Victorian Infertility Counsellors Group

Submission to the Senate Legal and Constitutional Committee

Inquiry into Donor Conception in Australia

July 2010

Opening Statement

The Victorian Infertility Counsellors Group (VICG) consists of social workers and psychologists who are ANZICA (Australian & New Zealand Infertility Counsellors Association) members working in ART clinics across Victoria. The group has been meeting for over 20 years and now consists of approximately 30 members who meet on a quarterly basis.

Together we have over 200 hundred years experience in working directly with donors and recipients through the provision of donor counselling, donor linking, running of support groups, education provision and our links with key consumer groups such as the Donor Conception Support Group.

Collectively we have also played a key role in the implementation of the new Victorian legislation, The Assisted Reproductive Treatment Act 2008 which was enacted January 1st 2010.

The Victorian Infertility Counsellors are proud that Victoria leads the way in recognising and protecting the rights of donor conceived persons through the establishment of the central and voluntary donor registers in 1988 and the implementation of legislation in 1995 to ensure that a donor conceived individual has the right to obtain information about their donor upon turning 18.

The VICG welcomes an inquiry into the past and present practices of donor conception in Australia. In particular,

- We welcome the opportunity for the establishment of uniform legislation across Australia that recognises the rights of donor conceived persons to information about their biological parents and genetic siblings.
- We also strongly argue for the inclusion of a comprehensive and integrated donor linkage counselling service that forms an integral part of donor linking for both those seeking information and those who information is being sought about. This counselling should be more than a single mandatory information provision session; it should be available for all individuals involved throughout the linking process and tailor-made to meet individual needs.

Summary of VICG Recommendations:

1. A national legislative framework is developed to ensure a uniform approach to donor conception and management of data collection, information provision and counselling and related support.
2. Any national legislation introduced does not support payment for donation other than for reasonable out of pocket expenses.
3. A national donor register is developed but not at the cost of there being a reduction in the quality of the management and provision of donor conception information that is collected and accessible through the Victorian Model. VICG would therefore recommend a national model based on the Victorian Model that also allows for retrospective access to the registers.
4. The provision of counselling for all parties involved in a donor arrangement prior to consenting to treatment remains a legislated and mandatory part of all donor programs. The inclusion of a donor's partner in the counselling process should be a mandatory requirement as was previously the case under the Infertility treatment Act 1995
5. Counselling support should form an integral part of donor linking for both those seeking information and those who information is being sought about and should be tailored to individual needs rather than as a single mandatory information provision session. An intermediary service such as the letterbox service should also be provided as occurs in adoption practice to enable parties to communicate in a non-identifying manner.
6. The number of offspring born from each donor be limited to 10 women
7. The import of gametes/embryos from overseas is banned where information about the donor cannot be provided for clinic records or BDM's registers and/or the donor cannot be counselled about and consent to donating within the legal jurisdiction within which their donation will be used.

Donor conception regulation and legislation across federal and state jurisdictions:

The Assisted Reproductive Treatment (ART) Act 2008 provides the legislative framework for donor conception in Victoria and leads Australia in terms of protecting the rights of donors, recipients and donor conceived offspring, particularly in regards to access to information and ensuring all parties involved in a donor arrangement fully understand the legal, moral, ethical and psychological implications prior to consenting to treatment. The ART Act 2008 stipulates that counselling is mandatory for recipients (and their partners) and their donors. An unfortunate omission in the 2008 legislation is the requirement that donor's partners participate in the consenting process and the Victoria Infertility Counsellors Group would recommend that donor's partners have the right to consent to the partner donating as was the case in the previous Act.

The Reproductive Technology Accreditation Committee (RTAC) Code Of Practice and National Health & Medical Research Council's (N HMRC) Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research provide a strong basis for setting minimum standards across Australia and New Zealand. However there are limitations to their effectiveness in ensuring uniformity across Australia and New Zealand given there is limited scope for these bodies to monitor practices across Australia and implement consequences for non-compliance. A national legislative framework would provide that extra step in ensuring that all states have a uniform approach to ensuring equitable access to treatment, protection of the rights of al parties involved in donor arrangements and systemised approach to data collection, information provision and counselling and related support.

The VICG recommends a national legislative framework to ensure a uniform approach to donor conception and management of data collection, information provision and counselling and related support.

a. **The conduct of clinics and medical services, including:**

(i) **Payment for donors**

The NHMRC guidelines stipulate that 'gamete donation must be altruistic. Commercial trading in human gametes and/or the use of direct or indirect inducements, must not be undertaken.' The RTAC Code of Practice requires clinics to show evidence that donors and recipients have been advised of 'the fact that donors will receive no financial gain, consideration or similar benefit for their donation'.

The VICG strongly argues for altruistic embryo/gamete donation as the altruistic framework is seen to protect recipients and their offspring and indeed donors from exploitation. Even within an altruistic framework of donation however, there are cases where potential donors have attempted to blackmail and exploit recipients but this is minimised through the comprehensive counselling process that both donors and recipients go through prior to donation. Altruistic donation also prevents the gamete trade that this is prevalent in the US for example, where young women and men are regularly donating gametes to finance themselves through college. It is unclear what the long term implications for these women and men will be if they have donated for financial reasons without giving due consideration to the long term implications for their emotional and physical wellbeing.

