadequacies of past records, but because of what is revealed about past practices. Egg swapping, sperm mixing, donor's identities not being verified or donors being encouraged to donate under pseudonyms, offering free vasectomies and sperm storage, STD testing and course credits in exchange for donating, knowingly creating up to 30 separate families or an excess of 40 children from one donor, using anonymous donors imported from interstate without paperwork, recoding donor's, the practice of on-donation, utilising patients as donor's whilst they are still in treatment and using donors for whom valid consent could not be verified are just some of the practices that I know to have occurred in Victoria – even after the introduction of legislation. These can be viewed very negatively from a current perspective. For this reason it might be worthwhile to consider the idea that Clinics, Hospitals, Doctors and allied health professionals might fear the repercussions of these practices coming to light.

The Committee needs to consider that any partial or incomplete information held in donor treatment records could be improved by providing the donor-conceived person with information accessed on their behalf from other sources. If the records only state a name without a date of birth and an address from 1981 then the agency releasing the information could be provided with other sources of data where they could corroborate or bolster this information already held. Modern privacy legislation does inhibit the ability to find people using old or incomplete information. At the former Donor Registers Service I was greatly helped in my search for past donors via access to the confidential electoral roll for Victoria. It can not be presumed that the current keeper of the Registers, Births, Deaths and Marriages in Victoria, either have other information or access to information about the people named on the Central Registers or in donor treatment records prior to 1988, and some access to federal sources of information would be required.

**b) *The relevance of a donor's consent or otherwise to the release of identifying information and the National Health and Medical Research Council's ethical guidelines on the use of assisted reproductive technology in clinical practice and research***

The Hospitals and Clinics in Victoria that have provided donor treatment, have used, and in many cases, continue to use a standard 10-year consent period. In my work at the Infertility Treatment Authority I encountered several instances where a donor had been improperly counselled relating to the consent and information release provisions of the relevant legislation, or been used outside of the legal consent period under the relevant law (though the 10 year consent period was still valid). Theoretically, every single time a new Act of Legislation in this area in Victoria is enacted, a donor should receive counselling to provide informed consent to the provisions in the new Act relating to any children yet to be born. In practice this has not and does not occur because the previous donor consent remains valid. For this reason, clinics were able to use donor's who had consented to the 1984 legislation for new families up until a few years ago (when the Infertility Treatment Authority forbid this practice), this is despite the fact that the 1984 legislation had been void since 1998. Legislation and regulation in this area in Victoria has continued to lack specificity regarding this issue. Donors are distanced from the use of their donations via time (quarantine and other) and exclusion from information (clinical policy) about the use of their donations, and can often express surprise that their gametes have been used many years after donation. Donors can feel very differently about their donation years after their donating.

In Victoria there are three main classes of donor-conceived people based on what the donor did or didn't consent to. The first are those born after 1 July 1998 for whom the provisions in the Infertility Treatment Act 1995 stand. All of these people have the right to access identifying information about their donor/s upon application for this information, because their donor/s consented to this. The second group is that listed on the 1984 Central Register, established as a result of the Infertility (Medical Procedures) Act 1984. This group have the right to apply for access to identifying information if the donor can be contacted to consent to the release of this information. The enactment of the Victorian Assisted Reproductive Treatment Act 2008 may have changed the way this second group is dealt with; however, there are births on this Register which took place as a result of donors who were not named or who may not have consented to this legislation and therefore the inclusion of their details on a Central Register (explained under **C**). The third group of donor-conceived people are the ones to whom this inquiry is directed, and that is everyone born prior to 1 July 1988. Some of these people were born as a result of donors who later consented to one or both of the subsequent Acts and whom would happily grant the right to access their information, but the vast majority were born to donors who may have been told that their donation was anonymous. The Committee needs to consider that the following may be true of these donors

- They were very young at the time of donation
- They received no counselling or inadequate information
- They did not understand or comprehend what they were doing or were or are now unaware that people have been born
- They donated because they were being compensated either with medical treatment, STD testing, money or course credits
- They had a wish to find out the results of their donating and were happy to be contacted but had been told that this was not possible (perhaps being told that the relevant files would be destroyed)
- They were told or had an expectation that the clinic would contact them on behalf of a donor-conceived person or their family (but this has not happened due to records being lost, clinics closing or current clinical policy)

Donors from this time often recounted to me any or all of the above as reflecting their experiences of donating. These factors would appear to be relevant in determining how informed the consent actually appears to be to modern eyes. The National Health and Medical Research Council's ethical guidelines in this area would appear to be irrelevant in any discussion relating to records and practices 20+ years ago. Community attitudes and clinical practices and technology have changed considerably. The Committee needs to consider whether it judges past practices regarding donor consent practices by current ethical guidelines.

