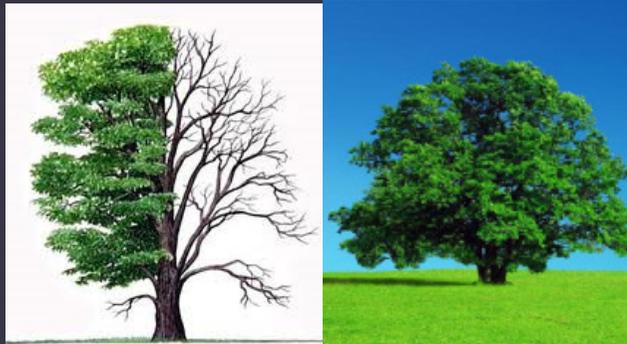


DONOR CONCEPTION PRACTICES:

DONOR 'CONTRACTS',
ACCESS TO INFORMATION,
AND
CURRENT LEGISLATION
AUSTRALIA & NEW ZEALAND

*"WE DANCE ROUND IN A RING AND SUPPOSE,
WHILE THE SECRET SITS IN THE MIDDLE AND KNOWS" —
ROBERT FROST*



Dr Sonia Allan

BA (Psych) (Hons) LLB
(Hons), LLM Global Health
Law, MPH, Phd (Law),
Grad Dip LP, GCHE

Associate Professor, Health
Law, Head of Department,
Health Systems and
Populations, Macquarie
University

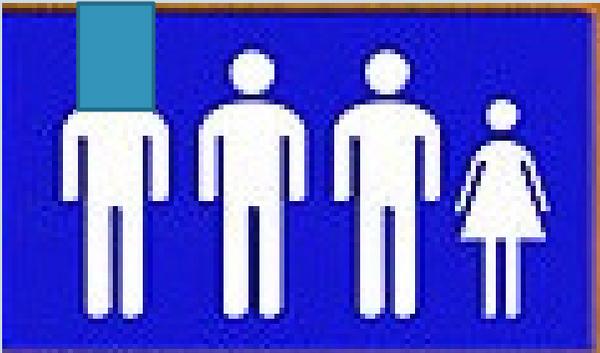
Churchill Fellow, 2011

Global Health Law Fellow,
Georgetown Law,
Washington DC 2012

Secrets
Secrets
Secrets
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Secrets

DONOR CONCEPTION: A LONG HISTORY OF SECRECY

Donor Doctor Husband Wife



•1960 UK interdepartmental committee, chaired by Lord Feversham:

- DI **'undesirable'** and should not be practiced...
- donation 'is an activity which might be expected to attract more than the usual proportion of **psychopaths**'.

- Adultery?
- Illegitimacy?
- Paternity?
- Inheritance of the child from the donor and/or husband?



+ve result

Secrets
Secrets
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DONOR CONCEPTION: A LONG HISTORY OF SECRECY

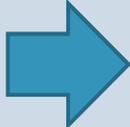
- frozen sperm
- Sperm banks (1970s)
- legal parentage
- First IVF baby (1978)
- Increased Use
- ‘Contracts’ for anonymity
- Commercialization
- New family formations

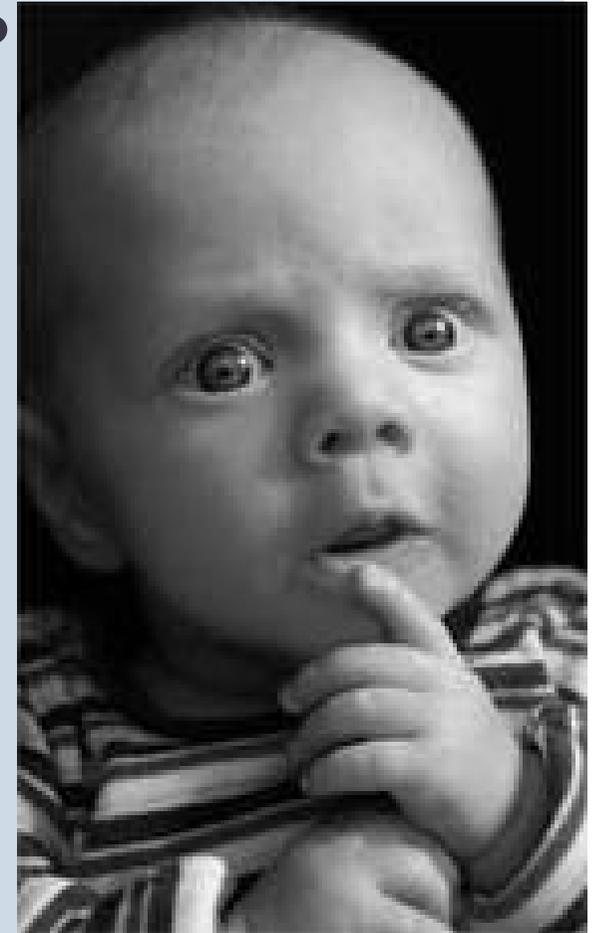
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DONOR CONCEPTION: A LONG HISTORY OF SECRECY

