

**VARTA**

Victorian Assisted Reproductive Treatment Authority

**Submission to the Law Reform Committee of the Victorian Parliament
Inquiry into Access by Donor-Conceived People to Information about Donors
Victorian Assisted Reproductive Treatment Authority
August 2010**

Background

The Victorian Assisted Reproductive Treatment Authority (formerly the Infertility Treatment Authority) is a statutory authority responsible for administering aspects of the *Assisted Reproductive Treatment Act 2008* (Vic) in Victoria. The Authority:

- 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

Prior to the introduction of the *Assisted Reproductive Treatment Act 2008* in January 2010, the Authority (as the Infertility Treatment Authority) also managed the donor registers under the *Infertility Treatment Act 1995*. This consisted of a Central Register and a Voluntary Register which housed information about all donor-conceived births in Victoria since 1988. These registers are now managed by the Victorian Registry of Births, Deaths and Marriages.

ART has been regulated in Victoria since 1988. The law has evolved over this time as technologies have developed and community views on family have evolved.

The Infertility Treatment Authority was established in 1996 under the *Infertility Treatment Act 1995* to:

- Administer the Central and Voluntary Registers;
- Administer a licensing and approvals system and grant exemptions where appropriate;
- Monitor compliance with licences, approvals and exemptions;
- Consider requests to approve the extension of storage time for gametes and embryos;
- Regularly review the progress of approved research;
- Monitor programs and activities carried out under the Act and programs and procedures carried out outside Victoria;

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

- Promote research into the causes of infertility; and
- Approve the import and export of gametes and embryos into and out of Victoria.²

Victoria was the first jurisdiction in the world to establish donor registers with the introduction of the Central Register in 1988 and the Voluntary Register in 1997. Other countries have since used this model as a basis for developing their own donor registers. The Authority has almost 15 years' experience in dealing with issues related to donor conception, including the management of donor registers. As a result of this unique history, the Authority has a wealth of knowledge and experience in the area of donor conception and donor-linking practice.

For the purposes of this submission, the term 'the Authority' refers to both the Infertility Treatment Authority and the Victorian Assisted Reproductive Treatment Authority.

The terms of reference for the Inquiry list seven principle areas of review. This submission addresses each of those areas in the order in which they were raised.

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 donor-conceived siblings, regardless of the date that the donation was made

Rights for access to information for donor-conceived people in Victoria vary according to when they were conceived. Ability to access information also differs depending on where their mother received treatment. In addition, differing legislation may apply to siblings from the same family and each child may have different rights and access to information about their donor. Amending legislation to allow all donor-conceived people to apply for identifying information about their donor would provide greater equity in relation to the rights of donor-conceived people in Victoria.

Victoria has lead the way with the implementation of voluntary donor registers, to enable donor-conceived persons born prior to the introduction of ART legislation to lodge and apply for information. However, information about their donor or another related party can only be obtained if the donor/other party also make an application and also lodges information. In the experience of the Authority, substantial publicity about the existence of a voluntary register is required to generate these types of applications.

When examining the issue of access to identifying information, the rights and privacy of donors must also be considered and balanced with the rights of donor-conceived people. Prior to the introduction of legislation, donors consented on the basis that their donation was anonymous. Options 1-3 presented later in this paper discuss this issue in more detail.

If retrospective access to information for donor-conceived people is granted, a number of issues may impact on their ability to receive this information.

A major issue that may arise is difficulty in contacting some donors. Over time, donors may have moved interstate or overseas or passed away and may not be able to be located. Problems may also arise if records pertaining to the donation are incomplete or if the records have been lost or destroyed. This applies mostly to women who received

² *Infertility Treatment Act 1995* (Vic).

treatment from doctors in private practice or at Queen Victoria Hospital prior to the introduction of legislation in 1988.

As the administrator of the donor registers, the Registry of Births, Deaths and Marriages has access to a number of channels for locating donors, such as searching the Victorian Electoral Roll. This enables donors whose contact details are out-of-date to be located. In the Authority's experience, it was usually possible to locate donors although there were some exceptions. Contact was made with a number of donors who now reside abroad. VANISH,³ also provided expertise in these instances in the past.

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

Donor consent is an important consideration in enabling donor-conceived individuals to access information about their donor.