**c) Any practical difficulties in releasing information about donors who provided their gametes before 1 July 1988, because in many cases records are not available either because the procedure was carried out privately or records were not stored centrally**

In actuality the date relating to the donation of gametes in relation to the Infertility (Medical Procedures) Act 1984 in 1988 is the 1<sup>st</sup> of January. This date was used in practice regarding the implementation of this Act (and has been used since); however the information relating to the origin of the two dates remains somewhat obscure. It is nevertheless, evidence that this aspect of the legislation had not been fully considered in not factoring in both gestation and donor quarantine periods.

The reality of births that were entered on the 1984 Central Register as a result of the implementation of this Act, and therefore due the rights accorded them in legislation and regulations - is that the only unifying criteria for inclusion was that the birth took place after 1 July 1988 (and the donor donated before 1 January 1998). A birth that took place a few days after this date is therefore eligible even though the donor had obviously donated prior to 1988. Therefore the issue of donor consent to this legislation is problematic. Despite Clinics and Hospitals being given several years to implement the provisions of this Act, in practice donors who donated after 1 January were counselled according to the information release provisions, but many donors who donated prior to this time were used for years after the implementation date. Sometimes this was for the purposes of creating full genetic siblings for recipient parents, but more often than not the donor was not 're-consented' because they had signed 10-year consents at the clinic and these remained valid (with clinics not considering that the provisions in the legislation should be paramount, and the Health Department – which at the time managed the information in the Central Register and all other aspects of the legislation – not establishing that there was compliance with ceasing to use donors who had not consented to the legislation). Therefore the use of this donation date is an issue.

Aside from this problem of clinics and hospitals utilising donors who did not consent to the legislation long after the 1988 date, there are problems with records relating to this time. In my experience (which also encompasses several years of directly accessing the records relating to the former clinic at Prince Henry's Institute of Medical Research 1978-1998), these records are not entirely clear; births are written in pencil, files contain variant names and details, important information concerning consent and counselling and treatment is obscure or omitted entirely. Donor's files can also contain very little information, and there were several donors who were used by this clinic during this time for whom no information exists as their sperm was imported from interstate (with the records remaining there now in bureaucratic limbo and accessible by no one). Files from this time are also missing. 'Complete' donor files from the period prior to 1988 often contain little more than serology results and a brief description of the donor (supplied by either the donor or the doctor and therefore quite subjective). There are also practical difficulties relating to information for people born after 1 July 1988, as the enactment of legislation (as described in the previous paragraph) did not provide an instant or systematic change in recordkeeping practices. My experience was that there was also inaccurate information relating to births and donors on the 1984 Central Register. In my four years managing this information, I sought to verify and attribute the source of all the information on the 1984 Central Register, comparing it with that held by the clinics, but was unable to do this for a variety of reasons. This unconfirmed and possibly incorrect information is presumably still contained on this Register, subject to potential release by the Registrar of Births, Deaths and Marriages.

The situation for people born prior to 1 July 1988 is extremely unequitable. When I was answering enquiries at the Donor Registers Service at the former Infertility Treatment Authority, one of my first questions I asked related to whether the enquirer knew where the treatment took place as this determined the possibility of fulfilling a person's request to discover information. If someone was born as a result of treatment at the Royal Women's Hospital, then they can contact the service there (which exists between the hospital and Melbourne IVF) where they are offered full counselling with the counsellor performing an outreach to the donor, regardless of the donor's stated consent at the time of donation. If a person was born as a result of treatment at the former Prince Henry's Hospital then they can apply to the Voluntary Register, as the clinic is closed and the files are now held at the Public Records Office (as closed files unable to be accessed except possibly by the Doctor who provided treatment). If a person was born as a result of treatment at the former Queen Victoria Hospital, then they can apply to the Voluntary Register but for the

most part no records exist prior to 1979 and only partial records exist after this date, now largely held by Monash IVF. If a person was born as a result of treatment at what is now Monash IVF then they can apply to the Voluntary Register, as current clinic policy does not extend to servicing people involved in treatment prior to 1988. If a person was born as a result of treatment with a Doctor in private practice (and this can also be a Doctor who practised at one of the other clinics but also saw patients privately) then they can expect that no information exists or may be held by the Doctor (though in my experience I did not encounter one instance of a Doctor admitting to being in possession of information that existed outside of known records).