■ Who/what is the focus for secrecy?

- Donors; doctors; recipient parents...
- Religion? (Against natural law)
- Morality? (Adultery; Masturbation)
- Shame? (Infertility)
- Fears regarding parentage?
- Fears regarding rights & responsibilities?
- Commercialization?

? WAS IT 



Secrets
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Secrets

DONOR CONCEPTION: A LONG HISTORY OF SECRECY

- However, on occasion there were calls for **openness** and **honesty**; and **a focus on the child**



ACCESS TO INFORMATION?

Medical history

Heritage

Demand increasing as donor conceived age

Identity formation

Legal,

Medical, Human rights

Recipient parents want to tell

Psych-social, and

Hereditary diseases

Ethical arguments

Donors want to share information

Equality

for providing access to

information

Fear/risk of consanguineous relationships

Desire to know about genetic siblings

Family secrets are detrimental

ACCESS TO INFORMATION?

The response?

- Laws were passed – slowly – in some places but not others...
- Access to identifying and/or non-identifying information in Australia about donors by donor-conceived individuals is currently **dependent on**
 - **the laws of the state/territory in which the individual was conceived and**
 - **the *time* that gametes (sperm/eggs) were donated.**
- In New Zealand timing is also relevant...

AUSTRALIA: STATE AND TERRITORY LAWS

- Some have access to information
- Many do not...



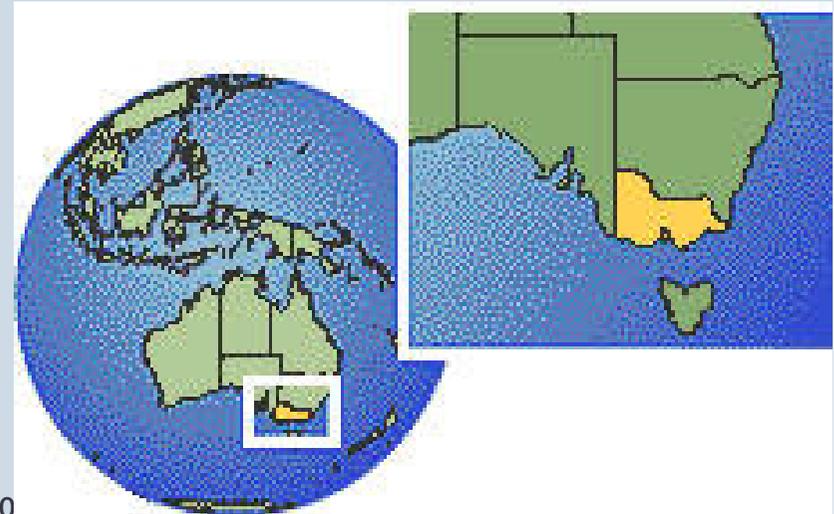
**Australian
State and Territory Laws:
Access to Identifying
and/or
Non-Identifying
Information**

AUSTRALIA: STATE AND TERRITORY LAWS WHO HAS ACCESS TO IDENTIFYING AND NON-IDENTIFYING INFORMATION?

