

Inquiry into access by donor-conceived people to information about donors

Interim report of the Victorian Parliament Law Reform Committee

September 2010

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Law Reform Committee

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Functions of the Law Reform Committee

The functions of the Law Reform Committee are set out in section 12 of the *Parliamentary Committees Act 2003* (Vic). That section states:

- 1) The functions of the Law Reform Committee are, if so required or permitted under this Act, to inquire into, consider and report to the Parliament on any proposal, matter or thing concerned with
 - a) legal, constitutional or parliamentary reform
 - b) the administration of justice
 - c) law reform.

Terms of reference

Referred by the Legislative Council on 23 June 2010.

To inquire into, consider, and provide an interim report by September 2010 and a final report by 2011 on —

- 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
- 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
- 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
- d) the options for implementing any changes to the current arrangements, including non-legislative options
- e) the impact that any such changes may have on the donor, the donor-conceived person and future donor programs
- 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
- g) the possible implications under the Charter of Human Rights and Responsibilities Act 2006.

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List of recommendations

report within 18 months.

Recommendation 1
The Committee recommends that, pending a further inquiry and report, the Victorian Government considers as a matter of urgency whether measures should be taken to ensure that existing and unprotected donor records are preserved.
Recommendation 241
The Committee recommends that the 57 th Parliament of Victoria refer the terms of reference for this Inquiry to the Law Reform Committee for inquiry, consideration and report. The terms of reference should ask the Committee to complete its final

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Glossary

ART assisted reproductive technology, the use of

procedures such as IVF or artificial insemination to

achieve pregnancy

AFRS the Adoption and Family Records Service, which

provides information and counselling to adopted people and their families, and provides one

information session to people wishing to access the

donor registers

BDM the Victorian Registry of Births, Deaths and

Marriages, which is responsible for registering and providing certificates for all births, adoptions, deaths and marriages in Victoria, and now manages the

donor registers

consanguinity a relationship between two people who share a

common ancestor: a 'shared blood' relationship

DC donor-conceived

donor a person who has donated gametes

donor-conceived person a person conceived using donated gametes

donor recipients people who use donated gametes to conceive a child

donor registers registers that record information about the people

involved in assisted reproductive technology, such as donors, donor recipients and donor-conceived people.

In Victoria, these registers are referred to as the

Central and Voluntary Registers

embryo an egg that has been fertilised by a sperm and has

undergone one or more divisions

gametes reproductive cells, sperm or eggs

GIFT gamete intrafallopian transfer, where eggs and sperm

are placed in the fallopian tubes for fertilisation inside

the body

ICSI injection of a single sperm into an egg for fertilisation

outside the body and replaced in the uterus

insemination the introduction of sperm into a female by natural or

artificial means

ITA the Infertility Treatment Authority, the former

statutory authority established under the *Infertility*

(Medical Procedures) Act 1984 (Vic)

IVF in-vitro fertilisation, where eggs and sperm are

combined in the laboratory for fertilisation outside the

body and replaced in the uterus

NHMRC guidelines the National Health and Medical Research Council's

Ethical guidelines on the use of assisted reproductive technology in clinical practice and research, which

provide ethical advice on the use of assisted

reproductive technology

treatment cycle the sequence of steps that involves the in-vitro

handling of eggs and sperm or embryos for the

purposes of establishing a pregnancy

VARTA the Victorian Assisted Reproductive Treatment

Authority, the statutory authority responsible for registering assisted reproductive treatment providers and providing education programs about assisted

reproductive technology

zygote the initial cell resulting from the fertilisation of an egg

by a sperm

Chair's foreword

The relatively recent emergence of new assisted reproductive technologies has seen a shift in community attitudes and resulted in new laws that have increased the focus on protecting the welfare of people born as a result of donor conception.

Despite these changes, an anomaly exists in the *Assisted Reproductive Treatment Act* 2008 (Vic) as it provides donor-conceived people with varying levels of access to information about their donors depending on when the gametes used to conceive them were donated.

On this basis, the Law Reform Committee was asked by Parliament to inquire into and report on the issues relating to providing people conceived using gametes donated prior to July 1988 with retrospective access to information about their donors.

The evidence gathered by the Committee reflected significant support for donor-conceived people having the right to access this information. Participants advocating for increased access did so on the basis of protecting the rights of the child.

On the other hand, some participants highlighted the need to protect donors' privacy as they were assured anonymity at the time of making donations. Donors who provided submissions expressed differing viewpoints on this issue. Some strongly opposed the release of identifying information about them, while others understood the desire of donor-conceived people to learn more about their ancestry.

The various points raised by participants reinforced the need to carefully balance the rights and interests of donor-conceived people, their families and donors.

Another important issue raised in this interim report is the impact of previously poor record keeping practices on the capacity of donor-conceived people to access complete and accurate information about their donors. The Committee acknowledges the challenges this may create if people are granted retrospective access to information about their donors.

In the short timeframe allocated for the completion of this interim report, the Committee received 36 submissions from various individuals and groups, including donor-conceived people, donors, donor recipients, support groups, academics and medical clinics. While various viewpoints were raised in submissions, the Committee was mindful that not all groups were equally represented. Ensuring that all groups are afforded an equal voice should be a priority for any Committee continuing this inquiry in the future.

With the preliminary consultations demonstrating a high level of interest in and varying viewpoints on this issue, the Committee believes it warrants further examination.

The Committee recommends that the next Parliament refer the terms of reference to the Law Reform Committee for further consideration. The Inquiry should include a comprehensive consultation process to ensure a diverse range of views are received.

On behalf of the Law Reform Committee, I wish to thank the individuals and groups who contributed to the Inquiry through providing submissions. I particularly wish to thank those participants who shared their personal experiences about their involvement in donor conception. The Committee acknowledges the highly sensitive nature of this topic and the need for some people to preserve the privacy of both themselves and their families.

I would like to thank my fellow Committee members – Mr Colin Brooks MP, Mr Luke Donnellan MP, Mr Martin Foley MP, Mrs Jan Kronberg MLC and Mrs Heidi Victoria MP – for their thoughtful contributions to the Inquiry. In particular, I wish to thank the Deputy Chair, Mr Robert Clark MP for his contribution and support throughout the Inquiry.

I also acknowledge the hard work of the Committee secretariat, led by Ms Kerryn Riseley and comprising Ms Yuki Simmonds, Ms Kerry Harrison, Ms Vathani Shivanandan and Ms Helen Ross-Soden. The secretariat team is to be congratulated for completing this interim report within extremely tight timeframes, while concurrently working on two other Inquiries.

Access by donor-conceived people to information about donors is an important issue that affects many people and requires thoughtful consideration. I hope this matter will be fully examined in the next Parliament, as recommended by the Committee.

Johan Scheffer MLC Chair

Executive summary

Donor conception practices have been taking place in Victoria for over 40 years. Estimates of the number of donor-conceived people currently living in Australia range from 20 000 to 60 000.

Donor conception raises many social and ethical issues which were beyond the contemplation of those involved in developing and honing these practices. Over time attitudes and practices have changed. Laws have also changed to reflect shifting understandings and expectations. However, anomalies remain. One significant anomaly, the disparate rights of donor-conceived people to access information about their donors, is the focus of this interim report.

The ability of donor-conceived people to access information about their donors depends on when the gametes used to create them were donated. Donor-conceived people conceived using gametes donated after 1 January 1998 have unconditional access to identifying information about their donors. People who were conceived using gametes donated between 1 July 1988 and 31 December 1997 can access information about their donors if donors consent to the release of that information. However, donor-conceived people conceived using gametes donated prior to 30 June 1988 cannot access identifying information about their donors on the basis that donors were guaranteed anonymity at the time of making the donation. Some gametes donated prior to 1988 are still being used in donor-conception procedures.

The ability of donor-conceived people conceived using gametes donated prior to 1988 to access information about their donors depends on where their mothers received fertility treatment. One Victorian clinic, as well as some individual doctors, assist donor-conceived people to obtain non-identifying information about their donors on an informal basis. This can be used to potentially make contact with donors or half-siblings, through a voluntary register.

Whether there should be greater access to information about pre-1988 donors involves a careful balancing of the rights and interests of donor-conceived people, their families and gamete donors.

Donor-conceived people may seek information about their donors for a number of reasons, including to help understand who they are and where they come from, to obtain information about medical and genetic history and to help identify half-siblings. Arguments presented to the Committee for increasing rights of access by donor-conceived people to information about donors focused on the paramountcy of the rights of the child.

Donors who donated gametes prior to 1988 did so on the basis that their identity would never be revealed. Fertility clinics required donors to sign agreements to this effect before donating. However, these donors received limited information and no counselling and it appears that many did not fully understand the implications of

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ⁱ Sonia Allan, *Submission 5*, 5. See also Donor Conception Support Group of Australia Inc, *National inquiry into donor conception practices*, http://www.dcsg.org.au/legislation/inquiry.html, viewed 17 August 2010.

gamete donation. Donors participating in this Inquiry voiced a variety of views. Some donors vehemently opposed the release of any identifying information on the basis that this would cause unnecessary disruption to the lives of both donors and their families. Other donors were seeking to contact their donor-conceived children, while others had made contact and, in some cases, formed ongoing relationships with their donor-conceived children.

Evidence presented to the Committee suggests that poor record keeping in the early days of donor conception practices is a significant barrier to providing greater access to information about pre-1988 donors. These records may have been destroyed, or may currently be located with individual doctors or clinics. Some participants in this Inquiry raised concerns about the need to locate and protect all donor records.

Since January 2010 the Registry of Births, Deaths and Marriages has had the responsibility for managing the Central and Voluntary Registers which contain donor-conception records. These registers allow people to access information about their donors, with information relating to donations made during different periods contained in different registers. Prior to 2010 these registers were maintained by a specialist authority, the Infertility Treatment Authority. Submissions to this Inquiry raised a number of concerns about the transfer of responsibility for records from the Infertility Treatment Authority to the Registry of Births, Deaths and Marriages, in particular in relation to the loss of specialist counselling services.

In the three months that the Legislative Council allocated for the completion of this interim report, the Committee has only been able to touch on the many complex and sensitive issues raised by the terms of reference. This interim report is based on evidence received as a result of a call for submissions advertised in July 2010.

This Inquiry will lapse at the end of the 56th Parliament in early November 2010. Thus the Committee will be unable to undertake the extensive consultation process that an inquiry of this nature warrants. While recognising that it is up to the 57th Parliament to determine its work priorities, in this interim report the Committee recommends that the terms of reference for this Inquiry be referred back to the Law Reform Committee, or another appropriate committee, in the next Parliament. This interim report explores the key issues raised by the terms of reference and maps an approach for a full and comprehensive review of this issue in the 57th Parliament.

Chapter 1: Introduction

On 23 June 2010, the Parliament of Victoria requested that the Law Reform Committee inquire into access by donor-conceived people to information about donors.

Donor insemination has been used by Victorians to achieve pregnancy for over forty years. Over time, new practices have emerged to address infertility, including the use of donor sperm, eggs and embryos (see figure 1). The number of people using assisted reproductive technology (ART) in Australia has steadily increased over the last two decades, since the birth in 1980 of the first Australian baby born as a result of in-vitro fertilisation (IVF).

Figure 1: Common ART procedures²

'ART encompasses procedures and techniques involving the manipulation of gametes, zygotes and embryos. The main ART procedures include:

- IVF, in which eggs and sperm are combined in the laboratory for fertilisation outside the body and replaced in the uterus
- ICSI, in which a single sperm is injected into an egg for fertilisation outside the body and replaced in the uterus
- GIFT, in which eggs and sperm are placed in the fallopian tubes for fertilisation inside the body.'