The information in pre-1988 records is often incomplete or erroneous or was specifically stripped of information after the implementation of the 1984 Act. Donor codes can be blacked out or in some way obscured and donors were encouraged to donate under false names or identities and it was not a priority of many Clinics or Doctors to ensure that correct information was kept. In addition to this, certain practices took place or were encouraged that now make the information in the records somewhat difficult to trust: women were inseminated over a three (fertile) day period with sperm from more than one donor, donor sperm was 'mixed' with that of the husband's, women were encouraged to go home and have sex with their husband (who may or may not have been clinically infertile). This anecdotal information from patients and donors of this time and clinic staff familiar with these processes and the records, presents a huge difficulty for anybody in a position to release this information – what information is correct? How do you verify it so many years after the fact?

Currently, people born prior to 1 July 1988 are only able to access information via applying to the Voluntary Register (and identifying information is only available if a half-sibling or donor also applies to this Register and agrees to its release). If people born prior to 1 July 1988 cannot have their mother's treatment or a donor code confirmed by medical records, then these people are not able to be placed on the Register. When the Donor Registers Service held the Voluntary Register, these people were offered specialised counselling and referral regarding this potentially distressing situation. Currently there are no provisions or help for these people. The Federal Senate Legal and Constitutive Committee's inquiry into donor conception in Australia may consider the establishment of a DNA databank (like the one in the United Kingdom) as a way of helping these people, but Victoria needs to consider whether it will provide any support to this otherwise biologically disenfranchised community.

**d) *The options for implementing any changes to the current arrangements, including non-legislative options***

My experience in administering the Donor Registers Service, collecting and managing information and releasing it to clients has led me to believe that the only option for implementing equal access to information is to make every effort to contact the donor regarding a donor-conceived person's application for information. In this way the situation can be managed to cause the least distress possible to parties involved and their families through the use of counselling and counsellors as intermediaries. People born prior to 1 July 1988 and those born as a result of the 1984 legislation should have the same rights as those born as a result of later Acts, but the release of information should not just be automatic but contingent on an attempt to contact the donor involved. Though there are several important questions to consider in relation to this: What if the donor opposes the release of information? Should the person making the application for information be informed of this opposition? If the donor is now deceased, does the donor's death mean that information can't be released and should an attempt be made to contact family or next of kin?

Any changes to the current situation regarding access by donor-conceived people to information, requires significant thought as to how to structure a service system to implement these changes. An unfortunate aspect of the Assisted Reproductive Treatment Act 2008 was the more or less complete lack of research or thought as to how the changes named in the Act would be wrought, and an absence of consultation as to how best service the needs of the donor conception community. The Donor Registers Service was not consulted regarding our experience with the donor-conceived, and users of the service were not surveyed. The current situation is de-personalised and not consumer friendly – requiring people to contact multiple agencies, lacking anything other than the ability to provide generic one-off counselling, and requiring recordkeeping by multiple government agencies and departments. It is therefore more labour intensive to administrate and costly than the two options to implement these changes provided below:

- I. Provide funding for clinics and hospitals to release their information and provide counselling and education to pre-1988 donor-conceived applicants:

Pro – # Expertise with the records and with providing specialised counselling in this area – history of successful service by RWH and Melbourne IVF, # Continuity - prior relationship with parties involved in an application for information

Con – # Resistance within the organisation, # Requires increase in funding to provide this service (which may be passed on to consumers therefore making assisted reproduction even more costly), # The need to communicate with other clinics and agencies holding records regarding gathering information about whether donor's donated at other clinics and if children were born, need for authority to do this, more likely to 'miss' information held elsewhere, # Lack of independence – prior relationship with parties involved in an application for information, # Closed agencies not covered, # Would require some change in legislation

- II. Set up a specialised independent agency to collect and release information and provide counselling and education to pre-1988 donor-conceived applicants:

