

Victorian Infertility Counsellors Group

Submission to the Victorian Parliament Law Reform Committee

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

August 2011

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, facilitation 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. We also welcome the important changes to Birth certificates which was introduced in the ART Act 2008.

The VICG welcomes an Inquiry into Access by Donor-Conceived People to Information about Donors. In particular,

- We welcome the opportunity for the establishment of uniform Victorian legislation that recognises the rights of donor conceived persons to information about their biological parents and genetic siblings regardless of when they were born.
- 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:

- A harmonised approach to providing consistent access to information for all donor conceived individuals should be developed that takes into account and protects the individual needs of all parties involved.
 - 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. For those born before 1988, the donor's consent should be required prior to the release of identifying information similar to the Infertility (Medical procedures) Act 1984 (Vic)
 - Contacting a donor is not in contradiction to the Charter of Human Rights or NHMRC guidelines as long as it is undertaken in a respectful and confidential manner that acknowledges the context in which the donor originally consented to donation
 - Pre 1988 donor information including Prince Henry donor treatment records should be stored with the donor registers and legal authority given to the administering body to utilise the records to outreach donors, donor-conceived people and their parents. Legal authority should also be given to that body to inform affected parties if a donor or donor-conceived person has a genetic medical condition which is likely to put other people they are genetically connected to at risk.
 - As early donor conception treatment records have often been destroyed or are incomplete, a voluntary DNA bank should be established to assist with verification of genetic links.
 - Counselling support should form an integral part of donor linking for both those seeking information and those who information is being sought about. The counselling should be more than a single mandatory information provision session; it should be available for all individuals involved and catering to their individual needs and wishes. The counsellor should work as a mediator and facilitator 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. For this to occur changes would need to be made to current legislation to allow for exchange of relevant information between bodies administering the donor registers and providing the support services to applicants and outreach parties
 - If legislation changes, VARTA should be funded to provide a community education service and could be expanded to again provide the integrated and comprehensive donor linking service they provided prior to the ART Act 2008.
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- 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;**

As a result of 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 have access only to information provided on the voluntary register or that clinics are willing to provide (with permission of the donor)

Offspring born between 1988-1997, their parents and donors, can access information from the central register 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 whose donor consented 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.

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 the 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.

At present, the only way a donor conceived person born prior to 1988 can access information about their donor is if their clinic still operates and is willing to assist them with contacting the donor on their behalf. The only clinic that currently routinely provides this service is Melbourne IVF.

The main challenges associated with giving all donor conceived people access to identifying information about their donors and donor conceived siblings includes:

- Balancing the rights of the donor conceived individual to their genetic information with respecting the privacy of the donor and the context in which they donated. However throughout this submission we have identified ways that the donor should sensitively be approached for permission to share information whether this is identifying eg name and contact details or non-identifying eg medical, family history, personal traits. In our professional experience detailed, personalised and up to date non-identifying information is often the most valuable to the donor conceived child.
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- Merely providing identifying information about the donor does not necessarily facilitate the exchange of important information especially if the name is common or the donor refuses contact or is ambivalent about contact and isn't provided the necessary support to and information to make a decision.
 - Placing the onus on the donor conceived individual to find and initiate contact can place them in a very isolated and vulnerable position and deter them from seeking their donor especially as many do not confide in others about their search for their donor.
 - If seeking the donor is left up to the donor conceived individual without access to sophisticated search support (as is the case with adoptees) this can compromise the donor's confidentiality as several people may be contacted in the attempt to locate the correct person including the donor's family members.
 - Every party in the donor linking equation is in a potentially vulnerable position if the linking is not undertaken with adequate counselling support for all parties throughout the process. The donor conceived person fears rejection, the donor is concerned about intrusion into his family life and recipient parents fear losing their relationship with their son or daughter.
 - People conceived through donation at facilities which have closed down or where adequate documentation was not kept are in a particularly unique position and require additional support to search for their donors, verify their donors and deal with the consequences of potentially never being able to find information about their genetic history.
 - If legislation changed to enable donor-conceived people to be given identifying information about their donor-conceived siblings, this would be a grave breach of confidentiality, especially as many donor-conceived people are not aware they are donor-conceived. It is best if people are informed of their conception by their parents. It would be particularly difficult for a donor-conceived person to be made aware of the situation of their conception by a direct approach by their donor-conceived sibling. It would also put the donor-conceived person making the approach in a very challenging position and may be unlikely to lead to a positive relationship. Donor-conceived people do value comprehensive information about their siblings. They are often concerned about unintended consanguinity. This can usually be 'ruled out' if the person is given a list of siblings including their gender, month and year of birth. If a donor conceived person remained very keen to contact
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a sibling, it would be more appropriate for them to be able to contact the parents of the siblings, giving the parents time to inform their son or daughter of their donor-conception before a direct approach is made. Again this approach should be made with the support of an intermediary as has been described earlier. The VICG also supports the Voluntary Registers as an important mechanism to allow information exchange or contact between donor-conceived siblings.

