

# Assisted Reproductive Treatment Further Amendment Act 2014 Q&A Briefing Victorian Assisted Reproductive Treatment Authority

# **Background**

Victoria was the first State in Australia to recognise and address the needs of donor-conceived people to access information about their genetic heritage. In 1988 it implemented legislation to regulate the use of assisted reproductive treatment and established central donor registers to record details of sperm or egg donors, recipient parents and their children. Since then there have been a number legislative changes made in Victoria, with a focus on increasing access to information for donor conceived people.

Legislation enacted in 1988 allowed donor conceived people born between 1988 and 1998 to have access to identifying information about their donor once they become adults, but only with the donor's consent. Since 1998, Victorian legislation has enshrined the right of donor conceived people to have unqualified access to identifying information about their donor from the central register once they reach adulthood or earlier if a counsellor has advised that the person is sufficiently mature to understand the consequences of the disclosure.

However, people conceived from gametes donated before 1 July 1988 have had no legislated access to identifying information (see below about the Voluntary Register). Before 1 July 1988, anonymity was a requirement of the consent to the donation process. Those born from gametes donated between 1 July 1988 and 1 December 1997 have been able to apply for information about their donor, but identifying information could only be provided with the consent of the donor.

The Registry of Births, Deaths and Marriages (BDM) manages the two registers from which information about people taking part in or born from, donor treatment is recorded:

- The Central Register, which includes identifying and non-identifying information about donor-conceived people conceived from gametes donated from 1 July 1988, their parents and the donor; and
- The Voluntary Register, where personal information can be lodged by the donor, donor-conceived person, recipient parent or relatives.

# **Changes to the Legislation**

On 21 August 2014, the Victorian Parliament passed amendments to the *Assisted Reproductive Treatment Act 2008* (Vic) which extends the current law applying to donor-conceived people conceived from gametes (sperm or eggs) donated between 1 July 1988 and 31 December 1997 to donor-conceived people conceived from gametes donated before 1 July 1988. These changes will come into force no later than 29 June 2015.

The amendments are designed to enable all donor-conceived people to apply for non-identifying information about their donors where it is available, and for those born with gametes donated before 1 January 1998, identifying information can be sought with the donor's consent. After 1998, new donors consented to making identifying information available to donor-conceived people and further consent is not required.



# **Q&A Briefing**

The amending Act expands the functions of the Victorian Assisted Reproductive Treatment Authority (VARTA) to provide donor-linking counselling, intermediary and support services to applicants of the donor registers and those affected by the applications including: donor-conceived people, donors, descendants of donor-conceived people, recipients of donor treatment and relatives. A letterbox service will also be provided for people who prefer to exchange information privately without giving their identifying details (name and address).

The amending Act also amends the *Human Tissue Act 1982* (Vic) to allow the Minister for Health to delegate approval of advertisements for egg donors to VARTA.

# Q&As

# Why is the Act changing?

The changes reflect society's changing attitudes to donor conception and the interests of donor-conceived people to have information about their genetic origins.

# What was the lead up to the amendments?

- The 2012 Parliamentary Committee Inquiry into Access by Donor-conceived People to Information about Donors was asked to consider legal, practical and other issues that may arise if all donor-conceived people had equal access to information about their donors, irrespective of when they were born.
- The Committee recommended the introduction of legislation to enable all donor-conceived people access to identifying information if they wished.
- When drafting the amendments, the government considered this recommendation, and the findings of VARTA's consultation with donors who donated gametes before 1 July 1998. A review of the literature and a detailed human rights analysis of the interests of all stakeholders also informed drafting of the Act.

# How do the amendments affect donor-conceived people?

- All donor-conceived people regardless of when they were conceived will be able to apply to the Central Register for identifying information about their donor.
- If contact details can be ascertained, the donor will be contacted and asked to give consent to the release of identifying information for those donor-conceived people conceived from gametes donated prior to 1998.
- There will be no change to the ability of donor-conceived people conceived from gametes donated from 1 July 1988 to access information about their donors.
- If available, donor-conceived people and their parents will be able to access non-identifying information about genetic half siblings following an application to the Central Register. This includes month, year of birth, sex and the number of children born to each recipient mother.

### What does donor siblings mean?

 Two or more people born as a result of eggs, sperm or embryos donated by the same donor are donor siblings.



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# How will the amendments affect information about donor siblings?

- Previously, the Voluntary Register was the only mechanism available for donor-conceived people and recipient
  parents to seek information about genetically related donor siblings. If a person conceived from the same
  donor's gametes has lodged information on the Voluntary Register, this information can be obtained by donor
  siblings if the person who lodged the information agrees.
- This Act will allow donor-conceived people and their parents to request non-identifying information about genetic siblings from the Central Register.
- This is a significant issue for donor-conceived people who may be concerned that they could potentially unknowingly form a romantic relationship with a donor sibling.

# How do the amendments affect registered ART providers?

- Registered Assisted Reproductive Treatment (ART) providers must provide a register of pre 1 July 1988 donor records to BDM.
- Registered ART providers may disclose non-identifying medical information about a donor to the donor's
  offspring, recipient parents and to patients intending to use the donated material and their doctors if the
  disclosure is necessary to save a person's life or to warn about a condition that may be harmful to them or their
  descendants.
- Similarly, registered ART providers can disclose non-identifying medical information about a donor-conceived person to the donor, other adult offspring or recipient parents and their doctors.

### How do the amendments affect doctors and other persons who hold pre 1 July 1988 records?

• Individual doctors outside of registered ART providers and other persons who hold pre 1 July 1988 donor records are encouraged to provide their records to BDM. It is an offence to destroy these records.

# What will the role of the Registry of Births, Deaths and Marriages be?

- BDM will continue to manage the Central Register and the Voluntary Register.
- BDM will be provided with a register of pre 1 July 1988 donor treatment procedures from ART providers in possession of such records. BDM will also accept pre 1 July 1988 records from doctors or other natural persons.
- Upon receiving an application for information, BDM will be able to access and disclose information obtained from records from Prince Henry's Hospital stored at the Public Record Office, Victoria.
- BDM will be able to disclose identifying information to ART clinics for the purposes of disclosing medical information to donor conception stakeholders.
- The Act will facilitate exchange of information between BDM and counsellors to assist with the effectiveness of counselling sessions.



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## Under the amended Act, what will the role of VARTA be?

- VARTA will assume the responsibility for providing counselling for the applicant following referral by BDM.
- VARTA will be able to provide support and counselling to partners of applicants and recipient parents.
- VARTA will provide donor-linking services to consenting donor-conceived people, donors, descendants of donor-conceived people, recipients of donor treatment and relatives.
- VARTA will facilitate exchange of information or correspondence and assist with contact between consenting parties.
- The Act will allow for the Minister for Health to delegate approval of advertisements for egg donors to VARTA under the *Human Tissue Act 1982* (Vic).
- VARTA will continue to provide education and resources about ART and fertility and continue to provide support to parents in telling their children about the circumstances of their conception.

### When will the amended Act come into effect?

The provisions will come into effect no later than 29 June 2015. The Assisted Reproductive Treatment Amendment Regulations 2014 have been developed to guide the information to be recorded in the Register of Pre-1988 Donor Treatment Procedures by registered ART providers.

# Why is there a delay?

Time is needed for ART providers to create registers for pre 1 July 1988 records and to transfer this information to BDM so that BDM can be prepared to receive applications about pre-1988 donor treatment procedures from 29 June 2015.