■ In Victoria

- Between 1984-1998 information entered on register, but access to identifying information is subject to donor giving consent

- Infertility (Medical Procedures) Act 1984



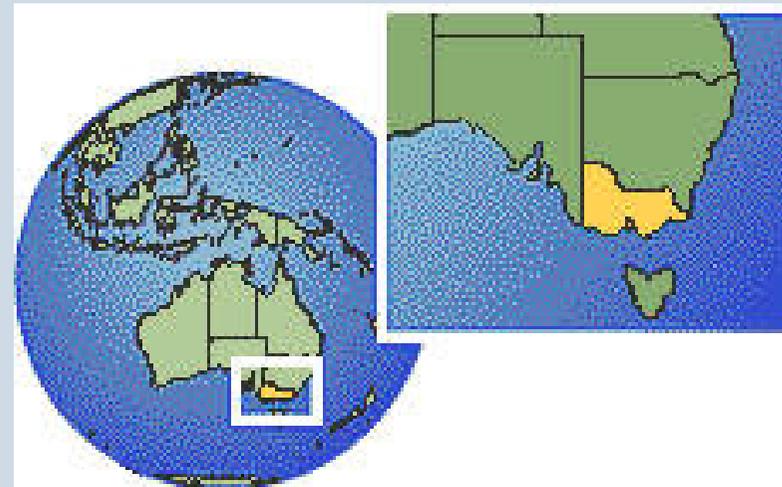
AUSTRALIA: STATE AND TERRITORY LAWS WHO HAS ACCESS TO IDENTIFYING AND NON-IDENTIFYING INFORMATION?

■ In Victoria

- Donations made post 1998 *required* donor consent, all information recorded on register and accessible by DC

individuals

- Infertility Treatment Act 1995
- Infertility Treatment Regulations 1997



AUSTRALIA: STATE AND TERRITORY LAWS WHO HAS ACCESS TO IDENTIFYING AND NON-IDENTIFYING INFORMATION?

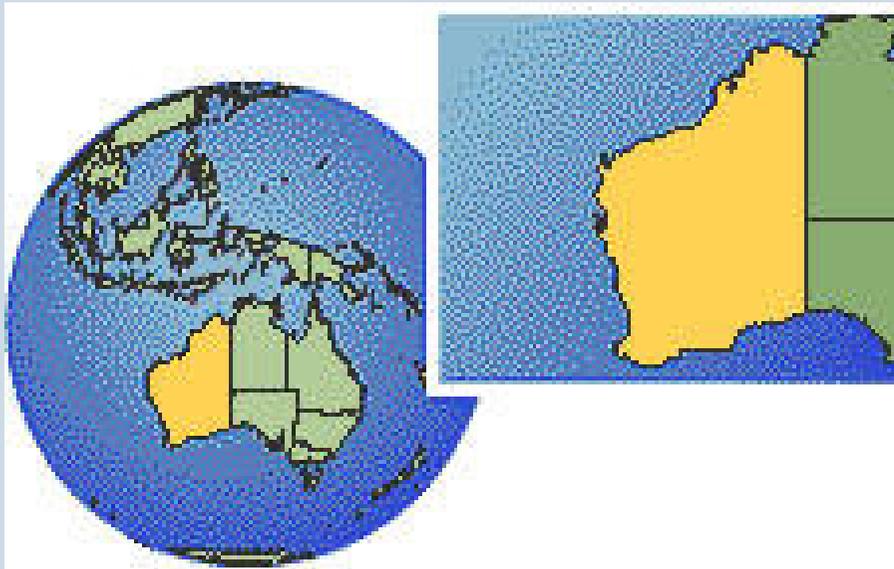
■ In Victoria

- Voluntary register set up in 2001 for pre-1998 (donor hadn't consented; or pre-1988 no laws/'contracts' for anonymity).
- From - 29 June 2015 - Legislative changes giving Victorians conceived through donor sperm donated before 1988 the right to access identifying information about their donors ***with their donor's consent***
- NOTE - if a donor does not consent DC people conceived pre-1998 are still left without information



AUSTRALIA: STATE AND TERRITORY LAWS WHO HAS ACCESS TO IDENTIFYING AND NON-IDENTIFYING INFORMATION?