In order to become a registered ART provider under the *Assisted Reproductive Treatment Act 2008*, all ART clinics must be accredited by the Reproductive Technology Accreditation Committee (RTAC) of the Fertility Society of Australia (FSA). One of the criteria for RTAC accreditation⁴ is adherence to ethical guidelines issued by the National Health and Medical Research Council (NHMRC).⁵ Section 6.13.1 of the guidelines outlines requirements for donor consent as follows:

When approached by a person who was conceived using donated gametes and who now seeks identifying information about his or her genetic parents, the clinic should examine the consent form of the gamete donor and proceed as follows:

- *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...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.*
- *If the consent form includes permission for release of identifying information, the clinic may notify the donor and release the information to the person requesting the information.⁶*

In addition to complying with the NHMRC guidelines, all clinics that have RTAC accreditation are required to meet the donor requirements outlined in the Code of Practice.⁷ For example, clinics are required to have processes in place to obtain informed consent, screen potential donors for infectious disease and genetic conditions,

³ Vanish is a community organisation based on the self-help model. Vanish offers a support service that aims to empower individuals to make informed decisions. Most staff members have a personal experience of separation from family of origin and so are able to empathise with service users and offer appropriate assistance and support. Two persons who were donor conceived serve on the Vanish Committee of Management. Vanish holds a support group meeting for persons who were adopted or donor-conceived once a month.

⁴ Reproductive Technology Accreditation Committee, *Code of Practice for Assisted Reproductive Technology Units* (2008) Fertility Society of Australia <<http://www.fertilitysociety.com.au/wp-content/uploads/20080924-rtac-cop-final2.pdf>> at 12 July 2010.

⁵ National Health and Medical Research Council, *Ethical Guidelines on the Use of Assisted Reproductive Technology in Clinical Practice and Research* (2007).

⁶ National Health and Medical Research Council, above n 5, section 6.13.1.

⁷ Reproductive Technology Accreditation Committee, above n 4.

maintain comprehensive donor conception records and provide adequate counselling. Donors across Australia are now required to give consent to release identifying information to donor-conceived people, if requested, after the person reaches 18 years of age.⁸

Donors who donated prior to 1988, under the condition of anonymity, would need to provide consent prior to identifying information being given to a donor-conceived person. Some donors who donated under the provisions of the *Infertility (Medical Procedures) Act 1984* re-consented under the conditions of the *Infertility Treatment Act 1995* to ensure that their gametes could continue to be used to start new families or add to existing families. It may be possible for this to re-occur and donors could re-consent under an amendment to the *Assisted Reproductive Treatment Act 2008* stating that they give permission for information to be released. However, this would mean that some donors would be needlessly contacted if no applications for information are made. As many donor-conceived people are unaware of their origins, this may be the case.

In order to consent to identifying information being released, donors would need to be made aware of what they are consenting to and the potential implications of their decision for themselves and the donor-conceived person. Counselling is an important part of informed consent.

If the *Assisted Reproductive Treatment Act 2008* was amended to include provision for retrospective access to information for donor-conceived individuals then the consent provisions in the Act would take precedence over any guidelines or code of practice.

If a non-legislative approach is taken, up-to-date donor consent to release information to a donor-conceived person would be imperative to ensure compliance with the requirements of RTAC and the NHMRC. If donor consent to release information is not obtained, conflict may arise with the RTAC Code of Practice and NHMRC guidelines. As RTAC accreditation is a prerequisite for registration as an ART provider in Victoria, this may jeopardise a clinic's registration and ability to operate in Victoria.

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

While there may be difficulties in obtaining some records of treatment prior to 1988, records could be obtained from clinics that are still practising and where records have been properly retained and stored. Some records in relation to the closed donor treatment clinic at Prince Henry's Institute are also held at the Public Records Office under restricted access. The Registry of Births, Deaths and Marriages has exclusive access to these records.

In general, donor-conceived people are aware of the difficulties in accessing old records and that records may be incomplete or destroyed. Many donor-conceived people would appreciate any possible information relating to their donor that was able to be located, even if it were minimal. Feedback from donor-conceived people indicates that this is preferable to no information being available, as is currently the case for many donor-conceived people. If no information is able to be found, knowing that the search for

⁸ National Health and Medical Research Council, above n 5.

information was properly conducted by an independent body may give more certainty to the validity of the outcome.

Counselling for donor-conceived people requesting information about donors who provided gametes prior to 1988 would help to prepare and support them if information is not available. In the Authority's experience, this is usually a very disappointing outcome for all concerned and the person may feel very frustrated and angry and require support to learn to live without this information.

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

Option 1: All donors could be contacted and asked to re-consent to being identified.

This option is likely to prove cumbersome as many donors would be needlessly contacted regardless of whether there had been an application for information. This would be a very time-consuming task for the organisation charged with this duty.

Option 2: Donors' identifying details could be released without consent, as occurs with retrospective access to identifying information about birth details for adoptees.

Open access to information could be available to all donor-conceived persons to give all people born prior to 1995 legislation the same rights as those born under the *Infertility Treatment Act 1995* and the *Assisted Reproductive Treatment Act 2008*. That is, consent does not have to be sought from the donor prior to releasing information to the donor-conceived person.

