

# 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.