■ Western Australia



- *Human Reproductive Technology Act 1991 (WA)*
 - Information held on WA register

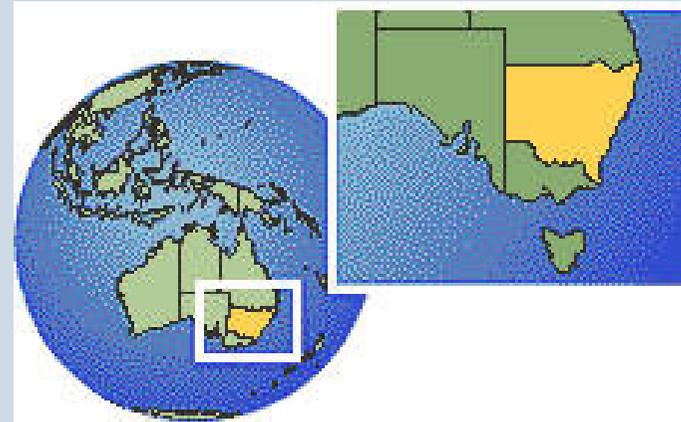
- People conceived using gametes donated after 2004 may access identifying information when they turn 16 about the donor.

- Voluntary register – pre 2004

AUSTRALIA: STATE AND TERRITORY LAWS WHO HAS ACCESS TO IDENTIFYING AND NON-IDENTIFYING INFORMATION?

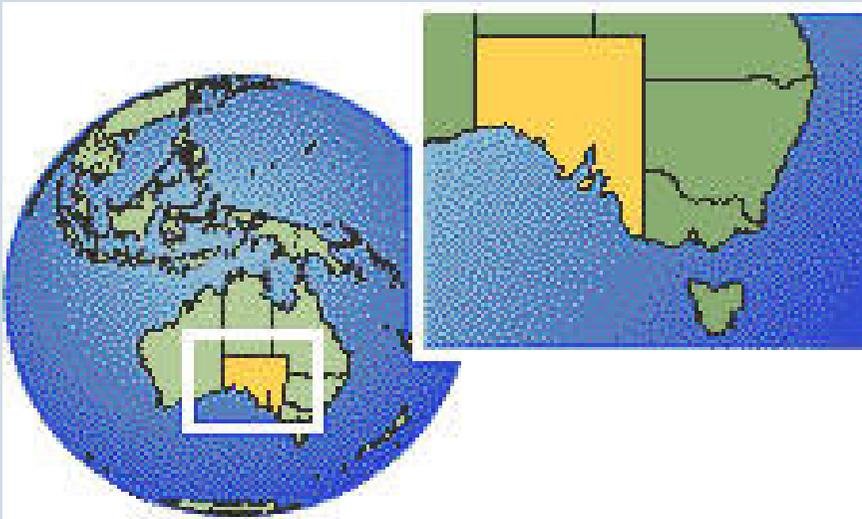
■ New South Wales

- From 1 January 2010 identifying information held on a register maintained by the NSW Department of Health. Donor conceived individuals may access this information when they turn 18.
- Voluntary register pre-2010
- NSW have also recommended release with donor consent



AUSTRALIA: STATE AND TERRITORY LAWS WHO HAS ACCESS TO IDENTIFYING AND NON-IDENTIFYING INFORMATION?

■ South Australia



- NB. The reality in SA is that access to information has been difficult if not impossible

- Access to information available with donor consent through clinics;
- No central register; no voluntary register
- Changes to the Act in 2010: Minister *may* keep a register of donors of human reproductive material
 - *Assisted Reproductive Treatment Act 1988 (SA)*

**WHAT IF THE 'DONATION'
WAS MADE
BEFORE THE LAW
IN THESE STATES
WAS IN PLACE?**

AUSTRALIA: STATE AND TERRITORY LAWS

- As above mentioned

Voluntary Registers

Donors may voluntarily place information on the register in Victoria, Western Australia, New South Wales (all maintained from different dates).

AUSTRALIA: STATE AND TERRITORY LAWS

**WHAT IF THE DONATION
TOOK PLACE IN A
JURISDICTION**

**WHERE THERE IS NO REGISTER or
the donor/donor conceived are not
on a voluntary register?**

Recognition of a Need to Know

AUSTRALIA: NHMRC GUIDELINES

- Ethical guidelines on the use of Assisted Reproductive Technology in clinical practice and research 2004 (2007)
 - all ART clinics, regardless of state or territory in which they operate, need to adhere to the NHMRC guidelines for ethical practice for registration purposes.