- ***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 strongly recommends that any harmonised approach to providing access to information for all donor conceived individuals takes into account and protects the individual needs of all parties involved.

- 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 NHMRC guidelines state that:

If the consent form does not include permission for release of identifying information (because the donation was made before the introduction of these guidelines and the gamete donor has not come forward in response to the public information campaign outlined in paragraph 6.1.3), the clinic should make an appropriate effort, consistent with the original consent document and the privacy rights of the donor, to contact the gamete donor and obtain his or her consent to the release of information.

And:

Voluntary exchange of information between persons conceived using donated gametes, gamete donors and gamete recipients, with the consent of all parties, is desirable. Access to further information may occur only with the consent of all parties involved or as specified by the law.

The NHMRC guidelines therefore allow for the provision of information to donor conceived individuals about their donor where the donor has not provided consent in the original consent form signed by the donor at the time the donation took place as long as there has been a reasonable attempt to gain consent from the donor or legislation allows this. Despite the NHMRC guidelines, some clinics do not assist donors and donor conceived individuals and recipient parents through contacting the other party for consent to release identifying information. Additionally, donations that occurred at clinics

that have now closed such as Prince Henry's and Queen Victoria do not have any clear process for accessing information. This leaves donor-conceived people conceived at these centres in a legal vacuum with no legal options to access information other than to register with the voluntary register.

The VICG recommends that it is preferable to establish a system where donors are approached by a donor linking counsellor who can inform them of their options, including the particular details of the request for information, support them in their decision making and facilitate any contact or sharing of information between the donor and donor conceived person.

In The VICG's professional experience, donors can be anxious or reluctant to initially give consent to the release of any information. However, once they understand the motivations behind the application and are supported in exploring the options available to them, they are usually comfortable and willing to participate in either providing further contemporary information about themselves (eg medical information) or initiating contact with the donor conceived person (usually via email or letter).

The counsellor usually works with the donor conceived offspring prior to contacting the donor to compile a list of questions that they have for their donor in case the donor is willing to provide information about themselves but not consent to give identifying details.

- ***The VICG does not believe that contacting a donor who has not previously consented to release of information is not in itself a contradiction to the NHMRC guidelines as long as it is undertaken in a respectful and confidential manner that acknowledges the context in which the donor originally consented to donation.***
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- 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;**

The collection and preservation of information regarding donor treatments prior to 1988 is inconsistent across clinics and medical practitioners. Therefore it is vital that any information that still exists is verified and preserved. It should be noted that interpretation of the pre 1988 records will require highly specialised skills and knowledge of documentation of the time.

The establishment of a voluntary DNA bank would assist where no or incomplete records exist. Great care would need to be taken however to ensure that proper verification is undertaken before links are made to confirm accuracy of the genetic link.

Prince Henry's Hospital's donor records are currently stored at the Public Records Office of Victoria. However, currently no organisation has legal authority to contact donors identified in these records. It is our understanding that Queen Victoria Hospital records have been largely destroyed.

This is of particular concern regarding genetic medical conditions. If donors come forward from clinics which no longer operate, to try to alert offspring regarding a genetic problem which can be passed on, there currently is no body which takes responsibility for this and no mechanism to ensure that people who may be affected by the genetic condition can be alerted and informed of this. There is also no mechanism if a donor-conceived person is diagnosed with a genetic condition and wishes to alert the donor and genetic siblings.

- ***The VICG recommends that pre 1988 donor information including Prince Henry donor treatment records be stored with the donor registers and legal authority given to the administering body to utilise the records to outreach donors, donor-conceived people and their parents. Legal authority should also be given to that body to inform affected parties if a donor or donor-conceived person has a genetic medical condition which is likely to put other people they are genetically connected to at risk.***

 - ***The VICG recommends the establishment of a voluntary DNA bank to assist where no or incomplete records exist.***
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d. the options for implementing any changes to the current arrangements, including non-legislative options;

The VICG identifies three possible models:

1. All donor-conceived individuals have the right to access identifying information from the age of 18 regardless of the year they were born without requiring consent of donor. This would be in line with the 1995 (introduced 1998) and 2008 (introduced 2010) legislation.
 2. All donor-conceived people have the right to make an application to the central register for identifying information from the age of 18. The donor's consent would be required prior to the release of identifying information similar to the 1984 legislation (introduced 1988).
 3. ART Clinics are government funded to provide a similar service to option 2. However, legislative changes would not be required. NB Consideration would need to be given to providing clinics with authorisation to manage Prince Henry's and private doctors' documentation.
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- ***Whilst all models would potentially work with an integrated comprehensive donor linking counselling model, the VICG would recommend Model 2. The second model strikes the most appropriate balance between protecting the rights of the donor conceived person to have access to information and protecting a donor's privacy.***
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e. the impact that any such changes may have on the donor, the donor-conceived person and future donor programs;