Pro – # Independent of clinics and hospitals, # Can take over the maintenance and access to records relating to closed agencies (i.e. Prince Henry's), # One-stop shop for consumers, # Recordkeeping in one place – may be less likely to 'miss' information, # Consumers may not need to apply for information in order to access specialised counselling and referral services regarding their situation

Con – # Need to build up or recruit specialised information or expertise, # Need to provide this service with the ability and authority to access these records, # Would require more comprehensive change in legislation

**e) *The impact that any such changes may have on the donor, the donor conceived person and any future donor programs***

Any changes that would aim to enable equitable rights to access information for the donor conceived, should also consider providing rights for donors and the children and descendents of donors. A donor who donated when he was 19 might feel very differently 30 years after the fact. If he has subsequently had children and shared with them the information about his donation, should these people all be able to know about and have a right to access this information? I think it is very important to consider not just the rights of the donor-conceived and their parents, but also donor's and their families. Often the donor is an isolated figure who, as they have waived their rights to parentage, is not considered to have any emotional investment in the result of their donations. Though I have encountered a great variety in donors' thoughts and feelings regarding having donated, it is my experience that many donors are interested in the welfare of the people that they helped to created. This does not mean that they wish to intrude upon the donor-conceived person's life or family unit, but that they are interested in gaining some sort of information or ensuring that they are available to provide information about themselves for a donor-conceived person or their family.

The fear about implementing equal rights to all donor-conceived people for access to information is that a donor from 30 years ago when approached, would be upset about this approach and believe that his wishes stated at the time of donation have been disregarded. Obviously this has and would continue to happen but this reaction represents a small minority of cases I encountered and was just as common an occurrence as donors who had consented to one of the later Acts, not responding to correspondence, refusing to supply information or contact or actually denying the reality to what they had clearly (as indicated by records) consented to. The reality is that donors did donate and in doing so may have created life, and while they may have felt one way regarding their donation, the donor conceived individual cannot be expected to be party to the consent that their parents agreed to. It is also important not to presume that a parents' consent was any more comprehensive than a donor's may have been. Many people who consent to treatment with donor gametes are vulnerable – they want children and this is possibly the only way they can achieve this wish. My experience with donors, the donor-conceived and their parents is that donor treatment is not a personally empowering experience. Providing all of these people with the right to access information is one way of empowering them.

In Victoria, there has been no actual anonymous donation sanctioned by law for over 20 years, so implementing equal rights would have no influence on the current or future amount of donors (who, these days are more likely to be female and in some way known to the recipients). This should also have very little impact on donor programs, aside from discouraging some recipient parents who strongly feel that the donation and nature of the conception should be anonymous and kept a secret from any children born. A lot of these potential problems can be minimised by providing funding for and empowering community education. The former Donor Registers Service was funded for and ran a community education program for three years, developing many 'world first' resources. The campaign was responsible for an increase in community awareness and more applications for information and requests for counselling from those involved in donor treatment. It also helped many parents and donor's to tell their children and families about their involvement in donor treatment.

**f) *The impacts of the transfer of the donor registers currently held by the Infertility Treatment Authority to the Registrar of Births, Deaths and Marriages***

The 1984 and 1995 Central Registers along with the Pre-1988 and Post-1988 Voluntary Registers were transferred to the Registrar of Births, Deaths and Marriages on 1 January 2010. With this transfer went the loss of information about the history and difficulties regarding the data in the Registers. It also resulted in the closure of the Donor Registers Service, a service that provided counselling, education and information for enquirers and applicants. It was not replaced with an equivalent service.

Another impact of this transfer relates to the role that the data provided to the Central Registers had in fulfilling the Authority's role in regulating the use of donors approved for use in Victoria (this refers to donors who donated in Victoria along with those imported and approved for use in Victoria). The information about births and donors received helped the Authority to determine whether clinics were complying with family limits, provisions relating to consent dates and standards of recordkeeping, and whether donors were donating at more than one clinic. It also created a site of expertise in relation to these records.