Recognition of a Need to Know

AUSTRALIA: NHMRC GUIDELINES

- The NHMRC guidelines:
 - *Recognise that persons conceived using ART procedures are **entitled to know their genetic parents.***
 - *Require **the donor to consent to the release of identifying information** about himself or herself....*
 - *Emphasise **the significance of the biological connection** that donors have with the persons conceived using their gametes.*
 - *Require donors to be advised that the persons conceived **are entitled to knowledge of their genetic parents and siblings.***

Recognition of a Need to Know

AUSTRALIA: NHMRC GUIDELINES

- State that clinics **must not use donated gametes in reproductive procedures unless the donor has consented to the release of identifying information** about himself or herself to the persons conceived using his or her gametes..

Recognition of a Need to Know

AUSTRALIA: NHMRC GUIDELINES

- Provide that **clinics, should** use forums for public information to **encourage** donors/donor-conceived to contact the clinic and register their **consent to being contacted** by their genetic children or genetic siblings and half-siblings, respectively.

Recognition of a Need to Know

AUSTRALIA: NHMRC GUIDELINES

- State that clinics should not use gametes or embryos collected before the introduction of the guidelines without the consent of the gamete donor to the release of identifying information for any future treatments
 - (nb. Exceptions = to create a sibling; embryos stored cannot contact donor)

Recognition of the Need to Know?

AUSTRALIA: NHMRC GUIDELINES

***BUT the NHMRC guidelines **are not law**,
and **do not link in to any register** to ensure
information is maintained and made available
to donor-conceived individuals.***

**THE IMPLEMENTATION OF THESE GUIDELINES IS
ALSO
ARGUABLY LACKING**

...

Sonia Allan 2015

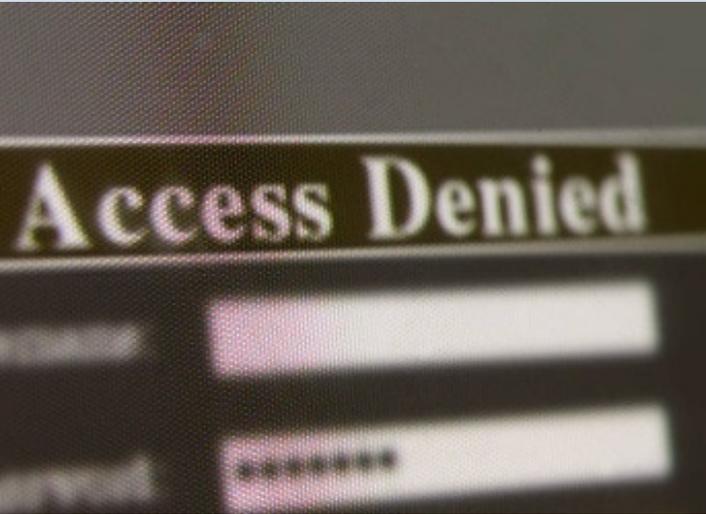


NEW ZEALAND?

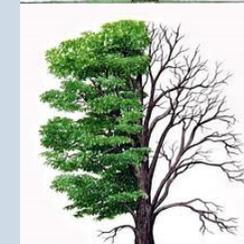
- In New Zealand, the HART Act, established the Human Assisted Reproductive Technology Register which holds information about donors, donor offspring and guardians.
- The register, which has been operational since 22 August 2005, is maintained by the office of Births, Deaths and Marriages within the Department of Internal Affairs which has the responsibility for establishing and maintaining the Register.
- Information about sperm, egg and embryo donors, donor offspring and their guardians is held the register. Access to information held on the register is restricted. Generally only the people named on the register can access the information, or the guardians of offspring under the age of 18.
- A voluntary register operates for those conceived pre 2005.