In 2007, 3.1% of babies born in Australia were as a result of ART.³ According to the Australian Institute of Health and Welfare, the number of ART procedures has increased on average by over 10% per year in Australia and New Zealand (NZ) over the last five years. There were 56 817 ART treatment cycles⁴ reported in Australia and NZ in 2007, representing an increase of 12.5% in the number of cycles undertaken in 2006 and a 53.7% increase in the number of cycles undertaken in 2003. 5.1% of all treatment cycles involved the use of donor gametes. ⁵ Of the 56 817 cycles, there were 10 856 live born babies (17.4%). 275 of these babies were as a result of donor conception. This estimated that there are between 20 000 and 60 000 donor-conceived people now living in Australia.8

Sonia Allan, Submission 5, 5; Helen Kane, Submission 16, 3.

Yueping Alex Wang, Jishan Dean et al, Assisted reproduction technology in Australia and New Zealand 2006 Assisted reproduction technology series no. 12 AIHW cat. no. PER 43 (2008).

Yueping Alex Wang, Georgina M Chambers et al, Assisted reproductive technology in Australia and New Zealand 2007 Assisted reproduction technology series no. 13 AIHW cat. no. PER 47 (2009), 1.

A treatment cycle is a sequence of steps that involves the in-vitro handling of eggs and sperm or embryos for the purposes of establishing a pregnancy.

Yueping Alex Wang, Georgina M Chambers et al, above n 3, 24.

Ibid, ix.

Ibid, 40. Note this does not include donor insemination cycles undertaken in hospitals or private clinics that are not fertility clinics.

Sonia Allan, Submission 5, 5. See also Donor Conception Support Group of Australia Inc, National inquiry into donor conception practices, http://www.dcsg.org.au/legislation/inquiry.html, viewed 17 August 2010.

The current legislative framework surrounding ART in Victoria reflects changing perceptions about the need for donor-conceived people to be able to access information about their donors. The *Assisted Reproductive Treatment Act 2008* (Vic) allows donor-conceived people who were conceived using gametes donated from 1 January 1998 to have unconditional access to identifying information about their donors. People who were conceived using gametes donated between 1 July 1988 and 31 December 1997 can access information about their donors if donors consent to the release of that information. However, donor-conceived people conceived using gametes donated prior to 30 June 1988 cannot access identifying information about their donors on the basis that donors were guaranteed anonymity at the time of making the donation. This is a key area of interest in the current Inquiry.

Allowing donor-conceived people to access information about their donors is considered important to provide them with information about their medical and genetic history. Providing greater access to information may help minimise some of the psychological difficulties experienced by donor-conceived people upon learning of their donor conception status. Another key reason for donor-conceived people to access information about their donors is to help identify their half-siblings.

However, donors who donated gametes prior to 1988 did so on the basis that their donations were anonymous. Many donors appear to have given little thought to the long-term ramifications of donor conception and the systems in place at the time did not promote this, with donors receiving little or no information and counselling. While some donors are happy to have their identifying information released, others wish to maintain their anonymity, fearing the repercussions for both them and their families.

1.1 The context of this Inquiry

The issue of providing all donor-conceived people with access to information about their donors was raised in the Parliament of Victoria at the time that the Assisted Reproductive Treatment Bill 2008 (Vic) was debated in the Legislative Council. This bill was introduced as a result of an extensive review of ART by the Victorian Law Reform Commission. ¹⁰

The bill provided for access to identifying information about donors for all donor-conceived people conceived using gametes donated after 31 December 1997. The bill also provided for access to such information to those conceived using donor gametes donated between 1 July 1988 and 31 December 1997, if the donor consented. The member for Southern Metropolitan Region, Ms Sue Pennicuik MLC, called for the bill to be amended to allow all donor-conceived people to have access to information about their donors regardless of when the gametes used to conceive them were donated. December 1997 and the support of the support

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Assisted Reproductive Treatment Act 2008 (Vic) s 59.

Victorian Law Reform Commission, Assisted reproductive technology & adoption Final report (2007).

Assisted Reproductive Treatment Bill 2008 Vic cl 59.

Victoria, *Parliamentary debates*, Legislative Council, 4 December 2008, 5456 (Ms Sue Pennicuik).

In debating the proposed amendment, the Government identified two barriers that could potentially prevent the release of identifying information about people who were donors prior to 1 July 1988. Firstly, donations were made on the basis of anonymity, which raises questions about whether releasing information about donors infringes their privacy. Secondly, the capacity for information to be identified and made available to relevant parties could potentially be limited as a consequence of inconsistent record-keeping practices among medical clinics prior to the introduction of the Central Register in 1988. The Central Register was established under the *Infertility (Medical Procedures) Act 1984* (Vic) to record information about people associated with births resulting from donor conception. 14

At the time the bill was debated, the Government proposed that this issue be referred to the Law Reform Committee for further examination. The member for South-Eastern Metropolitan Region, Mr Gavin Jennings MLC, read the following statement on behalf of the Government:

A number of people have raised concerns that people conceived using gametes donated before 1998 in Victoria cannot access information about their genetic origins on the same basis as those conceived using gametes donated since 1998. There are concerns that this may affect the health and wellbeing of some donor-conceived people.

The government would like to further consider the appropriateness of the current arrangements. The government proposes to refer issues associated with providing donor-conceived people with more access to information about their genetic origins to the Law Reform Committee of the Parliament. ¹⁵

However, this matter was not referred to the Law Reform Committee at that time.

On 23 June 2010, Ms Pennicuik brought forward the motion that this issue be referred to the Committee for review. This motion was passed and the Committee was requested to provide an interim report to Parliament by September 2010 and a final report by 2011. The request for an interim report reflects the fact that the 56th Parliament will be concluded in November 2010.

Access by donor-conceived people to information about their donors is an issue throughout Australia. The Legal and Constitutional Affairs Committee of the Australian Senate is also currently conducting an inquiry into donor conception nationwide. The terms of reference for that inquiry are broader than those for the Victorian inquiry, and require consideration of the past and present practices of donor conception in Australia, including regulation across federal and state jurisdictions; the conduct of clinics and medical services; the number of offspring born from each donor; and the rights of donor-conceived people. The federal inquiry is scheduled for completion by 30 November 2010. ¹⁶

Victoria, *Parliamentary debates*, Legislative Council, 4 December 2008, 5449 (Mr Gavin Jennings, Minister for Environment and Climate Change).

Victoria, Parliamentary debates, Legislative Council, 2 December 2008, 5556 (Mr Gavin Jennings, Minister for Environment and Climate Change).

¹⁴ Infertility (Medical Procedures) Act 1984 (Vic) s 22(1).

Senate Standing Committee on Legal and Constitutional Affairs, Inquiry into donor conception in Australia: Terms of reference, http://www.aph.gov.au/senate/committee/legcon_ctte/donor_conception/tor.htm, viewed 17 August 2010.

1.2 The scope of this Inquiry

The terms of reference for this Inquiry concern a number of issues relating mainly to the retrospective release of identifiable information to donor-conceived people about their donors. In particular, the terms of reference require the Committee to consider the legal, practical and social implications surrounding the release of such information, including:

- potential amendments to the Assisted Reproductive Treatment Act, as well as non-legislative options for reform
- whether the consent of donors who donated gametes prior to July 1988 is required prior to releasing information about them to donor-conceived people
- the existence and availability of medical records containing information about donors who donated gametes prior to July 1988
- the impact that any changes may have on donors, donor-conceived people and future donor programs.

A key component of the Inquiry is consideration of the welfare and rights of people conceived through donor conception, particularly their right to access information about their medical and genetic history, and consideration of the right of donors to privacy. As part of this, the terms of reference ask the Committee to consider the National Health and Medical Research Council's *Ethical guidelines on the use of assisted reproductive technology in clinical practice and research* and the *Charter of Human Rights and Responsibilities Act* 2006 (Vic).

The terms of reference also require the Committee to consider the impact of the transfer of the management of the donor registers, which contain information about people associated with donor conception (donors, donor recipients and donor-conceived people), from the former Infertility Treatment Authority to the Registry of Births, Deaths and Marriages.

1.3 The conduct of this Inquiry

For the purposes of this Inquiry, the Committee was interested to hear from people involved in and affected by donor conception. The Committee was aware, however, that the time constraints associated with tabling the interim report before the completion of the 56th Parliament would limit its capacity to target a broad range of participants. On this basis, the Committee decided that a call for submissions would be the most appropriate mechanism to ensure maximum involvement from participants in the set timeframe.

The Committee invited comments from members of the public in advertisements in *The Age* and the *Herald Sun* on 10 July 2010, and in the *Weekly Times* on 15 July 2010. Overall, the Committee received 36 written submissions from a range of individuals, including donor-conceived people, donors, donor recipients, medical clinics, support groups and academics (see appendix A).

The Committee's secretariat conducted a basic literature review that focussed largely on the Victorian Law Reform Commission's final report on *Assisted reproductive technology & adoption* and the parliamentary debates surrounding the Assisted

Reproductive Treatment Act.

The Committee acknowledges that a more comprehensive evidence gathering exercise will be required if the terms of reference are re-referred in the new Parliament and the Committee is asked to prepare a final report.

Chapter 2: Accessing information about donors – The current landscape

This chapter provides an overview of the relevant legislation and non-legislative guidelines that contribute to the discussion around access by donor-conceived people to information about their donors.

2.1 The Victorian framework

In 1984, Victoria became the first jurisdiction in Australia and the world to regulate assisted reproductive technology (ART) when it enacted the *Infertility (Medical Procedures) Act 1984* (Vic). As new technologies were developed and community views on families evolved, new legislation was introduced including the *Infertility Treatment Act 1995* (Vic) and the current *Assisted Reproductive Treatment Act 2008* (Vic). This section outlines the relevant components of these three acts.

2.1.1 The early years of donor conception practices

Since the beginning of donor conception, treatment practices and all associated processes have been managed by the medical field. Prior to the introduction of the Infertility (Medical Procedures) Act, the consent of donors to donate gametes was not legally required but rather was provided in private contracts between medical clinics, donors and donor recipients. The contracts assured anonymity to donors and persons born from donor conception. An example of a donor statement and consent form from 1977 is provided in figure 2.¹⁷

During this time, there were also no legislative requirements relating to the collection and retention of donor records. This was within the discretion of medical clinics and doctors performing donor conception procedures. As a consequence, there was significant variation in the way records were maintained, and whether they were kept or destroyed when medical clinics closed down.

The current form and existence of records created prior to 1 July 1988 is dependent on where donor conception treatments were performed. For example, the records arising from treatments conducted at the Royal Women's Hospital are kept at Melbourne IVF and non-identifying information contained in these can generally be accessed by donor-conceived people. For treatments conducted at the former Prince Henry Hospital, the records are held at the Public Records Office, although submissions to this Inquiry revealed uncertainty about who is able to access them. If the treatment took place at the Queen Victoria Hospital, many of the pre-1979 records no longer exist. Only partial records exist for treatments after this date, most of which are held at Monash IVF.

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Lauren Burns, Submission 3, 16.

Melbourne IVF, Submission 32, 2; Helen Kane, Submission 16, 3; Kate Dobby, Submission 33, 5; Kate Bourne, Submission 35, 1.

Victorian Infertility Counsellors Group, *Submission 22*, 5; Kate Dobby, *Submission 33*, 5.

Lauren Burns, Submission 3, 9; Kate Dobby, Submission 33, 5-6.

