



VARTA

Victorian Assisted Reproductive
Treatment Authority

ESHRE 2018

Removing donor anonymity retrospectively: outcome of applications for information about a person related through donor treatment following legislative change

L Johnson, K Bourne, T Thomson, K Hammarberg





Infertility (Medical Procedures) Act 1984 (Vic)

implemented mid-1988

“Whether or not a person pursues his or her origins, it should be possible for everyone to discover them.”¹

Waller Committee Report, 1983



30th anniversary of the Central Register in Victoria - implemented 1 July 1988

Applications from donor-conceived people, (DCP) parents and donors

Consent for IDENTIFYING information release

1 Committee to Consider the Social, Ethical and Legal Issues Arising from In Vitro Fertilisation, Issues Paper on Donor Gametes in IVF (Victoria, Standing Review and Advisory Committee on Infertility) August 1983.



Infertility Treatment Act 1995 (Vic)

Any person born as a result of the use of donated gametes may, upon reaching the age of 18, obtain identifying information about the gamete donor from the Central Register.

This recommendation is based on the clear belief that the interests of such a person in discovering his or her genetic parent or parents should be accorded primacy.²

Only identity release donors can be used from 1998

² Standing Review and Advisory Committee on Infertility, *Report on Matters Related to the Review of Post-syngamy Embryo Experimentation – Part III: Recommendations for Amendment of the Infertility (Medical procedures) Victorian Assisted Reproductive Treatment Act 2008 1984, SRACI, Melbourne 1991.*



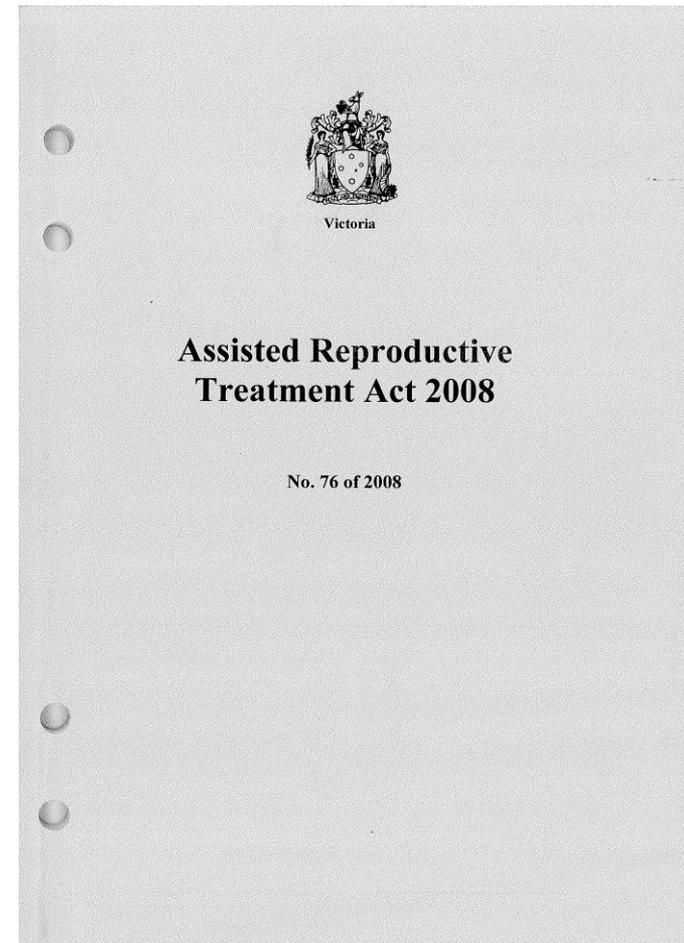
Assisted Reproductive Treatment Act 2008 (Vic)

implemented 2010

Guiding principles Section 5:

(a) The welfare and interests of persons born or to be born as a result of treatment procedures are paramount

(c) children born as a result of the use of donated gametes have a right to information about their genetic parents





Assisted Reproductive Treatment Act 2008 (Vic)

Amended, 2016 (from 1 March 2017)

**Affected families formed
pre-1998 and their donors**

Donor- conceived people

obtain donor identifying
information including pre -1998
name, DOB, donor code

Donor protection

specified / no-contact
preference

Parents

donor consent needed





“We believe all donor-conceived people should have the right to know about their genetic heritage, no matter when their donors donated.”

This information can make a huge difference to the lives of donor-conceived Victorians. If this information is available, it shouldn't be kept from them.”