It should be noted that Victorian Clinics generally report sufficient availability for altruistic donors to meet demand.

The ART Act 2008 also inhibits the importation of gametes or embryos where payment has been involved. The Act states that the importation of all donor gametes and embryos must first be approved by the Victorian Assisted Reproductive Technology Authority (VARTA) and that in doing this VARTA must be satisfied that similar procedures have taken place with the gametes/ embryos for which they can be used in Victoria. VARTA will only approve the import of donor gametes where payment has been made for reasonable expenses only.

The VICG recommends that any legislation introduced does not support payment for donation other than for reasonable out of pocket expenses.

(ii) Management of data relating to donor conception

The collection of data about donor conceptions and the parties involved has historically been poor. However in Victoria from 1988 donor registers were implemented which contained both identifying and non-identifying information about donors, recipients and donor conceived children and which could be accessed with the permission of the individual who the information was being sought about. Since then, two further changes to legislation have resulted in increased rights for donor conceived offspring to know of their donor origins and access information about their genetic background.

As a result of these legislative changes, Victoria currently operates under three different legislative frameworks in regards to the collection and provision of donor conception information. Donor offspring born before 1988 only have access to information provided on the voluntary register or that clinics are willing to provide (with permission of the donor)

Offspring born between 1988 - 1997 and their parents and donors can access information from the central (contains identifying information) and voluntary registers. Donor conceived individuals can access identifying information with the donor's consent once they reach 18 years of age. Recipients can request information about the donor whilst their child is under 18 but the donor has the right to refuse. The donor can also request to access information from the donor register but the recipients (If donor conceived child under 18) or donor conceived child (if over 18) has the right to refuse.

Donor conceived individuals born after 1998 have the right to the donor's name once 18 years of age. The donor has no right of refusal. The donor can choose to give further identifying information.

From 1st January 2010, donor conceived offspring will receive notification that there is further information about their birth when they apply for a birth certificate after the age of 18. They are asked to contact Births, Deaths & Marriages (BDM) and will be advised of their donor origins upon contacting BDM.

The ART Act 2008 and Regulations set out what information regarding donor treatments must be provided to BDM on an annual basis regarding donor conceived births.

The VICG strongly argues that donor conceived individuals born before 1988 in Victoria should be given the same access to information about their donor conceived origins as those born post 1988. The VICG would also argue that this retrospective access should apply to all donor registers across Australia as was the case for adoptees This is now accepted practice.

Counsellors who have worked in donor linking in Victoria have found that donors who donated prior to the 1988 legislation are often more than willing to be involved in providing offspring with information about their genetic origins. Donors who are not comfortable having their identity revealed are often willing to exchange information.
Donors will say that they have often been wondering about offspring, but had felt they had no right to know. Some expressed a great satisfaction from knowing that their donation had been successful and some have gone on to form good relationships and strong bonds with donor offspring.

The VICG strongly support a national donor register. However we would not support a

national model at the cost of there being a reduction in the quality of the management and provision of donor conception information that is collected and accessible through the Victorian Model. VICG would therefore recommend a national model based on the Victorian Model that also allows for retrospective access to the registers.

(iii) **Provision of appropriate counselling and support services**

The ART Act 2008 requires that ‘before a person gives consent …the person must have received counselling (including counselling in relation to the prescribed matters) from a counsellor who provides services for a registered ART provider’.

The NHMRC guidelines require that ‘clinics must provide readily accessible services from accredited counsellors to support participants in making decisions about their treatment, before, during and after the procedures’ and stipulates what should be included in this counselling and the RTAC Code of Conduct states that ‘donors and recipients….are required to meet with an infertility counsellor prior to any donation process commencing.’

The VICG recommends that the provision of counselling for all parties involved in a donor arrangement prior to consenting to treatment remain a legislated and mandatory part of all donor programs. The VICG also recommends that the inclusion of a donor’s partner in the counselling process be a mandatory requirement as was previously the case under the Infertility treatment Act 1995. Under the current Act an individual can donate without the knowledge of their partner. This has serious implications for a partner and any children or future children born to the relationship.

Ongoing counselling support to recipients and donors after treatment eg to provide support with telling children about their origins or with managing any issues that may arise between recipients and donors is not systematically provided in Victoria and is dependant on individual clinic policy. The Infertility Treatment Authority (ITA) now known as VARTA (Victorian Assisted Reproductive Treatment Authority) did provide a counselling service to recipients, donor and donor conceived offspring prior to 2010 but this service has been eroded to largely a community educational role. VARTA provides information and support to parents to assist them to talk to their donor-conceived children via the ‘Time to Tell’ campaign, website information and seminars for parents.