Figure 2: Donor statement and consent form from 1977

*	DONOR STATERENT & C	ONSENT	
			è
TO:	Doctor Johnston		ì
AND	TD: The Royal Women's Mospital.		
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		a the the understanding	i.
1.	I offer my services as a donor of semen		
	that it is your intention to use my sen	men tor burboses of artificial	ŀ.
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	disclosed to ma, nor shall you voluntar	rily reveal my identity to	
* .	any recipient.		ř P
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3	I am of the EAUCHSIAN race.		ì
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	physical, mental or paychologic		
	or abnormality whether inherits	sd or as a result of any	ir.
	disease, alleent or accident ex	xcept as follows:>	į

100			ş
Tele	(b) None of my relatives have ever		i.
44.	diseases except as follows :-		7
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			je K
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3.	For the purpose of determinating whether		
125	of agmen, I consent to a physical exam		
	of blood and other body [fulda, by you	or any other doctor or meates	
150	worker whom you may designate.		
			à.
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	semen odr seek to make many claim in re-	spect of any such child or	
5	children in any circumstances whatecover	er.	
Date	ed this tuention day of October	1977	
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••••	***************************************		e Si
in	che presence of:		¥.
4			
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Melbourne IVF is currently the only Victorian fertility clinic that assists donor-conceived people born prior to 1 July 1988 to access information about their donors, including identifying information if the donor consents.²¹ Melbourne IVF informed the Committee that people accessing information through its services are offered full counselling with the counsellor performing an outreach to donors, regardless of the donor's consent at the time of the donation:

Generally the aim of the linkage counselling is to trace the donor based on information kept on Melbourne IVF records and provide information and support to both the donor and the offspring. This information can be identifying if the offspring has requested this and the donor is willing to provide identifying information. ²²

2.1.2 Infertility (Medical Procedures) Act 1984 (Vic)

The Infertility (Medical Procedures) Act came into effect on 1 July 1988. Among other provisions relating to in-vitro fertilisation (IVF) procedures and the prohibition of commercial surrogacy, the Act established a process for people involved in donor conception to obtain information about donors, donor-conceived people, or parents or guardians of donor-conceived people. The Act established the Central Register for the purpose of recording information about people associated with births resulting from donor conception from 1988. ²³

The regulations established under the Act outlined the persons allowed to access the Central Register. Donor-conceived people could apply to access identifying and non-identifying information about their donors, although consent from donors was required prior to the release of identifying information. Parents or guardians of donor-conceived people could also apply for non-identifying information about donors. Donors were also permitted to access non-identifying information about the people conceived as a result of the use of their donated gametes.

2.1.3 Infertility Treatment Act 1995 (Vic)

The Victorian Government introduced the Infertility Treatment Act following a review of the Infertility (Medical Procedures) Act. This Act repealed the previous Act and came into effect on 1 January 1998. The Infertility Treatment Act contained guiding principles to underpin its operation, with the primary principle stating that 'the welfare and interests of any person born or to be born as a result of a treatment procedure are paramount'. ²⁷

A key difference between the two Acts was the right of donor-conceived people to obtain identifying information about their donors. The new Act allowed donor-conceived people who were aged 18 years or over to obtain identifying information

Melbourne IVF, Submission 32, 3. See also Lauren Burns, Submission 3, 3; Victorian Infertility Counsellors Group, Submission 22, 3.

Melbourne IVF, Submission 32, 3.

²³ Infertility (Medical Procedures) Act 1984 (Vic) s 22(1).

²⁴ Infertility (Medical Procedures) Regulations 1988 (Vic) sch 7.

Infertility (Medical Procedures) Act 1984 (Vic) ss 22(3), 23(2). See also Infertility (Medical Procedures) Regulations 1988 (Vic) sch 7.

²⁶ Infertility (Medical Procedures) Regulations 1988 (Vic) sch 7.

²⁷ Infertility Treatment Act 1995 (Vic) s 5(1)(a).

about their donors without the donor's consent.²⁸ This was the consequence of the Act requiring donors to be advised at the time of donating gametes of the rights of any children born as a result of their donation to access identifying information about donors.²⁹

The Infertility Treatment Act also established a new Central Register, which contained information about all donor-conceived births from gamete donations made on or after 1 January 1998.³⁰ Donors were required to provide prescribed information to be recorded in the Central Register, which could be provided to persons born as a result of the use of those gametes upon request.³¹

The types of information required to be recorded in the Central Register was information relating to the insemination; the donor; the donor recipient; any money paid to the donor in respect of the donation; the outcome of the insemination, such as a confirmed pregnancy; and the birth of the donor-conceived person.³²

Aside from donor-conceived people accessing information about donors, the Act allowed donors to access information about donor-conceived people and their parents and guardians, as well as allowing parents and guardians to access information about donors. Donors could apply to access identifying information about a donor-conceived person, however, consent was required prior to the release of that information by either the parents or guardians if the donor-conceived person was aged under 18 years, or from the donor-conceived person if they were aged 18 years or over. ³³ Donors could also apply for information about parents or guardians of a donor-conceived person, but identifying information could only be released with their consent and, if the information would identify a donor-conceived person who is aged over 18 years, the consent of the donor-conceived person as well. ³⁴

Parents and guardians, as well as donors, could access non-identifying information about each other without the consent of the person to whom the information relates, although consent was required prior to the release of identifying information about either party.³⁵

The Infertility Treatment Act also established the Voluntary Register.³⁶ This register contains information that people involved with a donor treatment procedure after July 1988 can voluntarily provide to be recorded on the register.

2.1.4 Assisted Reproductive Treatment Act 2008 (Vic)

In 2002, the Victorian Government requested that the Victorian Law Reform Commission (VLRC):

Infertility Treatment Act 1995 (Vic) s 79(1).

²⁹ Infertility Treatment Act 1995 (Vic) s 17(b)(i).

³⁰ Infertility Treatment Act 1995 (Vic) s 68.

³¹ Infertility Treatment Act 1995 (Vic) s 17(a).

³² Infertility Treatment Act 1995 (Vic) ss 62-66.

 ³³ Infertility Treatment Act 1995 (Vic) ss 76, 77(2).
 34 Infertility Treatment Act 1995 (Vic) ss 76(1)(d), 78(2).

Infertility Treatment Act 1995 (Vic) ss 74(1)(a), 75(2)(b), 76(1)(d), 78(2)(a).

³⁶ Infertility Treatment Act 1995 (Vic) s 82.

enquire into and report on the desirability and feasibility of changes to the *Infertility Treatment Act 1995* and the *Adoption Act 1984* to expand eligibility criteria in respect of all or any forms of assisted reproduction and adoption.³⁷

The VLRC released its final report in March 2007. It contained 130 recommendations reflecting the emergence of new developments in reproductive technology, in addition to changes in family structures and community attitudes towards those different types of family structures.

As a result of the VLRC's recommendations, the Victorian Government developed the Assisted Reproductive Treatment Act, which repealed the Infertility Treatment Act and sought to create an improved legislative framework to support people who need assisted treatment procedures to create a family, as well as protect the welfare and interests of people born as a result of ART. The key purposes of the Act include:

- to regulate the use of assisted reproductive treatment and artificial insemination procedures (other than self-insemination)
- to regulate access to information about treatment procedures carried out under the Act
- to promote research into the incidence, causes and prevention of infertility
- to make provision with respect to surrogacy arrangements
- to establish the Victorian Assisted Reproductive Treatment Authority
- to provide for the keeping of the Central Register and the Voluntary Register by the Registrar of Births, Deaths and Marriages.³⁸

The Act is underpinned by a set of guiding principles:

- a) the welfare and interests of persons born or to be born as a result of treatment procedures are paramount;
- b) at no time should the use of treatment procedures be for the purpose of exploiting, in trade or otherwise
 - i) the reproductive capabilities of men and women; or
 - ii) children born as a result of treatment procedures;
- c) children born as a result of the use of donated gametes have a right to information about their genetic parents;
- d) the health and wellbeing of persons undergoing treatment procedures must be protected at all times;
- e) persons seeking to undergo treatment procedures must not be discriminated against on the basis of their sexual orientation, marital status, race or religion. ³⁹

³⁷ Victorian Law Reform Commission, Assisted reproductive technology & adoption Final report (2007), 5.

Assisted Reproductive Treatment Act 2008 (Vic) s 51.

The VLRC made a series of recommendations regarding access to information by people associated with donor conception. The VLRC did not support the retrospective removal of the anonymity of pre-1998 gamete donors. However, it suggested that the agency responsible for administering the donor registers could do more to facilitate approaches to donors and help increase awareness of their options in relation to providing identifying information. The VLRC recommended a process for facilitating this contact:

Recommendation 97: If a person conceived with gametes donated prior to 1 January 1998 wishes to obtain identifying information about the donor and the donor has not registered his or her wishes on a voluntary register:

- The donor-conceived person should contact the agency managing the registers to request that it facilitate an approach to the donor.
- The agency managing the registers should contact the clinic where the
 person's mother received treatment (if it can be identified) and ask the
 clinic to forward a letter from the Infertility Treatment Authority to the
 donor.
- The letter from the agency managing the registers to the donor should explain the donor's options in respect of providing identifying information to the person conceived with his or her gametes, and should draw attention to the availability of counselling to explore those options further.⁴¹

This recommendation was not incorporated into the Act or subsequent practices of the Register of Births, Deaths and Marriages, which administers the registers.

The new Act provides different levels of access by donor-conceived people to information about their donors:

- Donor-conceived people can access identifying information about their donors if the person was conceived using gametes donated after 31 December 1997.⁴²
- Donor-conceived people can access information about their donors if they were conceived using gametes donated between 1 July 1988 and 31 December 1997 and the donor has consented to the disclosure of the identifying information.⁴³

The Act does not mention people conceived using gametes donated prior to 1 July 1988 and therefore they have no right to access information about their donors under this legislation.

The Act also permits other parties involved in donor conception to access information. The Act allows donors to apply for non-identifying information about the person born as a result of their donated gametes, although consent is required

Assisted Reproductive Treatment Act 2008 (Vic) s 5.

Victorian Law Reform Commission, above n 37, 157.

⁴¹ Ibid, 158.

⁴² Assisted Reproductive Treatment Act 2008 (Vic) s 59(b)(i).

⁴³ Assisted Reproductive Treatment Act 2008 (Vic) s 59(b)(ii).

prior to the release of identifying information.⁴⁴ If the donor-conceived person is under the age of 18 years, his or her parent or guardian can consent to the release of

under the age of 18 years, his or her parent or guardian can consent to the release of the identifying information. ⁴⁵ Parents of a donor-conceived child can also apply for information about a donor, however, the donor's consent is required for the release of identifying information. ⁴⁶ The Act also allows a person descended from a donor-conceived person to apply to access information, including identifying information, about the donor from whom the person is descended. ⁴⁷

2.1.5 Registers

In Victoria, there are currently two Central Registers and two Voluntary Registers, all of which contain identifying and non-identifying information about people associated with donor conception.

The 1984 and 1995 Central Registers were individually established under the Infertility (Medical Procedures) Act and the Infertility Treatment Act respectively. Registrations and other relevant data continue to be recorded on the 1984 register in cases where gametes donated prior to 1 January 1998 have resulted in recent live births. According to the Victorian Assisted Reproductive Treatment Authority (VARTA), the 1984 register received 114 birth registrations from January 2008 to 30 June 2009. The 1995 Central Register records information about all donors who consented to the use of their gametes after 1 January 1998 and continues to be used in respect of those gametes. Between January 2008 and 30 June 2009, a total of 282 donors were registered on the Central Register. In the same period, the register recorded a total of 611 births from donor treatments.

As noted previously, the Infertility Treatment Act established a Voluntary Register for the purpose of allowing anyone involved with a donor treatment procedure since July 1988 to voluntarily record information on the register. The persons allowed to place information on the register are a donor-conceived person; parent of a donor-conceived person; relative of a donor-conceived person; descendent of a donor conceived person; a donor; and a relative of a donor. Information that applicants can place on the register includes identifying information, photos, messages or any other information that may be of interest to other parties associated with the donor procedure. In the procedure of the proced

Up until 2001, there was no mechanism for people involved with a donor treatment procedure prior to 1988 to record information. The *Infertility Treatment* (*Amendment*) *Act* 2001 (Vic) provided for the establishment of a Voluntary Register that would operate similarly to the post-1988 register but would only apply to people

Assisted Reproductive Treatment Act 2008 (Vic) ss 56(1)(d), 57(2), 62.

⁴⁵ Assisted Reproductive Treatment Act 2008 (Vic) ss 58(1)(b).

Assisted Reproductive Treatment Act 2008 (Vic) ss 56(1)(b), 58(1).

Assisted Reproductive Treatment Act 2008 (Vic) ss 56(1)(c), 60.