It is the VICG counsellors' experience that donors are not as negatively impacted when contacted as may be expected. Donors can be initially ambivalent or anxious about the implications of contact or sharing information. Concerns can include: they assume the donor conceived child wants to have a parent/child relationship with them, telling family and partner of their donation if they haven't already done so, ungrounded concern about the donor conceived-person's right to any legal claims on them and anxiety that they won't live up to expectations. Counsellors who have worked in donor linking in Victoria have found that donors, even those who donated prior to the 1988 legislation, are often more than willing to be involved in providing offspring with information about their genetic origins, once they are informed of the motivation and expectations of the donor conceived person. Donors who are not comfortable having their identity revealed are often willing to exchange information once these issues have been explored and addressed.

This positive outcome is largely due to the sensitive, respectful way in which donors have been approached and supported through the linking process, particularly those who donated prior to the 1988 legislation.

Donor-conceived people also require assistance to make contact with their donor. It is insufficient to merely be given a name to contact. They will not have access to sophisticated search mechanisms, so if only given identifying information, they may in fact contact a number of people with the same name prior to contacting the correct person. These people could of course be related and so confidential information about the donor could be relayed to others.

In the VICG's experience both the applicant and the subject of the application find this an extremely daunting experience even though they may be positive about embarking on information exchange or contact. They may not have told family members (partners, parents, children) about wanting to find information about the other party as they may be concerned about their reaction. As contact with donors is a relatively new process there is little information available regarding what is appropriate. However, all parties are usually extremely sensitive and respectful to the other parties' personal and family situation and do not want to intrude or have any negative impact on them. Again counselling support is vital to support all who are affected by the application.

It is also the experience of the VICG that recipient parents even though they may not be applicants need support. They are usually highly anxious about the implications of contact on their relationship with their son or daughter. They also want to protect them from any potential hurt. The non-biological parent usually carries unresolved issues about their infertility often due to lack of counselling/preparation at the time. The couple may have not discussed the donation with their partner or with any one else, since the day it happened. The non-biological parent often has concerns that they are not the 'real' parent and that their child will favour the donor over themselves. In our experience this is not the case in families where there has been a previously healthy parent/child relationship. The parents need reassurance and the ability to air these concerns.

As such, if any legislative or other changes were to occur, a comprehensive community education program and donor linkage counselling service would need to form an integral part of service provision. It is our experience that with minimal counselling contact to educate and support the people involved initially, that the parties are usually able to manage themselves as long as the roles, boundaries and how they are going to communicate have been well established in the beginning. They may need occasional phone or email contact subsequently if further issues arise.

- ***The VICG recommends that VARTA is well placed to provide an adequately funded community education service and could be expanded to again provide the integrated and comprehensive donor linking service they provided prior to the ART Act 2008.***
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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 Infertility Treatment Authority (ITA) now known as VARTA (Victorian Assisted Reproductive Treatment Authority) now:

- Administers a registration system for assisted reproductive treatment (ART) providers under the Act;
- Undertakes public education about treatment procedures and the best interests of children born as a result of treatment procedures;
- Undertakes community consultation about matters relevant to the Act;
- Monitors programs and activities carried out under the Act;
- Monitors programs and activities carried out relating to the causes and prevention of infertility;
- Monitors programs and procedures relating to treatment procedures carried out outside Victoria;
- Promotes research into the causes and prevention of infertility; and
- Approves import and export of donor gametes and embryos into and out of Victoria.¹

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 previously 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.

¹ *Assisted Reproductive Treatment Act 2008 (Vic).*

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 Family Information Networks & Discovery (FIND). 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. We have been contacted by people who have made applications to the donor registers under this new system who are dissatisfied with the present arrangements. They have found the new system difficult to navigate as they have had contact with several different government agencies and have felt unsupported and lost. Those who had experience of the previous service provided by ITA have found the current service far inferior to the former.

- ***The VICG 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. The counselling should be more than a single mandatory information provision session; it should be available for all individuals involved and the counsellor should work as a mediator and facilitator 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. For this to occur changes would need to be made to current legislation to allow for exchange of relevant information between bodies administering the donor registers and providing the support services to applicants and outreached parties.***
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g. the possible implications under the Charter of Human Rights and Responsibilities Act 2006.

The Charter of Human Rights states:

A person has the right-

- (a) not to have his or her privacy, family, home or correspondence
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unlawfully or arbitrarily interfered with; and

The ART Act 2008's guiding principles state that:

- the welfare and interests of persons born or to be born as a result of treatment procedures are paramount;

and

- children born as a result of the use of donated gametes have a right to information about their genetic parents.
 - ***The VICG would argue that contacting a donor in itself is not in contradiction to the Charter of Human Rights as long as it is undertaken in a respectful and confidential manner that acknowledges the context in which the donor originally donated.***
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