ACCESS TO INFORMATION

For many in Australia, New Zealand and around the world...it is a case of



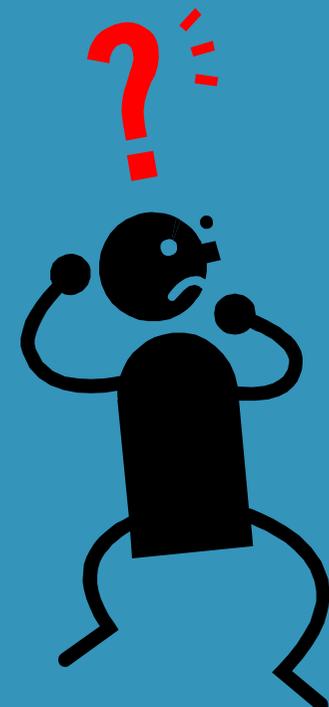
Access Denied



IN SUMMARY THE LAW IS
COMPLICATED;

DIFFERS ACROSS STATES AND
TERRITORIES OF AUSTRALIA;
NEW ZEALAND, AND THE
GLOBE.

THE LAW PROVIDES FOR
ACCESS TO INFORMATION FOR
SOME, BUT NOT ALL, DONOR
CONCEIVED INDIVIDUALS...



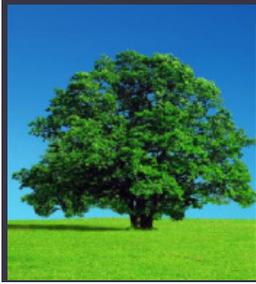
THE ARGUMENT FOR UNIFORM LAWS

The impact on society is far reaching.
Denial of access to information may affect donor
conceived individuals, their families, and
generations to come.



WHERE TO NOW

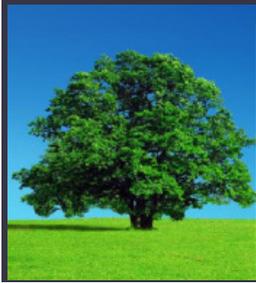




INFORMATION RELEASE FOR ALL



- **It is strongly arguable that all donor conceived people should be given access to information about their genetic origins.**



PROSPECTIVE RELEASE



INTO THE FUTURE -

- **Laws that demand complete disclosure of all identifying information are needed.**
- **Laws that apply prospectively may easily be introduced.**
- **Such laws would avoid *any interference* with a donor's right to privacy, simply because those who do not wish to be identified may choose not to donate their gametes/embryos.**



BUT WHAT ABOUT THE PAST?

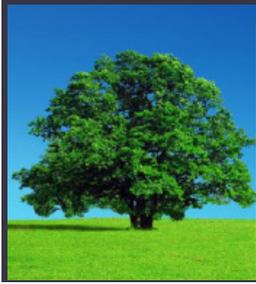


Weren't there contracts for anonymity?

- Consent forms – not a contract
- Agreed that donor would not contact recipients (or seek child)
- Agreed recipients would not contact donor
- **NOTHING TO BIND THE CHILD SEEKING THE DONOR**

- However, there were 'promises' of anonymity – if breached may lead to breach of confidence by doctor to patient/donor/recipients → **FEAR!**
- Need laws to release information so that everyone is clear on what may or may not be done...

Note – many donors say they had no choice – they didn't want to be anonymous but were told they had to be



BUT WHAT ABOUT THE PAST?



***There is however a need to
balance the interests of donors
and donor conceived people.***

(in situations where a donor might be opposed to release)

How should this be done?



WHAT ABOUT THE PAST?



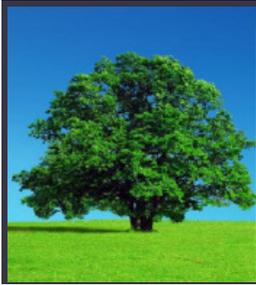
Retrospective laws

- Options considered:

- require release of non-identifying information, and
- **seek the consent** of the donor regarding identifying information.



However this approach may in effect leave donor conceived people in the same position they currently **are—absent of information.**



WHAT ABOUT THE PAST?



Retrospective laws

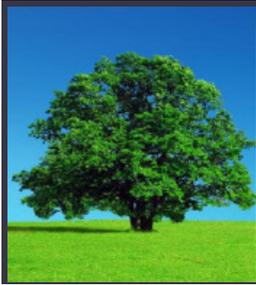
- Options considered:

- require release of all identifying information



Sub-Options:

- Unfettered release? → FEAR of unwanted contact?
- Contact veto – in 2010/11 I recommended a model for full release of information subject to a contact veto ... → a way to balance interests?