⁴⁸ Infertility Treatment Authority, *Annual report 2009: Twelfth and final report* (2009), 18.

⁴⁹ Ibid, 19.

Births, Deaths and Marriages Victoria, Assisted Reproductive Treatment Act: Questions and answers, http://online.justice.vic.gov.au/CA256902000FE154/Lookup/BDMContentSite-PDFs/\$file/ART-Q&As.pdf, viewed 18 August 2010.

Infertility Treatment Authority, *Annual report 2002* (2002), 17.

involved with donor procedures before 1 July 1988.⁵² This register was established in response to various requests from donors and families for a mechanism to allow voluntary contact between donors and donor-conceived people.⁵³

Information contained in the Voluntary Registers can only be released under specified circumstances, for example, the person to whom the information relates must consent to its release to an applicant.

Management of registers

Up until 1 January 2010, the Infertility Treatment Authority (ITA), a statutory authority established under the Infertility Treatment Act, was responsible for the management of the Central and Voluntary registers. In its report on ART and adoption, the VLRC recommended that the registers be transferred to a body separate from the ITA:

Recommendation 98: A service, independent of the Infertility Treatment Authority and connected to the Registry of Births, Deaths and Marriages - similar to the Adoption Information Service – should be established to manage donor registers. Donor registers should be transferred from the Infertility Treatment Authority to this new agency.54

This recommendation was based on the principle that donor information is for the benefit of the donor-conceived person, and his or her parents' infertility should not impact that person throughout his or her life. The VLRC also indicated that centralising all information about a donor-conceived person's birth would help to normalise donor conception.⁵⁵

In response to this recommendation, the management of the registers was transferred to the Registry of Births, Deaths and Marriages. 56

2.2 National Health and Medical Research Council guidelines

The National Health and Medical Research Council (NHMRC) first issued guidelines relating to ART in 1992. These guidelines were replaced by the Ethical guidelines on assisted reproductive technology in 1996, which stated that all medical clinics offering ART services must obtain accreditation by a recognised accreditation body and that such accreditation include consideration of compliance with the NHMRC guidelines.⁵⁷ The Reproductive Technology Accreditation Committee, established by the Fertility Society of Australia, is the recognised accreditation body.

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Infertility Treatment (Amendment) Act 2001 (Vic) s 6 which inserted a new s92C into the Infertility (Medical Procedures) Act 1984 (Vic).

Infertility Treatment Authority, Annual report 2002 (2002), 17.

Victorian Law Reform Commission, above n 37, 158.

Ibid, 158.

Assisted Reproductive Treatment Act 2008 (Vic) s 53.

National Health and Medical Research Council, Ethical guidelines on the use of assisted reproductive technology in clinical practice and research 2004 (as revised in 2007 to take into account the changes in legislation), Australian Government (2007), 5.

In 2004, the NHMRC revised and replaced the 1996 guidelines with the *Ethical guidelines on the use of assisted reproductive technology in clinical practice and research*. The current guidelines, which were updated in 2007, reflect the enactment of the *Prohibition of Human Cloning for Reproduction and the Regulation of Human Embryo Research Amendment Act* 2006 (Cth). ⁵⁸

The NHMRC guidelines contain a number of provisions that are relevant to the discussion around providing donor-conceived people with the right to access information about their donors. A key guideline is that all people involved in ART procedures should be respected:

5.1 Respect all participants

Assisted Reproductive Treatment (ART) procedures must be conducted in a way that is respectful of all involved. Clinical decisions must respect, primarily, the interests and welfare of the persons who may be born, as well as the long-term health and psychological welfare of all participants, including gamete donors. ⁵⁹

The guidelines also state that donor-conceived people are entitled to know their genetic parents, and on reaching the age of 18 years or a sufficient level of maturity, they should have access to information relating to their medical and family history; identifying information about the gamete donor; and the number and sex of persons conceived using the gametes provided by the same gamete donor, the number of families involved, and any identifying information that these siblings have consented to being released. ⁶⁰

The guidelines also state that the privacy of all persons involved in ART procedures should be respected, and that ART clinics must not release identifying information to another person without the consent of the person to be identified. In particular, the guidelines state that when a donor-conceived person requests information about his or her biological parents, the clinic needs to examine the consent form of the gamete donor and proceed as follows:

6.13 Respect the privacy of all persons involved in ART procedures

If the consent form does not include permission for release of identifying information ... 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. ⁶¹

⁵⁹ Ibid, 21.

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⁵⁸ Ibid, 7.

⁶⁰ Ibid, guideline 6.11.

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Chapter 3: Key issues raised in submissions

This chapter provides an overview of the issues raised in the 36 submissions received by the Committee as a result of the call for submissions advertised in July 2010. Most of the submissions directly addressed the Inquiry's terms of reference and the Victorian legislation that regulates assisted reproductive technologies (ART), the Assisted Reproductive Treatment Act 2008 (Vic).

The issues discussed in this chapter are:

- access to information about donors
- access to information about half-siblings
- balancing the rights of donors and donor-conceived people
- availability and protection of medical records
- management of donor registers
- impact on future donor programs
- other issues outside the terms of reference.

In considering the issues raised in the submissions, the Committee is mindful that not all groups are equally represented in the submissions received. In particular, the Committee received six submissions from donor-conceived people, ten from families who have used donated gametes, five from donor-conception support groups, while only six submissions were received from gamete donors. The Committee acknowledges that an important part of progressing this Inquiry will be ensuring that all groups are afforded an equal voice. The Committee addresses this issue in the next chapter, when it considers an appropriate consultation process to complete this Inquiry.

3.1 Access to information about donors

The submissions revealed that there was significant support for donor-conceived people to have the right to access information about their donors regardless of their date of birth or when the gametes used to conceive them were donated. 62

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Name withheld, Submission 2, 2; Lauren Burns, Submission 3, 2; Damian Adams, Submission 4, 1; Sonia Allan, Submission 5, 3; Name withheld, Submission 6, 1; Shelley Sandow, Submission 7, 1; VANISH Inc, Submission 8, 1; Barbara Burns, Submission 9, 1; Donor Conception Support Group of Australia Inc, Submission 10, 24; Name withheld, Submission 11, 1; Myfanwy Cummerford, Submission 12, 3; Susan Hurst, Submission 14, 1; Helen Kane, Submission 16, 2; Rainbow Families Council, Submission 17, 2; Narelle Grace Grech, Submission 18, 6; Victorian Assisted Reproductive Treatment Authority, Submission 19, 7; Kimberley Springfield, Submission 20, 2; TangledWebs Inc, Submission 21, 1; Victorian Infertility Counsellors Group, Submission 22, 2; Damien W Riggs, Submission 23, 1; Romana Rossi, Submission 25, 12; Monash IVF, Submission 26, 1; Public Interest Law Clearing House, Submission 27, 1; Sarah Nichols, Submission 28, 1; Name withheld, Submission 29, 2; Christine Whipp, Submission 31, 1; Melbourne IVF, Submission 32, 4; Kate Dobby, Submission 33, 2; Kate Bourne, Submission 35, 2; Name withheld, Submission 36, 1.

Case study 1: 'It came as the biggest shock of our lives' 63

'I found out about my donor conceived (DC) status when I was fifteen years old. Before this time I had no idea that things were so different about my place in my family or the way in which I entered the world. I grew up with a mum, a dad and a beautiful older sister, M, in the Northern suburbs of Melbourne. My sister M was conceived naturally by mum and dad. When my parents told us about my conception, this secret about me that they had carried for so many years, it came as the biggest shock of our lives. But it also made a lot of sense to me.

Initially being DC did not mean so much to me, mainly as I really had no idea what it meant. ART practices were still quite a taboo subject. It wasn't until I was a few years older that it all sank in and I started to realise how unjust a position I was in. For those first few years the small, non-identifying pieces of information about my biological father were enough; this is what the letter read from the professor who helped to conceive me to my initial query about my "donor":

"Thank you for your letter. I have identified who the donor was involved with your conception back in 1981. There were three people with a similar name in the telephone book and I have written them each a private and confidential letter asking them to contact me. I will keep you updated if there are any developments.

In the meantime I thought you would like to have the non-identifying information that we had on file.

As the donor who donated for you was recruited a long time ago, we don't have a great deal of information but here goes.

He was a student at the time of donating and was 5 foot 7 inches tall. He had dark brown hair, brown eyes and weighed 10 stone 3 pounds. He was married, had no family history of any disease and his blood group was 0 positive. Unfortunately we don't have any further biological data on him, but at least this will give you a little bit of a picture."

But when I began to become more curious and want to know more I was met with fierce denial and a lack of compassion from the very professor and the very institution who helped to conceive me. The "donor" was anonymous, and I was told that because my parents and the donor all agreed to this anonymity I would have to just accept this and get on with things.

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Narelle Grace Grech, Submission 18.

Activism & Pieces of the Puzzle

When I did start to meet other DC people and realise that I was not alone in my feelings of anger, powerlessness and loss I decided that I wanted to try to affect some change. So around 2003 I started to speak publicly about what it is like being DC, in the hopes of raising public awareness and trying to gain equal rights in accessing records. I was also slightly hopeful that my biological father might recognise my face on the TV, in the newspaper articles I was featuring in. Each time I had my photo taken I felt as though I was preparing to meet him for the first time. How sad this is to reflect upon now.

Meeting others in my situation also gave me hints as to who to ask for information; none of this journey has been easy. Even finding out the smallest bits of information has made me feel like a detective of sorts. One DC friend advised me about donor codes, which each donor was assigned at the clinic. If you found another DC person with the same donor code you were most likely siblings. I was able to learn that my donor code is T5. This became my biological father's name. Many years later I was to also learn the significance of what I thought was a random combination of a letter and a number. T represents the fact that his surname starts with the letter T and he was the fifth donor in the Prince Henry's program to donate sperm. Even this information made me happy beyond belief. It delighted me to think that my actual initials were N.T! My sister has always commented how sad she feels for me to be so happy with the scraps of information I have been given. It really is a bitter/sweet event in these terms.

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... In 2006 I was able to learn that my biological father's surname is of Maltese origin. This was an amazing discovery for me. It means a lot to me since I grew up with Maltese parents, so knowing my biological father shares the same (or part thereof) nationality as me is special. I was fortunate enough to travel to Malta this year and it really did feel familiar, like going back to my roots and one way to trace my genetic history. I have often wondered what my father looks like back home in Melbourne, and so being right there, in Malta where so many of my ancestors are from made me quite content. For the first time I felt as though I was somewhere I truly belonged.'

As noted in the previous chapter, persons born as a result of gametes donated prior to 1988 may have the option of accessing information about their donors through the Voluntary Register. However, many submitters did not view the existing registers as providing sufficient access to information. The Victorian Assisted Reproductive Treatment Authority (VARTA), the statutory authority responsible for administering aspects of the Assisted Reproductive Treatment Act, wrote:

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. ⁶⁴

3.1.1 Reasons for wanting access to information

The Committee is aware of the strong desire of donor-conceived people to learn more about their ancestry, particularly as a mechanism to understand more about themselves. A number of submitters spoke of the psychological difficulties often experienced by donor-conceived people, with many feeling a loss of identity and kinship when they find out about their donor-conceived status, and then further frustrations when they learn they have limited access, if any, to information about their donors. Ms Narelle Grace Grech, a donor-conceived person, wrote:

I cannot begin to describe how dehumanising and powerless I am to know that the name and details about my biological father and my entire paternal family sit somewhere in a filing cabinet in Melbourne, with no means to access it. Information about my own family, my roots, my identity, I am told I have no right to know. ⁶⁵

Mr Damian Adams, a donor-conceived person who has conducted research on donor conception issues, submitted:

The physical and psychological welfare of the donor offspring is further highlighted by the study of Marquardt et al (2010). This study showed that donor offspring suffer from greater levels of depression, delinquency and substance abuse. They also feel more isolated from and confused about their families when compared to children raised by both biological parents. ⁶⁶

Case studies 1 and 2 illustrate the reasons why a donor-conceived person and the parents of a donor-conceived person respectively sought information about their donors.