The change in legislation was not only unfortunate for myself and my two equally committed co-workers at the Donor Registers Service, it was a tragedy for donors, the donor-conceived and their parents who could formerly deal with one small staffed government agency representing experience and expertise in this area, but now had to receive their counselling from one agency, education and general information from another, and apply for information relating to their treatment from another. This splintering of services is not only confusing and deterring for consumers, but is costly and increases the chances of information and people 'slipping beneath the cracks'. We provided a service whereby people could receive counselling and some information before, during, after or outside an application for information, thereby helping to guide their decision-making. The Donor Registers Service also searched for and performed outreach to other parties on behalf of the person making an application, and acted as an intermediary providing a 'letterbox' service for people who wished to correspond anonymously. The current service system does not provide any of these services.

The Registry of Births, Deaths and Marriages is a large anonymous government organisation with no previous expertise or experience in assisted reproduction, and whose core business involves charging people for information about themselves. One of the main reasons for the movement to the Registry was to confirm the birth information in the Central Registers with that held in the main Victorian Birth Registry. This ignores the fact that many births on the Victorian Central Registers take place interstate or overseas. The Registry is also not experienced in running a service that involves anything other than providing information and therefore was not equipped to take over the complex operations of the Voluntary Register which requires the negotiating and brokering of agreements and arrangements for information exchange between multiple parties. The Adoption and Family Records Service who took on the role of counselling relating to applications for information from the Central Registers, similarly had no experience or expertise in the field of assisted reproduction, and due to constraints in the legislation are unable to directly access the information relating to the application, therefore being unable to provide the same level of service as that they provide to adoptees and relinquishing parents.

# SENATE LEGAL AND CONSTITUTIVE COMMITTEE

## INQUIRY INTO DONOR CONCEPTION IN AUSTRALIA

**Submitted by Kate Dobby**

My name is Kate Dobby. I'm an Information Manager/Librarian by profession and I passionately believe in the importance of collecting and maintaining information to enhance future opportunities for access, and in the promotion of rights to access information. From 2005-2009 I was the Registers Officer at the Donor Registers Service at the former Infertility Treatment Authority in Victoria, my employment ending with the January 2010 enactment of the Victorian Assisted Reproductive Treatment Act. My job was to maintain Registers and associated information relating to births occurring as a result of the use of donors. I was responsible for monitoring the use of these donors, responding to information enquiries about the Registers, and releasing information to donors, parents and the donor-conceived according to legislation. I believe I am possibly the only information professional to ever specialise in this field, and I have built up a wealth of knowledge in the area of donor conception. Therefore I am in a unique position to comment on various aspects of this inquiry. My purpose in making this submission is to draw the attention of the Committee to the difficulties of collecting and maintaining information about clinical practices and the people involved in (and born as a result of) donor treatment, imposed by Australia having many jurisdictions and bodies involved in regulation and monitoring. The implications of this regarding the rights of the donor-conceived, and my experiences with the interests and needs of those involved with donor treatment.

### **SUMMARY**

The many jurisdictions and different levels of regulation in Australia create conditions conducive to reproductive tourism. This not only allows patients and clinicians to engage in treatment that is prohibited or undesirable in certain jurisdictions, but also creates gaps in information and records. This means that the regulation that does exist is unable to properly regulate the correct use of donors (e.g. family limits, whether the donor is still alive etc). Multiple regulatory jurisdictions has also resulted in the situation of donor-conceived individuals having different rights and abilities to access information about themselves and people they are biologically related to (half and full siblings, one or more biological parents) depending on where they were born, which clinic their parent/s attended and the donor/s involved. While many people believe that donor-conceived persons have the right to access information regarding their biological parentage, proper attention, research and consultation has not been conducted by legislators regarding the specifics of what this information should be and how it is best collected, maintained and accessed, and what resources this would entail and how legislation should enable the accessing of these records. It is also important to consider the repercussions of specific or unregulated payment for gamete donations, as well as the future support and informational needs of the people involved in donor treatment (donors and their families and parents) and the children subsequently born.