Prior to 1998, donors did not routinely give consent to the release of information at the time they donated. This is similar to the situation prior to changes in adoption law in which birth parents had not signed consents to release information. Despite this, legislation was enacted in Victoria in 1984 to give identifying information to adoptees. At the time, there was great trepidation and anxiety about what would transpire. Now, 36 years later, the practice is commonplace and legislation has been passed giving similar rights to information Australia-wide. The needs of donor-conceived people are very similar to those of adopted people due to their search for information about their biological origins. If this option is introduced, donor-conceived people would require adequate counselling and support given their age and potential vulnerability. Donors would also require counselling support as they may be apprehensive about contact from a number of donor-conceived people and this would need to be handled sensitively.

Option 3: Donors could be contacted and asked to consent to release information **only when** a donor-conceived person makes an application for information to the Central Register.

Under this option, people born prior to 1988 would have equivalent access to information to those born under 1984 legislation (from 1988 to 1996). That is, consent must be sought from the donor before identifying information is released to the donor-conceived person.

In practice, this legislative approach has worked well. The Authority has extensive experience in linking donor-conceived people with their donors. From 2006 to 2009, there were 43 outreaches to donors as a result of Post 1988 Central Register applications from parents or young donor-conceived adults. In all but a very few of

these cases, the donor agreed to release information to the applicants. This usually resulted in the exchange of letters forwarded to each party using the Authority as an intermediary to protect privacy. In time, some chose to exchange identifying details and correspond directly. Some later met in person.

While donors may have had some initial reservations about being contacted, with sensitive counselling in which the counsellor relayed the motivations, and the short- and long-term aims of the applicant and discussed the concerns of the donor and their family, these were usually able to be resolved. Many donors had expected to be contacted. They were 'waiting in the wings' and had been wondering about the people conceived as a result of their donation, how they were going, if they were healthy and happy and whether they were alike in any way. Information exchange only ever occurred with consent as no donor-conceived applicants were old enough to apply under the 1995 legislation. This will occur in 2016 when the first children born under the 1995 legislation enacted in 1998 turn 18 years of age.

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

The Authority's experience of managing the donor registers was that counselling was a vital component for effective operation of the donor registers. Contact between donor-conceived people and their donors and genetic half-siblings is still very new and uncharted territory.

All parties generally feel quite vulnerable throughout this process as they are all strangers and there is no established protocol for writing to a donor for the first time or meeting them. All parties also struggle with what is appropriate or inappropriate information to give. Initiating possible contact with a donor is a significant personal decision and people may seek information and advice before committing themselves to making an application.

Risks can be mitigated if counselling is provided for applicants and donors, whose consent is required for the release of information. Counselling could provide an opportunity to explore the implications and potential outcomes of proceeding with an application/providing consent and the motivations and expectations of each person. Counselling could also outline different options for information exchange or contact between parties, setting boundaries and clear communication.

In the Authority's experience, providing donor-conceived people with an accurate record of their genetic half-siblings gave them some feeling of security regarding the risk of consanguinity. Knowing such non-identifying information as the gender, month and year of birth may relieve some stress for donor-conceived people who are concerned about the possibility that they may unknowingly form a romantic relationship with a half-sibling. Knowing this information could help them determine whether they could be related to a potential partner by asking their birth date.

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

It is not appropriate for the Authority to comment on this term of reference.

g). The possible implications under the *Charter of Human Rights and Responsibilities Act 2006*

The first guiding principle of the *Assisted Reproductive Treatment Act 2008* (Vic) provides that 'the welfare and interests of persons born or to be born as a result of treatment procedures are paramount'.⁹ In addition, the NHMRC ethical guidelines state that 'people conceived using donated gametes are entitled to know their genetic parents'¹⁰ and that they should at least have access to medical and family history, identifying information about the donor and the number and sex of other people born from the same donor, the number of families involved and any identifying information that these siblings have consented to being released.¹¹

In relation to the rights of the donor, the right to privacy and reputation as outlined in s 13 of the *Charter of Human Rights and Responsibilities Act 2006* highlights the importance of ensuring informed consent is obtained from donors before releasing information to a donor-conceived person.

Conclusion

There are strong grounds to support the principle of giving all donor-conceived people the opportunity to request identifying and non-identifying information about their donors.

If retrospective rights to apply for information about a donor are provided to donor-conceived people, consent could be obtained from donors before identifying information is released to ensure that no guidelines or human rights are breached in relation to the donor's privacy.

Signed

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⁹ *Assisted Reproductive Treatment Act 2008* (Vic) s 5(a).

¹⁰ National Health and Medical Research Council, above n 5, 29.

¹¹ *Ibid.*