Ms Kate Bourne, an infertility counsellor with over 18 years in donor conception practice, submitted that most donor-conceived people are seeking answers to questions such as:

- Who am I related to?
- What is my donor like? For example, appearance, personality, interests, occupation?
- Are we alike in any way?
- Why did my donor donate?
- Does my donor know I exist?
- Does my donor ever wonder about me?⁶⁷

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⁶⁴ Victorian Assisted Reproductive Treatment Authority, *Submission 19*, 2.

Narelle Grace Grech, Submission 18, 2.

Damian Adams, Submission 4, 3.

Kate Bourne, Submission 35, 2.

Case study 2: 'Our children are very clear on who Donor Dave is,'68

'I am the mother of three children who were conceived using donor sperm. My (female) partner and I were patients at Melbourne IVF, and therefore were fortunate enough to have access to an "identity release" donor. All three children (currently aged 3, 5 and 7) have the same donor.

Initially, we thought we wouldn't be able to get identifying information about the donor until our oldest child turned 18. However, through a combination of a good counsellor and a great donor, we first had contact with the children's donor when our oldest child was less than a year old. Initially, contact was by a series of emails ... but since then, we have met "Donor Dave", as we call him, on a number of occasions. He has met all our children, and we have met his wife and children.

This has been an entirely positive experience. David's children clearly understand who we are, and who our children are, and our children are very clear on who Donor Dave is. Meeting David, knowing who he is – and where he is – takes all the mystery out of the experience, and gives our children the certainty of knowing where they come from genetically. It doesn't confuse them about who their parents are – that's my partner and me – but it gives us all answers to those completely mundane questions that all kids have about "where they come from". Those questions cease to be mundane when the answers are unknowable, as is the case for children conceived prior to the changes in the law which required donors to be identifiable.

From our experience, and from listening to other donor-conceived kids tell of their longing to know, I believe very strongly that donor-conceived people should be given access to whatever identifying information there is.'

Similarly, Melbourne IVF (MIVF), which has considerable experience linking donor-conceived people with their donors, wrote:

In MIVF's experience, offspring wanting to make contact with their donor or seeking current information about their donor are typically seeking information about their donor's health, family details, why they donated and a profile of interests and talents that may help the offspring understand more about themselves.

It would be accurate to say, that these young adults are hoping to fulfil a deep desire for the answer to the perplexing questions about who they are genetically. Donor conceived offspring are primarily seeking information as it relates directly to their genetic heritage. They are not seeking a substitute parent or change in roles and responsibilities of the donor.⁶⁹

Allowing donor-conceived people to access information about their donors was also viewed in some submissions as necessary to provide them with information about their medical and genetic history. A lack of knowledge about their biological parents' medical history can potentially place donor-conceived people's health at risk from birth. Dr Damien W. Riggs, a researcher in the field of sperm donation at Flinders University, stated in his submission that at minimum, donor-conceived people should

⁶⁸ Sarah Nichols, Submission 28.

⁶⁹ Melbourne IVF, Submission 32, 9.

have the right to access information about their medical and genetic history, even if this does not include access to identifying information about their donors.⁷⁰

3.1.2 Disclosure of donor conception to children

In order to access information about their donors, donor-conceived people must be aware of their donor conception status. A common theme in submissions received from donor-conceived people and some families who had used donated gametes was the perceived culture of secrecy that surrounds donor conception.⁷¹

The Committee notes the efforts of organisations associated with donor conception to encourage disclosure of donor conception to children. In 2006-07, the former Infertility Treatment Authority (ITA) conducted the *Time to Tell* public education campaign to encourage parents to be honest with their children about how they were conceived. The National Health and Medical Research Council's (NHMRC) *Ethical guidelines on the use of assisted reproductive technology in clinical practice and research* also include a directive on the right to knowledge of genetic parents and siblings. In particular, the directive states that medical clinics should help donor recipients to understand the significant biological connection that donor-conceived people have with gamete donors and encourage recipients to tell their children about their origins. The control of th

From the evidence received in the submissions, it appears that there is still a strong reluctance on behalf of parents to inform their children about their donor conception. Some parents of donor-conceived people attributed their hesitance to reveal their children's donor conception status partly to the limited capacity to access information about donors. Ms Barbara Burns, mother of two donor-conceived children, submitted:

When I was thinking about telling I was aware that Jane and Lauren were not legally entitled to any information about their donor. It seemed almost a sick joke to have to admit to my children that they were conceived by a stranger whom they would never know anything about. Neither I nor anyone else should be placed in this position. Looking back now I do not know how I had the courage to speak given that I truly believed at the time that Jane and Lauren would never find out anything about their donor. I took a huge risk. ⁷⁴

Another mother, who has not yet told her adult son that he is donor-conceived, wrote:

On reflection I believe the main reason I have not told him is because I know he can't get access to information about his biological father. I do not want him to spend the rest of his life longing to know about half his origins, when legislation

Damien W Riggs, Submission 23, 1.

Name withheld, Submission 2, 1; Damian Adams, Submission 4, 4; Sonia Allan, Submission 5, 23; Barbara Burns, Submission 9, 1; Name withheld, Submission 11, 1; Myfanwy Cummerford, Submission 12, 3; Susan Hurst, Submission 14, 2; Romana Rossi, Submission 25, 1; Christine Whipp, Submission 31, 1.

⁷² Infertility Treatment Authority, 2008 Annual report (2008), 18.

National Health and Medical Research Council, Ethical guidelines on the use of assisted reproductive technology in clinical practice and research 2004 (as revised in 2007 to take into account the changes in legislation), Australian Government (2007), 26.

⁷⁴ Barbara Burns, Submission 9, 1.

won't allow him that access \dots I do not want him to be like some children, who search forever. ⁷⁵

Some submissions drew attention to what they considered to be the contradictory nature of the *Time to Tell* campaign. Ms Lauren Burns, a donor-conceived person, wrote:

This campaign encourages parents to be open and honest with their children about their donor origins. The government message is confused. It promotes telling, but also says it is illegal to have information for the questions that will inevitably follow, forcing parents to make cruel choices about what to do. ⁷⁶

The submission from action group TangledWebs argued that all persons involved in donor conception procedures should be required to agree to inform their donor-conceived child about the circumstances of their birth at the earliest opportunity. Ms Susan Hurst, the parent of a donor-conceived child, suggested there could be more counselling post-birth in order to assist parents to talk to their children about donor-conception. 78

3.2 Access to information about half-siblings

Aside from wishing to access information about donors, the Committee is aware that many donor-conceived people are also interested in identifying any half-siblings. This may be for a range of reasons, for example to eliminate the risk of consanguinity or to have the opportunity to know their genetic half-siblings. At present, the only way that siblings conceived using gametes donated before July 1988 can locate one another is if they have both placed information on the Voluntary Register, including a donor linking code.

Melbourne IVF stated in its submission that it does not provide assistance to donor-conceived people wishing to contact donor-conceived siblings, although it does provide non-identifying information in accordance with the NHMRC guidelines. ⁷⁹ In her submission to the Inquiry, Ms Grech, a donor-conceived person, referred to her efforts to obtain information about her potential half-siblings:

One DC [donor-conceived] friend advised me about donor codes, which each donor was assigned at the clinic. If you found another DC person with the same donor code you were most likely siblings. I was able to learn that my donor code is T5 ... Not long into my degree I was able to find out that I have eight half siblings (five sisters and three brothers) as a result of my biological father's donations. We were all born between 1982 and 1985 and all conceived in Melbourne ... As for my DC siblings I often wonder about them, whether we have met or I have walked past them in the street. Do they know they are DC? Will their parents ever tell them? Will I ever have the chance to meet any of them?

Name withheld, *Submission* 2, 1.

Lauren Burns, Submission 3, 3. See also Barbara Burns, Submission 9, 2.

TangledWebs Inc, Submission 21, 2.

⁷⁸ Susan Hurst, Submission 14, 2.

⁷⁹ Melbourne IVF, Submission 32, 3.

Narelle Grace Grech, Submission 18, 3.

Ms Bourne, an infertility counsellor, told the Committee that recent changes to the donor registry have restricted the information now available about donor-conceived siblings:

Under the previous legislation it was routine practice for donor-conceived people to be provided with non-identifying information about their genetic siblings. This included details of the number of other people conceived by the same donor, their gender, month and year of birth. This information was also routinely given to parents making application on behalf of their children ... Unfortunately this information is no longer released by the registry to parents and donor-conceived people. Only donors are given a list of the people they helped create.⁸¹

In its submission to the Inquiry, VARTA stated that providing donor-conceived people with non-identifying information about half-siblings, such as gender, month and year of birth, was considered to minimise this risk and relieve stress among donor-conceived people.⁸²

3.3 Balancing the rights of donors and donorconceived people

Consideration of issues affecting rights inevitably involve a balancing act. In this case, the competing interests are the rights of donor-conceived people and the rights of donors. There were divergent views among the submission about how these rights should be balanced.

3.3.1 The framework for protecting rights

An important consideration when discussing the rights of donor-conceived people and the rights of donors is the *Charter of Human Rights and Responsibilities Act* 2006 (Vic). The Committee notes that the following sections of the Act are relevant to the issue of providing donor-conceived people with access to information about their donors:

- Section 8: Recognition and equality before the law
 - 3) Every person is equal before the law and is entitled to the equal protection of the law without discrimination and has the right to equal and effective protection against discrimination.⁸³
- Section 13: Privacy and reputation

A person has the right -

a) not to have his or her privacy, family, home or correspondence unlawfully or arbitrarily interfered with.⁸⁴

Kate Bourne, Submission 35, 7.

Victorian Assisted Reproductive Treatment Authority, Submission 19, 6.

⁸³ Charter of Human Rights and Responsibilities Act 2006 (Vic) s 8.

⁸⁴ Charter of Human Rights and Responsibilities Act 2006 (Vic) s 13.

- Section 15: Freedom of expression
 - 2) Every person has the right to freedom of expression which includes the freedom to seek, receive and impart information and ideas of all kinds, whether within or outside Victoria. 85
- Section 17: Protection of families and children
 - Families are the fundamental group unit of society and are entitled to be protected by society and the State.
 - Every child has the right, without discrimination, to such protection as is in his or her best interests and is needed by him or her by reason of being a child.⁸⁶

Some submissions supporting the release of identifying information about donors also drew the Committee's attention to the *United Nations Conventions on the Rights of the Child*, particularly the following articles:

Article 2 (Non-discrimination): No child should be treated unfairly on any basis.

Article 3 (Best interests of the child): The best interests of children must be the primary concern in making decisions that may affect them.

Article 7 (Registration, name, nationality, care): All children have the right to a legally registered name, officially recognised by the government. Children have the right to a nationality (to belong to a country). Children also have the right to know and, as far as possible, to be cared for by their parents.

Article 8 (Preservation of identity): Children have the right to an identity – an official record of who they are. Governments should respect children's right to a name, a nationality and family ties. 87

3.3.2 The rights of donors

As discussed in the previous chapters, prior to 1 July 1988, the consent of donors to donate gametes was not legally required but rather was provided in a private contract between medical clinics and donors. These contracts assured donors that they would remain anonymous. On this basis, various submissions argued for the protection of donors' rights to privacy.

Dr Riggs from Flinders University informed the Committee that his research shows:

many of the men who donated sperm in private arrangements did not appear to have given adequate consideration to the emotional consequences of sperm donation, particularly any mismatch between their desired level of contact with children

⁸⁵ Charter of Human Rights and Responsibilities Act 2006 (Vic) s 15.

Charter of Human Rights and Responsibilities Act 2006 (Vic) s 17.