## STATEMENTS ADDRESSING THE SCOPE OF THE INQUIRY

### *Past and present practices of donor conception in Australia, with particular reference to:*

#### **a) Donor conception regulation and legislation across federal and state jurisdictions**

As with many areas of the Australian health services sector, the practice of donor conception has been shaped by Australia's multi-jurisdictional environment. What one prospective parent, donor or clinician has been unable to do in one jurisdiction they are permitted to do in another, leading to the existence of reproductive tourism (and the presence of clinics in border towns between states). Even before the enactment of legislation in Victoria in 1988, prospective parents, donors (or just their donations) and clinicians travelled interstate. This has resulted in situations where donor gametes have been donated in one jurisdiction, been transported to another, and used by patients who have travelled from another jurisdiction, who can then have their child anywhere they wish. This can and still does occur, and makes a mockery of jurisdiction-based attempts to maintain records of donor conception and the people born. It also dilutes any attempt by one or another jurisdiction to effectively regulate practices. You can't effectively maintain limits on the amount of families created as a result of one donor, when you don't know if a child has been born or if the donor has donated elsewhere or under another or variant name or details. Clinics and regulators are aware of this and can do very little to stop reproductive tourism within and outside of Australia. Another result of this is that specific data sharing and information exchange agreements need to be made by agencies and organisations to enable the regulation of practices and meet obligations such as being able to release information to the donor-conceived. In practice the range of legislation and regulation, and government agencies and private organisations involved provide significant barriers to enable the establishment and enforcement of such agreements.

#### **b) The conduct of clinic and medical services, including:**

##### **i. Payments for donors**

Increasingly practice (especially in Victoria) has moved towards the use of 'known' donors. This situation encompasses donors who are related to recipients as well as donors whom have been recruited over the Internet and have only recently met the recipients. Although payment (for anything other than expenses incurred) is prohibited in most jurisdictions, in practice, clinics and doctors can do nothing but turn a blind eye to payments between parties. The main issue regarding setting payments for gamete donors is in creating situations where a prime motivation for gamete donors becomes financial, and that payment may involve setting conditions on future access to information (e.g. a recipient paying a donor more to impose conditions on the donation – for example, to be more or less available to provide information should any children born later seek it). One of the main questions posed by donor-conceived individuals and their parents in relation to donors, is a desire to know why their donor donated (this is also a universal question in donor questionnaires). When regulation allows for donors to receive significant payments for donating, the donor's motivation is less likely to be altruistic and can open the door towards possible exploitation of the recipients and donors, and the creation of individuals conceived as a consequence of the financial gain of another.

**ii. Management of data relating to donor conception**

Clinics and Hospitals cannot and should not be expected to keep track of gamete donors and past patients and yet most legislation and regulation sets up situations whereby they are implicitly expected to. Donor gametes may be legally used many years after their original donation with there being no onus on (or ability of) the clinic to maintain any regular schedule of contact with the donor. Furthermore, many jurisdictions outlaw or greatly restrict the use of gametes by persons known to be deceased. In practice, actual monitoring of this would entail a clinic being in contact with a donor each time their gametes are proposed to be used in a procedure. In my experience, this was far from the practice in any Victorian clinic, which, since 1988 has had the most restrictive legislation in this area in Australia. This situation is even more fraught when gametes are donated, imported or exported or stored by recipients for significant periods. State or Territory-based assisted reproduction and privacy legislation, and the fact that assisted reproductive clinics are competing businesses, mean that clinics are not freely able to communicate with each other regarding patients and donors. Important information is not shared and gaps and variant information is created.

Although my experience is with clinics and records in Victoria, my work also encompassed contact with interstate clinics and records. One of the main difficulties that I encountered in my work was the inability to access the information (whether held by a Victorian or interstate clinic, hospital or other body holding records) that was needed in order to fulfil the management of the Registers. This was not just because there has been a history of this information being destroyed or haphazardly collected by practitioners and clinics, but was also a direct result of the lack of specific provision in legislation and regulations to enable the Regulator to have the authority to access relevant information, whether in making provisions for access to records relating to a clinic or agency which had closed, or to access records held interstate by a body outside of jurisdiction (but involving records of patients or donors relating to the requesting jurisdiction). This had implications for my ability to release information to people whom the legislation granted rights of access.

**iii. Provision of appropriate counselling and support services**

Through my work at the former Victorian Infertility Treatment Authority, I dealt with many donors, recipient parents and donor-conceived individuals who were in need of very specific counselling and support services. In Victoria, ability to access such services depends on where and when the donor treatment occurred. Our service attracted many enquiries from interstate (and sometimes overseas), as no equivalent service offering counselling, education and the ability to access information existed in another jurisdiction. The Victorian Assisted Reproductive Treatment Act enacted in January 2010, ended the ability of the Regulator to provide such a service by moving the information/records to one government agency and the counselling to another while leaving the education services with the Regulator/Monitoring Body. This is not only confusing for consumers but the splintering of services and the severing of the regulator and counselling provider from the records results in counselling that can't address the specifics of the enquirers' situation and the regulator can't monitor records as proof of clinical adherence to regulations like donor limits or gain a sense of how well licensed clinics, hospitals and practitioners are providing support or services to former donors, recipients, and the donor-conceived.