Jill Hennessy
Victorian Government Minister for Health



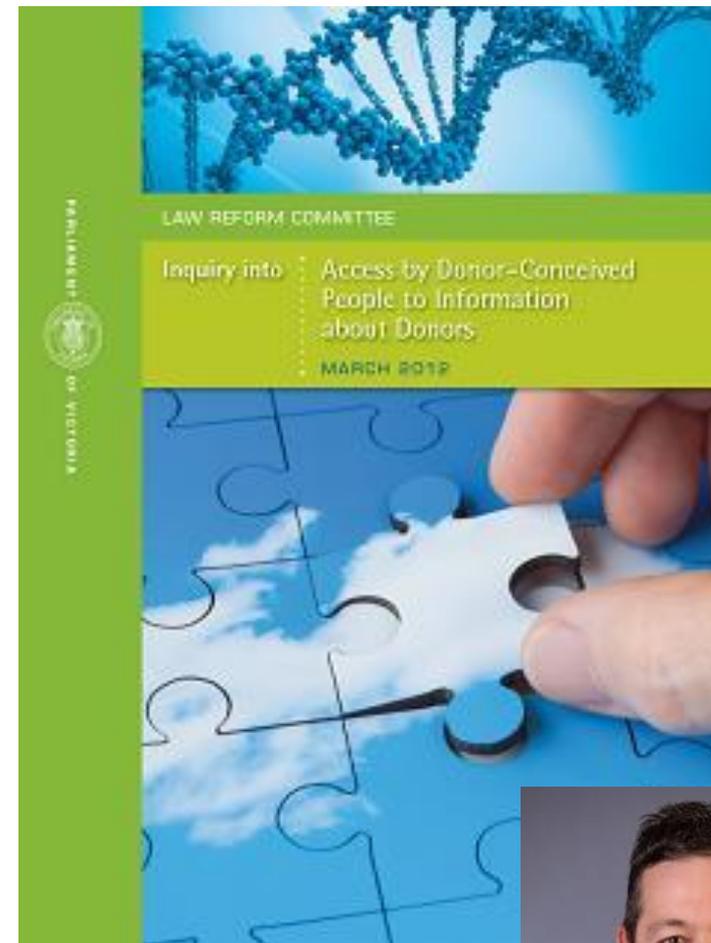
“I must say that at the start of the Committee’s inquiry.....

.... we all probably had the perception that if one donated anonymously that should be respected...

.....but as time went on and we heard from many people who submitted evidencemy views changed.

The rights of donor-conceived children were not being heard and listened to at that particular time (prior to 1988) ...

....we came up with conclusive recommendations, and this has been reflected in the legislation we have before us today.”



*Russell Northe,
Member, Law Reform Committee*



Evaluation framework – HREC approved

Victorian legislation unique world-wide

Elements of monitoring, evaluation and research:

- **Who uses VARTA services and why?**
- **Outcomes of service use**
- **How are VARTA's services received, how can we improve?**
- **Informs advice to Victorian Government**



After 1 year

'One door in' services:

- Management of donor registers
- Support and information
- Public education
- DNA testing result support

101 **Pre-1998 applications** to Central Register from:

- 71 donor-conceived persons (DCPs)
- 6 parents
- 24 donors

61 applications with **known outcome**:

- 49 for donor information
 - (47 DCPs, 2 parents)
- 12 from donors





Known outcomes

1 Mar 2017 – May 2018

61 applications with known outcome

49 for information about donors

47 from
DCPs

2 from
parents

8 withdrawn after counselling

2 wanted non-ID information

9 donors not located / information missing

4 deceased

26 donors located

- 17 agreed to be contacted
- 7 lodged a no-contact preference
- 2 did not respond

12 from donors for
information about donor-
conceived persons (DCPs)

1 withdrawn after counselling

1 wanted non-ID information

3 DCPs not located / information missing

7 DCPs located

- 4 agreed to contact via donor-linking services
- 3 did not consent to contact
- 0 lodged a no-contact preference



Range of outcomes with support

Donor-conceived applicants



No contact

release of up-to-date
medical information

contact 
information exchange
donor-linking services

Donor applicants



Telling support -
donor-conceived +
family members

no contact


contact 
information exchange
donor-linking: donor + siblings



Independent consultant interviews

- Enormity of the experience of seeking information +/- or connection
- Respect for the privacy of families
- Unexpected contact with donors from parents of young children – to convey information as children grow up
- Importance of having an understanding of biological origins
- Importance of maintaining appropriate boundaries and careful navigation
- Telling
- Donor sensitivity around whether someone knew they were donor-conceived
- Misconceptions at the time of donation decades ago
- Exchange of medical information & photos
- Positive feedback about VARTA services
- Surprise about the degree of similarities



Sometimes people find amazing similarities...such as Roger..





.... and his donor daughter!





Conclusion

- Outcomes from the removal of donor anonymity vary.
- The number of donors who donated on an anonymous basis, willing to share information with their donor-conceived offspring, is greater than those who submit no-contact preferences.

**Supportive services can yield positive outcomes
and provide protection**

Thank you



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