UNICEF, Fact sheet: A summary of the rights under the Convention on the Rights of the Child, http://www.unicef.org/crc/files/Rights_overview.pdf, viewed 17 August 2010. See also Narelle Grace Grech, Submission 18, 5; Convention on the Rights of the Child, opened for signature 20 November 1989, 1577 UNTS 3, arts 2, 3, 7, 8 (entered into force 2 September 1990).

conceived of their donations and the desires of the recipients of their sperm and indeed the children themselves. 88

Melbourne IVF, which has been involved with sperm donation since 1976, stated in its submission that the rights of donor-conceived people to access information about their genetic background should not override donors' rights to privacy and control over the release of their personal information. In particular, Melbourne IVF told the Committee that it 'feels a strong obligation to protect the privacy of our donors and respect the circumstances under which the donations were made'. ⁸⁹ In contrast, Monash IVF supported retrospective access to identifying information for all donor-conceived people, based on the precedent of adoption laws which are discussed in more detail below. ⁹⁰

In a submission to the Senate inquiry into donor conception in Australia which is currently in progress, the Fertility Society of Australia indicated that it would be a violation of privacy to require these donors to consent to the release of identifying information:

However, we think it would be quite wrong to now compel the donor, through retrospective legislation, to release his identifying information. These men, and to a lesser extent women, previously agreed, in good faith, to donate sperm to help another family on the basis of anonymity. It would be a grievous violation of their privacy, with potentially devastating consequences for their own families, to now compulsorily change these arrangements in retrospect. 91

Case study 3: 'As a donor, I fear contact'92

'As a donor, I fear contact. While the Inquiry is about "access by donor-conceived people to information about donors", the real outcome is contact. "Access to identifying information" means "contact".

I do not want to have any contact with any persons conceived with the assistance of my donations. Giving donor-conceived people access to identifying information about their donors, regardless of the date that the donation was made, would mean that my details would become available to donor-conceived people to access without my consent. This would mean that I could be contacted, without any warning, by persons claiming to be conceived from my donations. I do not want this to occur. Such contact would be extremely distressing to myself and to my spouse and children, and I do not want the wonderful relationships with them upset by the sudden onset of donor-conceived people.'

Two submissions received from donors who donated gametes prior to 1988 stated that the position of donors who wish to remain anonymous and non-contactable should be considered. One of these donors stated that he fears contact with people

Damien W Riggs, Submission 23, 2.

Melbourne IVF, Submission 32, 4, 2.

Monash IVF, Submission 26, 3.

Fertility Society of Australia, submission 106 to the Senate Standing Committee on Legal and Constitutional Affairs, Parliament of Australia, Inquiry into donor conception in Australia (2010), 11.

Name withheld, Submission 13, 1.

who may have been conceived using his gametes, as he believed it would be distressing to both himself and his family:

I do not want to be subjected to "fishing expeditions" by donor-conceived people, for whom my donations have **not** been used in their conception, trawling for their donor, as once one contact is made, word is likely to spread through the donor-conceived community. The knowledge of my identity information is then out of my control and out of the control of the holder of the records. ⁹³

Case study 3 illustrates the concerns that this donor has about the potential impact that the release of identifying information about him will have on the lives of both him and his family.

A submission received from a donor who has regular and positive contact with a person conceived using his gametes (see case study 4) indicated that pre-1988 donors should have a complete right to confidentiality, and the opportunity to decide whether they wish to be contacted by a donor-conceived person. ⁹⁴

Case study 4: 'It has been very good to know the person' 95

'I was a medical student in the 1970s in Melbourne and during a lecture we were asked to please consider donating sperm for infertile couples as there was a lack of donors at the time, a cause of unhappiness.

A small dollar amount possibly \$10 was part of the deal, but the idea really was that there were people that needed our help.

I enquired about this and filled in a very small form, was counselled for a brief time (this was a long time ago!) and made aware that my donation would be forever confidential and have no effect on my future life.

I have now married and divorced. I have three adolescent children.

Prof De Kretser wrote to me and suggested I contact him about a "project".

This was a year ago. I have since found out about 5 successful donations. One of them had gone to very great lengths to contact their donor. I agreed to follow up this contact and have since met her and got to know her well.

This has been a bizarre experience for me. At first I was overwhelmed and felt saddened ... not knowing or being around this person as she lived her life.

. . .

It has been very good to know the person and we get on very well and have a lot of surprising connections and similar interests. My children are very positive and have enjoyed knowing her.'

95 Ibid

⁹³ Ibid, 2

Name withheld, Submission 1, 1.

3.3.3 The rights of donor-conceived people

A number of submissions suggested that the promise of donor anonymity and the subsequent right to privacy is untenable on ethical and legal grounds as it impinges on donor-conceived people's rights to access information about their medical, social and genetic heritage. On this basis, it was argued that a donor's right to privacy must be balanced against the rights of a donor-conceived person to recognition and equality before the law and not to be exposed to discrimination:

Inequity across different legislations in the same state makes it difficult to adequately preserve a person's rights to information about their biological origins. Some of the systems currently in place could be argued to be discriminatory, giving some people rights and others none, purely based on the timing of their birth. This would appear to be in direct conflict with the guiding principles of the Charter.⁹⁷

According to the Donor Conception Support Group of Australia, the needs and interests of children and all people created through the use of donor conception must be of paramount concern. This was a common view in the submissions received, with many stating that denying donor-conceived people access to information about their donors directly violates the guiding principle of the Assisted Reproductive Treatment Act, that 'The welfare and interests of persons born or to be born as a result of treatment procedures are paramount.'98

Some submissions argued that because donor conception is perceived as a medical procedure to overcome infertility, the wellbeing of adults has typically been the overarching priority while the needs and welfare of the children born in the process have been neglected. For example, Ms Kimberley Springfield, a donor-conceived person, stated in her submission that while she is an adult now, she is still a child of donor conception and she does not believe her welfare has been acknowledged as paramount. ¹⁰⁰

In weighing the promise of anonymity for donors against the rights of donor-conceived people, a number of submissions questioned the circumstances around which anonymity was guaranteed. Ms Lauren Burns argued that the concept of anonymous donors was established to minimise confusion around the parental obligations of biological parents, and to also protect recipients of donor conception from donors attempting to claim parental rights. ¹⁰¹ This anonymity was not protected by statute or judicial authority. Another donor-conceived person, Ms Myfanwy Cummerford, stated that any contractual agreement for donor anonymity was

Lauren Burns, Submission 3, 5; Damian Adams, Submission 4, 4; Myfanwy Cummerford, Submission 12, 2; Kimberley Springfield, Submission 20, 2; TangledWebs Inc, Submission 21, 2.

Monash IVF, Submission 26, 6. See also Donor Conception Support Group of Australia Inc, Submission 10, 13; Myfanwy Cummerford, Submission 12, 2; Helen Kane, Submission 16, 2; Narelle Grace Grech, Submission 18, 7; Kimberley Springfield, Submission 20, 3; Romana Rossi, Submission 25, 6; Christine Whipp, Submission 31, 1.

Assisted Reproductive Treatment Act 2008 (Vic) s5.

⁹⁹ Romana Rossi, Submission 25, 4; Damian Adams, Submission 4, 1.

Kimberley Springfield, Submission 20, 2.

Lauren Burns, Submission 3, 6.

between the parents and the donor and not applicable to a donor-conceived child who did not exist at the time the contract was made. 102

Ms Helen Kane, the former manager of the Donor Registers Service at the ITA, questioned the capacity for donors who donated gametes prior to 1 July 1988 to have provided informed consent to the use of their gametes as they did not undergo any counselling. Consequently, many would not have had a comprehensive understanding of potential future outcomes nor given adequate consideration to the emotional consequences of their donation:

Donors were required, at certain points in the history of donor conception in this state, to swear that they would never ask, and would never be told, the results of the donation. Donors did not see counselors in this state until the 1984 legislation required this. There are questions, prior to that, about the "informed consent" of any donor. ¹⁰³

Ms Kate Dobby, who worked as a Registers Officer at the former ITA, also raised a number of issues regarding the concept of anonymous donors and the capacity of those donors to have provided informed consent:

- They were very young at the time of the donation
- They received no counselling or inadequate information
- They did not understand or comprehend what they were doing or were or are now unaware that people have been born
- They donated because they were being compensated either with medical treatment, STD testing, money or course credits
- They had a wish to find out the results of their donating and were happy to be contacted but had been told that this was not possible (perhaps being told that the relevant files would be destroyed)
- They were told or had an expectation that the clinic would contact them on behalf of a donor-conceived person or their family (but this has not happened due to records being lost, clinics closing or current clinical policy). 104

Further, the Donor Conception Support Group of Australia stated in its submission that some donors who donated gametes during this time indicated that they would have been happy to be identifiable but this was never discussed as an option. ¹⁰⁵

Other submissions, including VARTA, Monash IVF, Melbourne IVF and the Public Interest Law Clearing House, advocated for the adoption of a more balanced approach, whereby the rights and privacy of donors are considered and balanced with the rights of donor-conceived people. ¹⁰⁶

¹⁰⁴ Kate Dobby, Submission 33, 4. See also Donor Conception Support Group of Australia Inc, Submission 10, 10.

Myfanwy Cummerford, Submission 12, 3. See also Christine Whipp, Submission 31, 1.

Helen Kane, Submission 16, 2.

Donor Conception Support Group of Australia Inc, Submission 10, 10.

Victorian Assisted Reproductive Treatment Authority, Submission 19, 2; Monash IVF, Submission 26, 3; Public Interest Law Clearing House, Submission 27, 8.

3.4 Options for change

Throughout the submissions, various options were proposed as a way to move forward on this issue. As discussed previously, some submissions indicated that donors' privacy should be protected while others believe that donor-conceived people should be provided with access to identifying information about their donors without donors' consent. Submissions that sought to achieve a balance between the rights of donor-conceived people and the rights of donors suggested that donors be given the opportunity to provide consent prior to the release of identifying information about them.

The following three options for implementing changes to the current arrangements were commonly identified in submissions:

- All donors to be contacted and asked to re-consent to being identified VARTA stated that this option would be time-consuming as it would require contacting many donors regardless of whether an application for information has been received.
- 2) Donors' identifying information to be released without donors' consent upon request from approved persons, for example, donor-conceived people or donor recipients, as occurs with retrospective access to identifying information about birth details for adopted people.
- 3) Donors to be contacted and asked to consent to the release of information only upon request for information by a donor-conceived person. This would provide people born prior to 1988 with the same access to information as those born between 1988 and 1996. 108

All of the submissions that put these three options forward indicated their support for option three, including Ms Dobby, the former Registers Officer at the ITA, who submitted:

My experience in administering the Donor Registers Service, collecting and managing information and releasing it to clients has led me to believe that the only option for implementing equal access to information is to make every effort to contact the donor regarding a donor-conceived person's application for information. In this way the situation can be managed to cause the least distress possible to parties involved and their families through the use of counselling and counsellors as intermediaries. ¹⁰⁹

The Victorian Infertility Counsellors Group noted that option three could be implemented in one of two ways, either through a central register, or through ART clinics directly. However, the Group concluded that administration through a central register would strike 'the most appropriate balance between protecting the rights of

Victorian Assisted Reproductive Treatment Authority, Submission 19, 5.

Ibid, 5; Victorian Infertility Counsellors Group, Submission 22, 5; Melbourne IVF, Submission 32, 8; Kate Dobby, Submission 33, 6; Kate Bourne, Submission 35, 3-4.