As a result of my experiences dealing with enquiries and applications for information from this population, I have come to strongly believe that clinics and hospitals offering programs involving donor conception need to be able to provide free counselling for past patients, donors and their families, and the donor-conceived. Where this is not available (in instances where the clinic or hospital no longer exists) the legislative jurisdiction should endeavour to make available resources for these people. If the State regulates and allows assisted reproductive practices involving gamete donation with the aim of prioritising the 'best interests' of any children born, then the State should be providing resources for the future psychological welfare of people involved in and born because of these practices – whether these resources are provided by the State or a condition imposed on a clinic or hospital by a regulatory body or Act of legislation. Donor conception is a difficult and sensitive area and many people are ashamed of and/or secretive about their involvement. Not adequately resourcing community education and support services leaves this community further isolated.

**c) *The number of offspring born from each donor with reference to the risk of consanguine relationships***

With multiple jurisdictions, and no centralised regulation in relation to recordkeeping and data sharing, the State is not in a position to effectively guard against the possibility of (unwitting) consanguine relationships between donor-conceived individuals or between donors and recipient parents. Even if two adults are both aware (and disclose to each other) that they are donor-conceived, they may not have the legal means or opportunity to be able to discover whether they share biological parentage. The State is also unable to track the use of donors - people can (and do) cross jurisdictions (interstate and overseas) and donate, as well as donate under assumed or variant names and details. Realistically, the pool of donors is probably always not going to be great enough to satisfy demand, and this situation is exacerbated when unrealistically small family or child limits are imposed. Small donor limits also require more intensive monitoring and regulation, and by limiting the pool of donors available, encourage more 'black market' donation outside of the clinical (and regulated) system. The issue is not so much how many children are being born, but the clustering of families created within certain localities and populations. Furthermore, if the risk of unwitting consanguine relationships are the concern of legislators, then adequately resourcing education and support services and providing sufficient ability for records to be kept and accessed by or on behalf of those involved in donor treatment should be prioritised. Keeping donor conception a secret is the collusion between deliberate parental choice or inaction on telling the child/ren about the nature of their conception and the absence of specialised and community resources encouraging openness about donor conception and access to information provided by the State.

**d) *The rights of donor-conceived individuals***

In Victoria alone, successive acts of legislation, as well as differences in clinical practice have created a situation whereby children born to the same donor or within the same family have different rights to access information from each other, despite one of the aims of the legislation being to grant the rights to access information. Having spent almost five years working in this area and dealing first-hand with information requests from donors, parents and donor-conceived individuals, I can state that past and current clinical practices and regulation have created significant barriers to people being able to access information about their biological parentage and close relatives. Despite all the well-meaning legislation that has been enacted in various States and Territories (and overseas), nowhere has the need for donor-conceived individuals seeking information about their half or full biological siblings been recognised. In some jurisdictions, donors can seek information about recipients and the children born and parents and the donor-conceived can seek information about donors, but donor-conceived individuals cannot seek information about people who are either full or half-siblings. This has consequences regarding the inevitability of unwitting consanguine relationships. It is also important to consider the granting of rights to access information to the direct descendents and relatives of donors who are also at risk of unwittingly entering into consanguine relationships with donor-conceived individuals.

Currently, the rights of donor-conceived individuals, though explicitly granted in Victorian law, are implicitly constrained and inhibited by the inequalities of accessing information. Though it is true that for many donor-conceived people (especially those born prior to the use of frozen sperm in 1976), there are no records or information to access, there is no provision (like in the United Kingdom) for DNA testing. In my work, I was contacted by many donors and donor-conceived people for whom there were no records who were willing to place DNA on file, which in the absence of authoritative or any records at all, is the only way to establish biological relationships. It is important that the Committee consider the fact that a voluntary DNA databank is the only way of granting the potential to access information for this completely disenfranchised segment of the donor-conceived population (as well as the donors and their families), as well as providing more certainty regarding genetic links than is often provided in the relevant medical records.