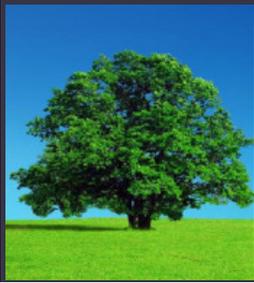


WHAT ABOUT THE PAST?



■ The contact veto/preference system

- operates to protect people from unwanted contact by another person, while still allowing the release of information;
- means that prior to information release a donor or a donor-conceived person could lodge a veto which prohibits contact by the other party (or limits the type of contact wanted – eg. By email, letter, etc). The person seeking information would have to undertake not to make contact with the person who has lodged the veto. There may be penalties imposed if a veto is breached.
- is the system that was implemented in some states of Australia (for eg. NSW) when retrospective release of information about adoption occurred.
- is a way to ensure proportionality by **protecting the donors right to privacy** (by way of ensuring contact does not occur if it is unwanted), **but still providing for access to information.**
- is not arbitrary or unfair, and is based upon rational considerations of how best to balance interests.
 - (Vic Law Reform Committee, led by Clem Newton Brown & with bi-partisan support, recommended this system in their 2012 report – ‘Narelle’s Law’...)



BUT WHAT ABOUT THE PAST?



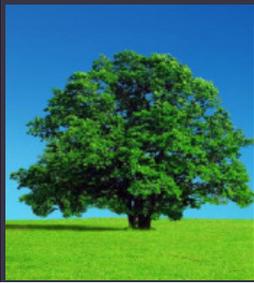
WHICH OPTION WAS ADOPTED?

■ **Victoria**

- VARTA - supported a consent first approach
- then Liberal Government in Victoria – wound back LRC recommendations to implementing a consent first approach. Reflects changes to come in on 29 June 2015.

■ **NSW committee then recommend the same...**

- A good first step – but again, not far enough...



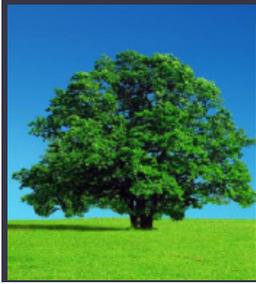
BUT WHAT ABOUT THE PAST?



- ***The consent first approach leaves the final decision to donor***

- **Argument against full release –**
 - **eg. TOBIN:**
 - *It is difficult to see how a law that is amended to allow for disclosure of identifying information several years after a donation was made by a man, in the expectation that his anonymity would be protected by law, can be sensibly said to comply with the requirements of accessibility and foreseeability.*

 - ***i.e. argues people couldn't have foreseen that anonymity might be overturned***

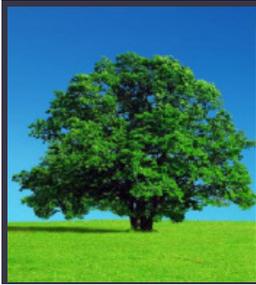


BUT WHAT ABOUT THE PAST?



My Response

- Donors might never have *reasonably* expected to remain anonymous;
 - 1983 Waller Committee said that ‘the donor shall be advised that there can be no guarantee of permanent, complete anonymity’.
 - the Western Australian Reproductive Technology Council has also for some years notified donors that ‘some time in the future it is possible that legislation may be further amended to make it a retrospective right for all donor offspring to access identifying information about the donor.’



BUT WHAT ABOUT THE PAST?



My Response

- The contact veto/preference system is truer to balancing interests as it
 - does not deny any DC people information while
 - simultaneously protecting donors from unwanted contact.
- However NOTE – that any such system must still be sensitive to those donors who do not want contact.
It should be implemented sensitively, and with lead times so that people can prepare.

The fundamental aim for donor-conceived individuals
is to be able to move from



to



AND REMEMBER: There are many donors, recipients, and donor-conceived people who want this to happen...

The issue is about **choice** and **equality**, and without laws that support access for all, donor-conceived people are left without choice and without equality.

END

- I wish to thank the organisers of the donor conception conference for inviting me to speak today, all of the donor conceived people, donors, and recipients who have shared their stories with me over the past 12 years, and also all of those who I do not know, but who I greatly support whatever their choices!
- For more information on the laws regarding access to information in each state and territory of Australia, as well as around the world, please see the Health Law Central website – donor conception – access to information pages...



<http://www.healthlawcentral.com/assistedreproduction/donorconception/access-information/>