Kate Dobby, Submission 33, 6.

the donor conceived person to have access to information and protecting a donor's

A number of submissions referred to the NHMRC *Ethical guidelines on the use of assisted reproductive technology in clinical practice and research*, with which all registered ART clinics must comply. According to the Victorian Infertility Counsellors Group, the NHMRC guidelines allow for the provision of information to a donor-conceived person about his or her donor where the donor has not provided consent, as long as there has been a reasonable attempt to gain consent from the donor. Similarly, Melbourne IVF indicated that the guidelines provide a framework to allow donor-conceived people to have access to information in a manner that is respectful of all parties involved. In contrast, Ms Lauren Burns felt that the guidelines do not provide sufficient guidance about how to resolve a conflict

between a donor-conceived person's desire to access information about a donor and a

donor's desire to have their identifying information kept confidential. 113

3.4.1 Counselling services

privacy'. 110

Various submissions indicated that counselling should accompany any change to existing arrangements, particularly to accommodate circumstances where donor-conceived people will seek contact with donors. All parties involved (donor-conceived people, donor recipients and donors) may feel vulnerable throughout the process and are often unaware about what is appropriate. As stated by VARTA:

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 unchartered 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. ¹¹⁴

In the context of options one and three, VARTA suggested that counselling be implemented to ensure informed consent is achieved among donors. The Victorian Infertility Counsellors Group shared this view, stating that counselling is helpful in assisting donors recognise the motivations behind donor-conceived people wanting access to information about them:

In the VICG's professional experience, donors can be anxious or reluctant to initially give consent to the release of any information but 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 without disclosing

Victorian Infertility Counsellors Group, Submission 22, 5-6. See also Kate Bourne, Submission 35, 3-4.

Victorian Infertility Counsellors Group, *Submission* 22, 4.

Melbourne IVF, Submission 32, 6.

Lauren Burns, Submission 3, 6.

Victorian Assisted Reproductive Treatment Authority, Submission 19, 6.

identifying information (eg medical information) or initiating contact with the donor conceived person (usually via email or letter). 115

3.4.2 Adoption Act 1984 (Vic)

In supporting the provision of retrospective access to identifying information about donors, a number of submissions drew comparisons with provisions contained in the *Adoption Act 1984* (Vic). Through the implementation of this Act, Victoria became the first state in Australia to provide adopted adults with unqualified access retrospectively to their original birth record. The Act states:

An adopted person who has attained the age of 18 years may apply to a relevant authority for information about the adopted person, whether or not a natural parent or a natural relative (within the meaning of section 97) of the adopted person may be identified from that information. ¹¹⁷

Under the Act, all adopted people can access their adoption files regardless of previous assurances of anonymity to the biological parents. Submissions indicated how the adoption model of legislative and social reform provides a unique insight into some of the issues impacting donor-conceived people. For example, the Donor Conception Support Group of Australia commented:

In the debate held about the Victorian Adoption Act in 1984, it was accepted there was paramountcy in the welfare and interests of the child in relation to accessing information. The members of the Victorian Parliament at the time accepted the principle that the right to know about your genetic origins and heritage overrode any concerns about the right of relinquishing parents to privacy and that it should apply to ALL adopted children regardless of when they were adopted. ¹¹⁸

Submitters also argued that the Adoption Act established a precedent about the capacity of the Victorian Parliament to legislate on these matters retrospectively:

Donor conception today is in the same awful state as adoption was thirty years ago. The adoption experience has taught our community the horrors of unknown genetic origins, secrecy and depriving people of their genetic family. There is already in place in the Adoption Act 1984 (Victoria) a model for the legal and practical issues of giving retrospective rights to DC [donor-conceived] people to have identifying information about their family ... Legislators do not have to reinvent the wheel to give retrospective rights to DC people. ¹¹⁹

The paper, Does opening adoption records have an adverse social impact? Some lessons from the U.S., Great Britain, and Australia, 1953-2007, provides an international history of the adoption reform movement and the impact on birth parents and their families. In surveying international adoption disclosure systems, the author concludes that the fear articulated by birth parents and adopted adults that

Victorian Infertility Counsellors Group, Submission 22, 4.

Damian Adams, Submission 4, 5; Sonia Allan, Submission 5, 15; VANISH Inc, Submission 8, 3; Barbara Burns, Submission 9, 3; Donor Conception Support Group of Australia Inc, Submission 10, 12; Romana Rossi, Submission 25, 3.

¹¹⁷ Adoption Act 1984 (Vic) s 93(1).

Donor Conception Support Group of Australia Inc, Submission 10, 15.

Romana Rossi, Submission 25, 3-4.

their privacy would be invaded and their families disrupted if adopted adults were given the right to access their birth records was not an issue in reality. 120

3.5 Availability and protection of medical records

As noted in the previous chapter, prior to the establishment of the Central and Voluntary Registers in 1984 and 1995 respectively, there were no legislative requirements or consistent procedures around the collection and retention of donor records. This was entirely within the discretion of medical clinics and doctors performing donor conception practices. As a consequence, there was significant variation in the way records were maintained, and whether they were kept or destroyed when medical clinics closed down. This potentially creates practical issues for providing donor-conceived people with the right to access information about their donors.

Several submissions referred to the inconsistent nature of donor records created prior to July 1988, many of which are considered to provide inaccurate or incomplete information. Ms Dobby referred to the unreliability of such records:

In my experience (which also encompasses several years of directly assessing the records relating to the former clinic at Prince Henry's Institute of Medical Research 1978-1998), these records are not entirely clear; births are written in pencil, files contain variant names and details, important information concerning consent and counselling and treatment is obscure or omitted entirely. Donor's files can also contain very little information, and there were several donors who were used by this clinic during this time for whom no information exists as their sperm was imported from interstate (with the records remaining there now in bureaucratic limbo and accessible by no one). Files from this time are also missing. 'Complete' donor files from the period prior to 1988 often contain little more than serology results and a brief description of the donor (supplied by either the donor or the doctor and therefore quite subjective). ¹²¹

Ms Dobby also suggested that some medical practitioners and clinics may oppose granting greater access to information because it may also reveal past practices that are unacceptable by current standards:

Egg swapping, sperm mixing, donor's identities not being verified or donors being encouraged to donate under pseudonyms, offering free vasectomies and sperm storage, STD testing and course credits in exchange for donating, knowingly creating up to 30 separate families or an excess of 40 children from one donor, using anonymous donors imported from interstate without paperwork, recoding donors, the practice of on-donation, utilising patients as donors whilst they are still in treatment and using donors for whom valid consent could not be verified are just some of the practices that I know to have occurred in Victoria. 122

There are also a number of practical issues associated with the identification of records created prior to July 1988, with their location dependent on where the donor conception treatment originally took place:

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E. Wayne Carp, 'Does opening adoption records have an adverse social impact? Some lessons from the U.S., Great Britain, and Australia, 1953-2007' (2007) 10(3-4) *Adoption Quarterly* 29.

Kate Dobby, Submission 33, 5. See also Helen Kane, Submission 16, 3.

Kate Dobby, Submission 33, 3.

Prince Henry Hospital – physical paper records are now located at the Public Records Office, however, the lack of access to these records was of particular concern to several participants in this Inquiry. 123

- Queen Victoria Epworth Hospital surviving records are located at Monash IVF, although Monash IVF does not currently support contacting donors.
- Royal Women's Hospital now Melbourne IVF where records have been preserved. As indicated previously, Melbourne IVF is the only ART clinic that assists donor-conceived people to make contact with donors. 124

Other records may also be held by doctors who performed donor conception procedures in their private practices. 12

A number of submissions expressed concern about the possibility of donor records being destroyed, and the impact this may have on donor-conceived people. For example, Ms Lauren Burns stated, 'Pre-1988 donor records still held by clinics and doctors have no special status and like other medical files may be destroyed after 7 years'. 126 On this basis, there were calls to attempt to locate donor records, and accord them with the same protected status as donor records maintained in the Central Register. 127

While recognising that many old records are incomplete, several submissions emphasised that the release of even small amounts of information can be valuable to donor-conceived people. VARTA submitted:

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. 128

Some submissions also proposed that records be checked and confirmed prior to the release of information to relevant parties. 129 In circumstances where no or incomplete records exist, it was suggested that voluntary DNA testing be conducted and compiled in a voluntary DNA bank to assist with determining genetic links. 130

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See for example, ibid, 2, 5.

Lauren Burns, Submission 3, 10; ibid, 5; Kate Bourne, Submission 35, 1.

Lauren Burns, Submission 3, 10; Kate Dobby, Submission 33, 6.

Lauren Burns, Submission 3, 3. See also Sonia Allan, Submission 5, 6; Helen Kane, Submission 16, 4; Victorian Assisted Reproductive Treatment Authority, Submission 19, 4; Monash IVF, Submission 26, 4.

Lauren Burns, Submission 3, 2; Helen Kane, Submission 16, 4; Kimberley Springfield, Submission 20, 2; Victorian Infertility Counsellors Group, Submission 22, 5; Kate Bourne, Submission 35, 3.

Victorian Assisted Reproductive Treatment Authority, Submission 19, 4. See also Monash IVF, Submission

Helen Kane, Submission 16, 3.

Damian Adams, Submission 4, 7; ibid, 4; Victorian Infertility Counsellors Group, Submission 22, 5; Kate Bourne, Submission 35, 3.

The Committee believes that, pending a further inquiry and report on this matter, the Victorian Government should consider whether measures should be taken to ensure that existing donor records are preserved.

Recommendation 1

The Committee recommends that, pending a further inquiry and report, the Victorian Government considers as a matter of urgency whether measures should be taken to ensure that existing and unprotected donor records are preserved.

3.6 Management of donor registers

From 1 January 2010, the Assisted Reproductive Treatment Act transferred the management of the Central and Voluntary Registers from the former ITA to the Registry of Births, Deaths and Marriages (BDM). This was based on a recommendation of the Victorian Law Reform Commission in its report on ART and adoption, with the intended purpose of de-stigmatising infertility and donor conception. As indicated in chapter 2, this recommendation was based on the principle that donor information is for the benefit of the donor-conceived person, and his or her parent's infertility should not impact that person throughout his or her life. 132

While the ITA's role was to both manage the donor registers and provide various counselling services, the role of BDM is solely information provision. Donor linkage counselling is provided by a separate organisation, Adoption and Family Record Services (AFRS).

A number of participants addressed the transfer of the management of the donor registers from the ITA to BDM in their submissions. The following issues were raised in the submissions:

- A specialist body such as the ITA was viewed as the appropriate body to manage the registers. In particular, the ITA had almost 15 years experience in dealing with issues surrounding donor conception and the knowledge and expertise the ITA had developed has been lost. ¹³³
- There has been a reduction in the counselling services offered to parties involved in donor conception that wish to obtain information from the registers. Also, due to privacy restrictions within BDM, the AFRS counselling service does not have access to information about the other party involved and is thus not able to act as an intermediary or to assist parties to make informed decisions.¹³⁴

Victorian Law Reform Commission, Assisted reproductive technology & adoption Final report (2007), 158.

Assisted Reproductive Treatment Act 2008 (Vic) s 149.

Narelle Grace Grech, Submission 18, 7; Lauren Burns, Submission 3, 11; Kate Dobby, Submission 33, 6; Victorian Infertility Counsellors Group, Submission 22, 7.

Kate Bourne, Submission 35, 6; Melbourne IVF, Submission 32, 10; Victorian Infertility Counsellors Group, Submission 22, 7.

- There is a risk that donor-conceived people may learn of their donor conception status through a letter from BDM advising them that their donor has applied to access information about them, but without any accompanying support or counselling.¹³⁵
- The Donor Register Service, an information, counselling and communication education service, is no longer provided. A key component of this service was the 'Letter Box Drop', which allowed donors and recipients to send each other information and/or requests for information without identifying themselves. This was viewed as an important service as it allowed parties involved in donor conception to exchange correspondence in a neutral environment. ¹³⁶
- A perceived lack of experience within BDM in handling the complexities of a voluntary register, which can require the negotiation and brokerage of agreement and making arrangements for information exchange.¹³⁷
- People may find it difficult to navigate the new system due to the different areas of responsibility sitting within separate organisations, rather than the 'one-stop-shop' that was originally provided by the ITA. ¹³⁸

The Committee notes that it did not have the opportunity to fully examine the objectives behind the transfer of the donor registers and counselling arrangements from the ITA to BDM and AFRS, nor any of the claims made in submissions about the impact of this change. The Committee also did not receive submissions from BDM or AFRS and recognises that these organisations will need to be given the opportunity to contribute should this Inquiry be continued in the next Parliament.