VARTA was also responsible for management of the voluntary and central registers until January 2010. In addition to the provision of information from the registers, ITA also provided a comprehensive donor linking counselling service for donors, donor recipients and donor conceived offspring. This service provided counselling to support parents to tell their children of their donor origins, for stepping a donor conceived individual through the process of first learning they are donor conceived to considering contacting their donor, to assisting them to make contact with their donor and then to managing the outcome of this contact. ITA would also provide support to a donor who was considering accessing information from the registers or who received a request for contact from a donor conceived child or their parents.

ITA also provided a ‘Letter Box’ service where donors and recipients could send each other information/requests for information without identifying themselves.

Since January 2010, the donor registers are managed by Births Deaths & Marriages (BDM). BDM’s role is purely information provision. Counselling support is not given to those considering making an application. Donor-conceived people or their parents are no longer entitled to receive non-identifying information about other people born from the same donor as they were entitled to previously.

The donor linkage counselling is provided by Adoption & Family Record Services. Due to legislative and funding constraints this service provides one generic information session to individuals seeking information from the registers and to those consenting to the release of identifying information This is mandatory under the legislation. The counsellor is not provided any information about who the party is linked to and so cannot act in a facilitative role to communicate to the other party the wishes of the person making the application or provide any ongoing support to assist in the exchange of information. VICG is concerned about this reduction in counselling support to those accessing the registers or having information accessed about them.

The VICG strongly recommends that counselling support should form an integral part of donor linking for both those seeking information and those who information is being sought about. This counselling should be more than a single mandatory information provision session; it should be available for all individuals involved throughout the linking process. An intermediary service such as the letterbox service should also be provided as occurs in adoption practice to enable parties to communicate in a non-identifying manner.

The VICG recommends that the provision of counselling for all parties involved in a donor arrangement prior to consenting to treatment remain a legislated and mandatory part of all donor programs. The VICG also recommends that the inclusion of a donor's partner in the counselling process be a mandatory requirement as was previously the case under the Infertility treatment Act 1995.

b. The number of offspring born from each donor with reference to the risk of consanguine relationships

Individual clinics set their limit for the number of families that could be created from a single donor up until 1995 when the IVF ACT 1995 introduced a limit of 10 families. The ART Act 2008 has now introduced a limit of 10 women (including any children born to donors/donors partners'.

It should be noted that managing the number of offspring born from a donor is not just about reducing the risk of consanguinity. An important reason for limiting the numbers of offspring is to reduce the complexity for donor conceived individuals around concepts such as identity and kinship, when linking with their donor and genetic-half siblings. It is not unusual for offspring to discover that they have up to twenty genetic half siblings when they start searching and this can be daunting for someone trying to come to terms with finding out they are donor conceived and trying to make sense of their identity and what 'family' means for them.

The VICG recommends that number of offspring born from each donor be limited to 10 women

c. The rights of donor conceived individuals

Both the NHMRC guidelines and RTAC Code of Practice refer to the donor conceived individual's right to access information about their donor/s including information about genetic half siblings.

Victorian legislation has recognised the rights of donor conceived children to have access to information about their donor origins in a centralised and systemised way since 1988 when central and voluntary registers were developed. These registers do not however recognise the rights of donor conceived offspring born before 1988 and this group have largely been forgotten about and their rights to access information ignored.

A further discrepancy regarding equal access to information occurs in the same sex and single parent community. Up until the ART Act 2008 was implemented in Jan 2010, fertile women had to travel interstate to seek treatment and did therefore not come under Victoria legislation. These women and their children therefore do not have the same access to information about their donor origins as do donor conceived offspring in the rest of the Victorian community. These women find it particularly difficult not to be able to provide their children with up to date and accurate information about their donor, often only having a few lines of information to share with their child. A retrospective national register would assist in rectifying this inequality.

An integral part to a donor conceived individual's right to information about their origins is ensuring that this information is provided in a supportive and comprehensive way that maximises successful outcomes for all parties involved. The VICG strongly recommends that counselling be available to both the individual seeking information from the registers and the individual who the information is being sought about and that this counselling support be provided in an integrated way and tailored to individual needs as was the case when ITA (Now VARTA) were managing the registers. The current counselling service offered by AFRS is a tokenistic gesture and not one that adds real value to the donor linking process.

An important key to ensuring donor conceived individuals' access to information about their genetic origins is protected is to legislate against the use of gametes/embryos from overseas clinics (this does not involve known donation of gametes/embryos from overseas) as this practice puts at risk the hard fought for rights of the donor conceived individual to have easily accessible information about their donor origins. The ART Act requires that donor information must be able to be held by the clinic and subsequently provided to BDM upon the birth of a donor conceived child. This is a complex and difficult task when involving overseas donor programs that do not necessarily offer the same protection and rights to access information for the donor conceived individual. The rights of the donor must also be considered, particularly to ensure that they have been appropriately counselled and fully comprehend the implications and legal framework regarding donation within Victoria.

The VICG strongly recommends that counselling be available to both the individual seeking information from the donor registers and the individual who the information is being sought about and that this counselling support be provided in an integrated way and tailored to individual needs.

The VICG also recommends that the import of gametes/embryos from overseas is banned where information about the donor cannot be provided for clinic records or BDM's registers or the donor cannot be counselled about the legal framework in which they will be donating.