3.6.1 Development of a national register

Four submissions proposed the establishment of a national register to help donor-conceived people attempt to find information about donors and/or half-siblings regardless of where in Australia a person was born or conceived. In particular, it was suggested that a national register could help alleviate concerns and minimise the risks around donor-conceived people forming relationships with unknown biological relatives.

3.7 Impact on future donor programs

The terms of reference required the Committee to consider the impact of providing donor-conceived people with retrospective access to information about their donors on future donor programs. A common view in submissions was that there was

Kate Bourne, Submission 35, 6.

Name withheld, Submission 29, 1; Victorian Infertility Counsellors Group, Submission 22, 7.

Kate Dobby, Submission 33, 8; Name withheld, Submission 34, 4.

Kate Dobby, Submission 33, 6; Donor Conception Support Group of Australia Inc, Submission 10, 21; Helen Kane, Submission 16, 6.

Name withheld, Submission 2, 2; Sonia Allan, Submission 5, 17; Narelle Grace Grech, Submission 18, 6; TangledWebs Inc, Submission 21, 1.

unlikely to be any impact because the current arrangements already allow donor-conceived people to access information about their donors once they are aged 18 years or over. In particular, Monash IVF stated that any change to the current arrangements as they relate to pre-1988 donations will not influence future donations:

The future of ART programs would not be adversely affected by the introduction of retrospective legislation about access to identifying information about donors. All donors who have donated since 1995 have known that their donation was conditional and donated on the basis that they knew there was a possibility that one day someone may be able to access their records. This will not impact on new people donating in the future. ¹⁴¹

Ms Kane, the former manager of the Donor Registers Service at the ITA, suggested that the impact on future donor programs could be a positive one:

Future donor programs will learn more about what it means to the people concerned, and will hopefully recognise the need to respond, both by providing good processes and information at the time of donation and treatment, and to store information in an accessible manner, for the purposes of future access to this. 142

A donor who donated gametes prior to July 1988 indicated that future donor programs could be impacted, although his concern was the need for relevant parties to be consulted about important changes. 143

3.8 Other issues outside the terms of reference

The submissions raised some additional issues relating to donor conception which are outside the Inquiry's terms of reference, including the specified number of families permitted to use one donor's gametes to help them conceive; the information contained on donor-conceived people's birth certificates; and the right to make decisions about gametes.

3.8.1 The number of families permitted to use one donor's gametes

The Assisted Reproductive Treatment Act provides that up to ten families can use one donor's gametes to conceive a child. Four submissions expressed concern with this, suggesting that the number of families should be reduced. The Donor Conception Support Group of Australia proposed that no more than five families, including the donor's own family, should be allowed to use the same donor's

Lauren Burns, Submission 3, 11; Helen Kane, Submission 16, 5-6; Monash IVF, Submission 26, 5; Melbourne IVF, Submission 32, 10; Kate Dobby, Submission 33, 8.

Monash IVF, Submission 26, 5.

Helen Kane, Submission 16, 6.

Name withheld, *Submission 36*, 5.

Assisted Reproductive Treatment Act 2008 (Vic) s 29.

gametes. 145 This is currently the number allowed under the New South Wales' Assisted Reproductive Technology Act 2007 (NSW). 146

3.8.2 Information contained on birth certificates

A number of submissions raised issues regarding the information that is included on the birth certificates of donor-conceived people. Four submissions in particular argued that because birth certificates do not include donors' names, they are fraudulent and foster deceit by not being indicative of true parentage. 147

3.8.3 The right to make decisions about gametes

Monash IVF's submission highlighted that there are inconsistent rules for making decisions about gametes. The submission states that under the Assisted Reproductive Treatment Act gamete donors must consent to the storage of an embryo created from their gametes. Monash IVF submitted:

Apart from being fraught with many practical issues this is also in direct contradiction to part 14 of the Act which deals with the definition of parentage in situations where donor gametes are used. In essence it means that the woman and her partner are the legal parents of any child born from donor gametes, and that the donor does not have any legal parenting rights over the child.

So how is it possible then that a donor has the right to say how long a person's embryos may or may not stay in storage when the embryo is also genetically half of another person, the recipient. 148

Monash IVF suggested that the Act be amended to make it clear that the donor only has rights to make decisions about gametes before they are inseminated. No other submissions raised this issue.

Monash IVF, Submission 26, 7-8.

Donor Conception Support Group of Australia Inc, Submission 10, 22-23. See also Shelley Sandow, Submission 7, 2; Narelle Grace Grech, Submission 18, 6; Name withheld, Submission 29, 1.

Assisted Reproductive Technology Act 2007 (NSW) s 27

Myfanwy Cummerford, Submission 12, 3; Susan Hurst, Submission 14, 2; Narelle Grace Grech, Submission 18, 6; Romana Rossi, Submission 25, 6. See also Patricia P Mahlstedt, Kathleen LaBounty and William T Kennedy, 'The voices of adult offspring of sperm donation: Forces for change within assisted reproductive technology in the United States' (2008) 90 Fertility Sterility s178 as appendix v in Lauren Burns, Submission 3.

Chapter 4: A way forward

The Legislative Council referred the Inquiry into access by donor-conceived people to information about donors to the Law Reform Committee on 23 June 2010, requesting an interim report by September 2010 and a final report by 2011. The Committee has completed the first stage of this Inquiry within extremely tight timelines.

Time constraints have meant that the Committee has only been able to undertake limited consultation about the issues raised by the terms of reference. The Committee placed advertisements in major newspapers calling for submissions to the Inquiry on 10 July 2010. There was a high level of interest in the Inquiry. The Committee received 36 submissions from a wide range of individuals and organisations, including donors, donor-conceived people, donor recipients, medical clinics, support groups and academics.

As discussed in the previous chapter, the submissions received contain a diversity of views and raise a number of significant and challenging issues. The Committee believes that the evidence from its preliminary consultation demonstrates that this complex topic warrants full exploration.

The 56th Parliament will dissolve prior to the completion of this Inquiry and this Inquiry will lapse. The Committee therefore recommends that the 57th Parliament refer the terms of reference back to the Law Reform Committee, or another appropriate committee, for comprehensive investigation in the next Parliament.

Over 40 years of donor conception practices mean that this Inquiry potentially impacts the lives of many Victorians. Therefore an extensive consultation process should be undertaken to ensure that the Committee has the opportunity to hear the full range of views on this issue. The submissions to the Inquiry were highly informative, with many containing moving accounts of personal experiences. The Committee notes that if the terms of reference are re-referred to the Law Reform Committee in the 57th Parliament, that committee will be able to consider these submissions. The current Committee strongly encourages any committee considering this issue in future to give full consideration to the submissions already received.

The tight timelines for the present Inquiry meant that people wishing to contribute only had a very short time to prepare their submissions. Several submitters indicated that they would have liked more time to write their submissions. Therefore the Committee suggests that the Inquiry should be widely advertised in the 57th Parliament, with interested persons and organisations given a further opportunity to make submissions.

Time constraints also meant that the Committee did not have an opportunity to meet and talk with people and organisations interested in contributing to this Inquiry. Many submitters stated that they would like to meet with the Committee to provide

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Parliamentary Committees Act 2003 (Vic) s 29.

further information about their experiences and views. A public hearing process will be an important part of continuing this Inquiry, providing an opportunity for a wide range of stakeholders to share their perspectives with the Committee.

The limited consultation process undertaken by the Committee revealed several challenges that will need to be addressed if this Inquiry is continued in the next Parliament.

Firstly, the Committee believes it is important to hear the full gamut of views on the issues raised by the terms of reference. The submissions received by the Committee were predominantly from donor-conceived people and their families. The Committee considers it is also imperative to hear the views of donors, particularly those who donated gametes prior to 1988 when all donations were made anonymously. One donor who made a submission highlighted the difficulties of engaging donors in this discussion, commenting:

The existence of a donor support group is unknown to me. I'd expect that one does not exist as I'd understand that the anonymous donors do not want any attention and keep their history to themselves. This means that donors may generally be silent, in contrast to the donor-conceived community. 150

If the Inquiry is continued in the 57th Parliament, the Committee's consultation process will need to be carefully designed to ensure that all interested groups are equally aware of the Inquiry and encouraged and supported to provide input.

Secondly, this Inquiry raises many highly sensitive issues. A number of participants were reluctant to make public submissions. Some are parents who have not yet told their offspring that they are donor-conceived, others are donors who want to preserve the anonymity of both themselves and their families. Again it is crucial that the consultation process is thoughtfully designed in order to ensure that these people are encouraged to participate to the maximum extent possible. All people contributing to an inquiry of this nature must be confident that their input will be given full weight and, where necessary, protection.

Based on the preliminary scoping conducted by the Committee and taking into account the complexity of issues raised and the extensive consultation process required, the Committee believes that the 57th Parliament should allocate 18 months for the completion of this Inquiry. This will also enable the Committee to conduct an extensive literature review and give consideration to how similar issues have been addressed in other jurisdictions.

The Committee's preliminary consultations suggest that the terms of reference provided to the Committee are adequate and do not need further expansion or clarification. However, the Committee notes that the federal inquiry into donor conception currently being conducted by the Senate Standing Committee on Legal and Constitutional Affairs will be completed by the end of 2010. Therefore it suggests that the findings of that inquiry be considered in determining whether there

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Name withheld, Submission 13, 1.

are any additional issues that need to be included in the terms of reference for this Inquiry.

In the previous chapter the Committee noted a number of issues raised in submissions that are outside the current terms of reference. These are:

- How many families should be permitted to use one donor's gametes?
- Should a donor's name be included on a donor-conceived person's birth certificate?
- At what stage does a donor's right to make decisions about gametes end?

While recognising the significance of these issues, the Committee does not believe that the terms of reference for this Inquiry should be extended to include these matters. The Committee considers it important that the focus of the current Inquiry remain on the issue of access to information. Instead the Committee believes that the Victorian Government should give consideration to these additional issues through a separate process.

Recommendation 2

The Committee recommends that the 57th Parliament of Victoria refer the terms of reference for this Inquiry to the Law Reform Committee for inquiry, consideration and report. The terms of reference should ask the Committee to complete its final report within 18 months.

Appendix A: List of submissions

	Name of individual or organisation	Date received
1	Name withheld	20 July 2010
2	Name withheld	28 July 2010
3	Ms Lauren Burns	29 July 2010
3A	Ms Lauren Burns – supplementary submission	06 August 2010
4	Mr Damian Adams	30 July 2010
5	Dr Sonia Allan	02 August 2010
6	Name withheld	03 August 2010
7	Ms Shelley Sandow	03 August 2010
8	VANISH Inc	03 August 2010
9	Ms Barbara Burns	03 August 2010
10	Donor Conception Support Group of Australia Inc	04 August 2010
11	Name withheld	04 August 2010
12	Ms Myfanwy Cummerford	04 August 2010
13	Name withheld	05 August 2010
14	Ms Susan Hurst	05 August 2010
15	Anonymous (confidential)	30 July 2010
16	Ms Helen Kane	06 August 2010
17	Rainbow Families Council	06 August 2010
18	Ms Narelle Grace Grech	06 August 2010
19	Victorian Assisted Reproductive Treatment Authority	06 August 2010
20	Ms Kimberley Springfield	06 August 2010
21	TangledWebs Inc	06 August 2010
22	Victorian Infertility Counsellors Group	06 August 2010
23	Dr Damien W. Riggs	06 August 2010

	Name of individual or organisation	Date received
24	Mr Paul Ruff	06 August 2010
25	Ms Romana Rossi	06 August 2010
26	Monash IVF	06 August 2010
27	Public Interest Law Clearing House	06 August 2010
28	Ms Sarah Nichols	06 August 2010
29	Name withheld	09 August 2010
30	Name withheld	09 August 2010
31	Ms Christine Whipp	09 August 2010
32	Melbourne IVF	09 August 2010
33	Ms Kate Dobby	10 August 2010
34	Name withheld	11 August 2010
35	Ms Kate Bourne	11 August 2010
36	Name withheld	17 August 2010

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